

# MEDITERRANEAN MEETING ON BIOETHICS

Edgar Busuttil, S.J.

Bioethics is fundamentally concerned with the problem of the quality of life. Promoting it involves first of all the protection of the quality of life which already exists. Every effort must be done nationally and in international fora to promote an ever better quality of life in the conditions of life of humanity as a whole and of all individual persons. Bioethics is not only concerned with medical problems. Its horizons include all other problems connected with human and non-human life. In fact it is only within the understanding of this wider context of life in general that bioethics can tackle any problem which it comes across and seeks to understand.

The "Istituto Siciliano di Bioetica" has organised several Mediterranean Meetings on various topics of bioethics. These meetings are intended to promote intercultural dialogue between the peoples of the different cultures and religions who inhabit the regions around the Mediterranean Sea, to help in the search for a bioethics which would be common to these different countries. They are also intended as opportunities for the search of that ethical truth that goes beyond the differences in cultural religious backgrounds which the participants represent. This search for truth must be done together since it lies beyond the points of views and judgements of any participant. These intercultural exchanges on the subject of life are very important for another reason: to sensitize, more and more, each culture represented (Western, Islamic, Balcan, Hebrew, Greek, Latin) to the value of life.

The first such meeting was held in Acireale, Sicily, between the 31 October and 5 November, 1992. The topic chosen was: "The Quality of Life in the Mediterranean Countries". The participants hoped to demonstrate that although the participants came from diverse cultures and backgrounds, they shared a fundamental sensitivity towards life. The meeting produced a book bringing together the various contributions by the participants. The book is edited by Salvatore Privitera, Director at the Istituto Siciliano di Bioetica in Palermo; it carries the same title as the Meeting and has been published in collaboration with the Palermo Facoltà di Teologia in 1993; in this review article I will present a short summary of the papers as well as a brief note of evaluation.

***The quality of life in Italy (Salvino Leone, Italy)***

Within the past few decades, Italian society, like other western societies, has been marked by profound social phenomena, which have had deep effects on the quality of life. The most visible of these has been the progressive growth in material wealth which has been accompanied by an analogous increase in social problems. Besides the crisis in the institution of the family which had already begun to be felt years ago, today we find a crisis of the middle aged generation, faced with the dilemma of whether to care for children or for old people. More than in the past there is also a crisis in public representation. The fall of ideologies, as well as the corruption of the political class have led to a profound loss of trust in political institutions. There is also an explosion of poverty with old and new factors connected with it. In fact traditional material poverty has been made more acute by the economic crisis which has affected the whole country; it is expressed in psychophysical marginalization and a progressive degradation of affectivity among many new classes who are socially emarginated.

In addition there is the crisis of the health service. This has led to the indefinite postponement of the planned rational control of health care costs, the elimination of party control in the service, a more efficacious planning of university studies to include formation in bioethics, and their humanization. The regional mentality which has pervaded the whole of Europe is markedly present in Italy. Finally one must not forget the problem of organized crime and the Mafia as well as problems connected with social services.

In spite of all these problems, Italy has a lot to offer: "...our imagination, our creativity, our capacity to continue to live, to hope and love in spite of all the difficulties..."

***The problem of limits in the economical resources for health care in Spain (Miguel A. Sanchez-Gonzales, Spain)***

In Spain, as well as in the West in general, it is assumed that there is a positive correlation between the number of years lived and the quality of life. Is this acceptable from a moral point of view? And ought this correlation be considered as a valid criterion on which to formulate and actualize any health care programme?

The "Movement of Social Indicators" began to operate in the 20s at the University of Chicago through the work of William Ogburn. However as from the

70s the QALY has been progressively gaining support. QUALITY ADJUSTED LIFE YEARS consists in a complicated calculation which is intended to define the ideal standard of the quality of life.

QALY is based on philosophical premises which are derived from hedonistic and individualistic conceptions. If QALY's principle of maximalization is to be applied, then it necessarily has implications in the economy and in the clinic and has repercussions on informed consent. What are the implications of all this to the aged in contemporary society?

### *The notion of Quality of Life in Health Care (Marie-Louise Lamau, France)*

The notion of Quality Adjusted Life Years (QALY) first appeared during the 50s. It became very commonly used as from 1964 following a speech by Lyndon Johnson, the then President of the United States. In recent years three needs have been affirmed:

1. The first which is explicitly ethical in nature, affirms that progress can never take the place of the human person and justice.
2. Progress cannot be made solely through the prolongation of life but involves a wider horizon of well being.
3. The third is economic in nature and proposes an equitable redistribution of the limited resources possessed by man.

The integral vision of the person is considered to be the foundation of all criteria with which to evaluate progress in the quality of life.

### *The War in Croatia (Igor Primoratz, Croatia)*

While the conference was meeting, war raged in Croatia. Igor Primoratz informed the delegates of the situation of this war. The war in Ex-Yugoslavia is part of the reality of the state of the Quality of Life in the Mediterranean.

The war in Croatia has not been fought according to the law which protects civilians, that seeks to protect social, economic and cultural life. From the beginning of the conflict, Croatia was practically a defense against that which is the third largest army in Europe. From the very beginning the military might wielded by the Serbs was enormous; no wonder they caused the destruction of entire cities, and

were able to catch and kill their populations. Realistic data on the war atrocities committed are not available because of the total disorganization present as well as because of the fact that the Serb army and irregular Serb forces have destroyed all clues of their acts. This applies also to Slovenia and Bosnia. The methods used by the irregular forces are particularly cruel: they use any means imaginable to kill people.

Another fact is the sacking of conquered towns and the total destruction of every building which has some cultural value or social significance: hospitals, churches, cemeteries, farms, factories... The population which remains after the invasion are treated as slaves and are abused of with all kinds of violence. They live in the worst possible - hygienic conditions and suffer hunger.

The Croats or any others who are not Serbs, are deported to concentration camps. In January 1992 there were already 36 concentration camps. In these there are men and women of all ages from 14 to 86 years old. These people are systematically and daily maltreated. Ethnic cleansing is practised. Masses of people are expelled. Incalculable numbers of Croat and Serb refugees are forced to leave. The health care structure: hospitals and clinics are totally destroyed. International law is violated. In Croatia there have been numerous war crimes and genocide perpetrated by the Serbs. In proportion the violations committed by the other groups are very small. The international community has often simply looked on when it ought to have intervened. What will the judgement of future generations be on this war?

### ***Bioethics: The situation in Portugal (Jorge Teixeira da Cunha, Portugal)***

In Portugal bioethical issues have not yet become frequent in public debates. However through the mass media these issues have begun to be raised more frequently. In general the situation is not qualitatively very different from what it is in other European countries.

It must be emphasised that the ethical debate is heavily conditioned by the ongoing conflict between lay thought and confessional thought, which in Portugal is identified with Catholic. The two positions assume contrasting views with regard to practices of artificial fertilization. The lay position use criteria which are exclusively utilitarian, while the Catholic position considers that human life ought to be respected.

Among the bioethical problems which are at the centre of the general discussion the issue which raises most interest is that on artificial methods of fertilization. Issues on the objection of conscience by the doctor and those connected with AIDS follow. However the discussion tends to widen and to involve other aspects as for example the relationship of man with the biosphere.

Several institutions promote the ethical dimension in Portuguese society. The most prestigious is the "National Council on the Ethics and the Sciences of Life". The ultimate end is the definition and promotion of the dignity of the human person, its identity, its value and its unique nature.

An important role is played by the "Commissions of Hospital Ethics" which operate in the principal health care centres, as well as by associations of various medical professions. These include the Pharmacological Corporation, the Order of Doctors and the Association of Catholic Doctors which have promoted medical ethics for the last sixty years or so.

Research in the country is still fragmentary on the national scene. The two main research institutions are both found in Coimbra. These are "The Centre of Studies on Bioethics" and "The Committee for the Juridical control of the New Technologies connected with Life" at the Faculty of Jurisprudence of the University.

### ***Bioethics in Greece (Anna Kalandidi, Greece)***

In Greece there has been a debate on doctors' professional secret which is founded on the Hippocratic Oath. From this secret it follows that the free consent of the patient must be obtained before carrying out any medical investigations. This moral principle has not always been given adequate attention.

In order to give his informed consent it is indispensable that the patient be told the truth by his doctor. This is another area in which significant changes of attitude are taking place in Greece.

All those in the medical profession as well as in the general public, consider medical research involving human beings to be indispensable; however present legislation is emphatically in favour of the absolute respect for human life and for the protection of the body, even after the informed consent of the patient has been obtained, especially in the case of non-therapeutic experiments.

There are two or three ethics communities in Greece. While euthanasia is not accepted, as it is not in many other European countries, termination of pregnancy, within limits, is legal in Greece.

In Greece as in Cyprus, the genetically based disease of Thalassaemia is a problem. This problem is often tackled through prenatal testing, genetic counselling which would include the use of selective termination of pregnancies as an option.

There is no legislation on methods of artificial procreation as yet, however one finds an ever growing acceptance of such methods among the general public. Public consciousness of the problem of AIDS is not very strong. Public opinion is very much in favour of organ transplants.

***Maltese Government on family planning and Artificial Human Procreation  
(George Grima, Malta)***

In various countries there have been heated debates on several bioethical problems including family planning and artificial human procreation. In these problems the interests of couples are often in conflict with those of the civil community and those of current legislation. Christianity has for millenia had a great influence on Maltese culture. Today Maltese society is no longer homogeneous even if it is not exactly pluralistic. The government's legislation on marriage may be seen as an expression of its political will to assert the State's independence from the Church.

In 1990 a document was published by the Ministry of Social Policy. In this document the intention of the government to guarantee non-financial services, especially for the well-being of the weakest citizens and families is spelt out. However in the area of family planning and artificial procreation the Maltese government's policy is very poor. Very little legislation has been introduced and there is no sign that this lacuna is to be filled in the near future.

Taking into account the value which human life from the moment of conception and marriage still have for the great majority, the report on reproductive technology, submitted by the Bioethics Consultative Committee, recommended, among other things, that sperm or ovum donation should not be legally permitted, and that all embryos produced "in vitro" should immediately be implanted in the mother. However it is difficult to see how in practice the new reproductive technologies can be used without exposing nascent human life to the risk of manipulation and possibly death. In a country where abortion is a crime, legislation on the use of

human reproductive procedures has to be quite stringent. But how stringent should it be to protect human life from the moment of conception and at the same time to allow enough freedom for the new procedures to be used at all?

*Programme for the prevention of Thalassaemia (Frosso Parrisiadou, Cyprus)*

The Thalassaemia programme in Cyprus had its origins in 1973. This project has been concerned with methods of prevention of this disease. The result of this programme is that, as from 1986 no children have been born with this disease in Cyprus. Haemoglobinopathies are a worldwide problem, though especially acute in developing regions, where they are considered to constitute an economic burden, as well as an urgent public health problem. In spite of its earlier origin, the Cypriot programme follows certain principles present in the declaration of ALMA ATA in 1978. This programme was characterised by four independent aspects: public education, population screening, genetic counselling and antenatal diagnosis.

In order to obtain satisfactory results the active participation of all social forces was essential. Also necessary were the education of the people and the participation of the whole of society.

The realization of the programme was facilitated by a number of factors:

- \* The small proportions and its population.
- \* The high standard of living and literacy of its people.
- \* The low birth rate
- \* The high level of health care institutions
- \* The fact that the people are well-informed.

However difficulties include the lack of funds and the absence of a university. In Cyprus the percentage of the population suffering from thalassaemia was very high. The political will to confront the problem, as well as government aid, which began as early as the 60s in support of the prevention programme, have contributed to the development of well-defined strategies to tackle the disease. The decisive policy steps were:

1. The international support offered by the World Health Organization (WHO)
2. Improved techniques in the therapies for patients with the disease,

3. The working out of a prevention programme,
4. The setting up of a thalassaemia centre,
5. The rehabilitation of homozygotes for thalassaemia in society.

As these strategies were worked out several associations were set up, including one by sufferers of the disease and their parents and another by blood donors. Even the Cypriot Church was involved. Ever since 1977 the costs have been completely carried by the government; however many sponsors are involved, including the WHO and individuals.

The success of the project has encouraged doctors to come up with prevention programmes in other sectors. A Cytogenetics Department which deals with the various chromosomal anomalies has been set up.

***Urban Deterioration and the quality of life: An overview (Mohammed El Gawhary, Hanaa El Gawhary, Egypt)***

The type of habitation in which a large proportion of the citizens of Cairo live is one of the main manifestations of urban degradation in Egypt and of the rising concern for the degradation of its quality of life. In the capital city the rate of population growth is very high. In 1960 there were 3 million people living in Cairo, in 1987 there were 6 million, in the year 2,000 a population of 10 million is expected. The present infrastructure of the city is not able to provide many of its citizens with their most basic needs. At the same time, the gap between the rich and the poor classes within the city is deepening and this provokes greater social class polarization.

The pattern of lumpen housing forms expresses this critical situation: houses constructed without a building permit or not according to any form of urban planning constitute over 35% of the city. The rapidly decreasing green spaces, the setting up of shops and kiosks which obstruct the streets, and many other similar phenomena give an indication of the gravity of the situation.

The problem of housing seems to be insoluble, the necessary funding and space are lacking. Meanwhile people continue to construct even poorer slums. In these slums 24% of the population live in only one room, in opposition to 42% in flats. In fact there are nearly 58.5 rooms per 100 flats in slum areas. The more important fact is that people living in one room are eating, sleeping, bathing... all in that one



room, that usually never exceeds 10 square meters. Socially these people's lives are primitive, because they are not provided with the basic utilities and services. About 58.5% of the families get water from outside the house, about 67.4% do not have a kitchen indoors and about 50.9% do not have a private bathroom or toilet.

1% of the population of Cairo live in courts above the cemeteries. In these areas there are no public utilities, such as water, electricity... nor are there any public utilities, such as medical care hospitals. 1,200 families live in garbage storage areas. Most garbage collectors raise pigs, since they feed on nothing but garbage. The sanitary conditions in these places are extremely unhealthy: infectious diseases are very widespread in these places and infant mortality rates are very high.

After a recent earthquake in Cairo, 8, 035 families live under tents. The government is incapable of providing new houses. Even before the earthquake 2 to 4 buildings collapsed every day. Many buildings in Cairo are in a very bad state.

The overpopulation of the city has forced a large proportion of its inhabitants to live in crowded conditions. This also has led to urban deterioration. Over and above the fact that these houses are extremely underdeveloped, suffering of public utilities deficiency and expressing the lowest quality of life, they suffer, due to high population density, from overloading. Urban deterioration facilitates the deterioration of social relationships and values. In one-roomed residences the area never exceeds 50cm squared per person. Entire families sleep in a single bed. There is not privacy for married couples. All these factors point to the extremely low quality of life in the city of Cairo.

### *Quality of Life: Deep and Shallow (David Heyd, Israel)*

David Heyd raises a very general critical point on the concept of the Quality of Life as it is used today. In its original meaning the term 'quality of life' connotes the deepest issues of what makes human life worth living. It expresses the ultimate ethical value, the highest good in the classical Aristotelian sense. The modern environmentalist movement contrasts the quantity of life with its quality. It is not good enough to live or even to live long; we should strive to live well. However this movement has almost exclusively limited this term to the context of the relationship of human beings with their external environment.

Previously the term quality of life was closely associated with the ideals of self-realization, self-control, achievement, integrity, intimacy, friendship,

citizenship, justice, loyalty... More recently it has come to be associated with the external environment. Since Arne Naess' pioneering work in environmental ethics, there is a long heated debate over the distinction between shallow ecology and deep ecology. The shallow view understands the value of the non-human environment in human terms. The environment must be preserved, otherwise humanity would suffer the consequences.

The deep approach takes the values of pristine nature, uninhibited development of non-human species, as independent of any human need or interest.

According to Heyd, the choice of the term "shallow" is unfortunate, since it prejudices the issue at hand. It tends to undermine the real equilibrium between humanity and nature. In effect only the anthropocentric approach, which takes the value of nature as subservient to the interests, needs, desires and ideals of human beings makes ethical sense.

The "deep" approach, on the other hand, potentially endangers the good and moral integrity of human beings and of Society. Human beings ought never to be sacrificed for nature's sake. Nature ought to be placed at the service of humanity.

It is important to determine the right order of priorities. Often ecology is given a higher value than the demands of social justice. This attitude is prevalent in the attitude of western nations in their dealings with developing nations. The survival of humanity itself, ought to be given more value than the quality of life. Poor nations are hard-pressed to ensure life rather than to struggle for a better quality of life. Israel is an interesting case. Being a new society, struggling for its existence and identity in hard social and political circumstances, Israel paid in the past only little attention to environmental problems similar to Third World countries.

Mediterranean countries ought to strive to improve their quality of life in the current ecological sense without losing sight of the old truth that: "Man is the measure of all things" with all its implications for the way the truly good life should be sought.

***Our responsibilities towards future generations: Malta's contribution  
(Emmanuel Agius, Malta)***

Each generation has moral responsibilities towards future generations; these involve the duty of each generation to transmit to future generations an ever better quality of life. Two main factors have contributed considerably to today's global awareness

of this duty: First, it has now become quite evident that technological power has altered the nature of human activity. Modern technology has given present generations the unprecedented power to influence the lives, not only of those now living, but also of those who will live in the far-distant future. Secondly, today there is an ever growing sense of belonging to the community of mankind as a whole. Recent human experience has shown that absolutely nothing exists in isolation. A new vision of human community is emerging which includes all past, present and future generations.

In 1967 the Government of Malta put forward for the first time at the United Nations, the concept of the "Common Heritage of Mankind", in the context of the new Law of the Sea. The concern of the Maltese Government was to propose international legislation which would protect the marine environment and its living resources from competitive national appropriation. Another important step taken by Malta in the interests of posterity was the decision to collaborate with the Future Generations Programme of UNESCO. In 1986 UNESCO delegated the Future Generations Programme to the Foundation of International Studies, which is part of the University of Malta.

Malta's proposal on future generations at the Rio Earth Summit has received a broad spectrum of support. It is indeed encouraging to note that the three documents signed in this Summit contain the principle of our responsibilities towards future generations. The Maltese Government had taken the initiative to propose the concept of a "Guardian" at the UNCED Prep Comm Meetings in preparation for the summit, this "Guardian" would be an authorised person or an organ appointed to represent future generations at the various international fora, particularly the U.N.

Malta has been active in protecting the interests of future generations in its regions too. Being at the centre of the Mediterranean sea, Malta has over the years taken a leading role in the work of the Mediterranean Action Plan by organising conferences and seminars and by hosting the Regional Marine Pollution Emergency Response Centre (REMPEC).

### ***Medical Ethics, Universality and Culture (Hmida Enneifer, Tunisia)***

It is clear that the Western culture has influenced the style of life of Arabic/Islamic peoples. Thus it is not surprising to find similar problems in these societies too: problems which are related to the advances in medicine and ethical problems have been felt recently.

These problems have provoked heated controversies in the Arabic-Muslim world, both on the religious as well as on the moral and judicial plane, whereas in the recent past the Arabic-Muslim world was able to adapt gradually the changes brought about by scientific progress of western origin to its own rules of civil life, there are now serious doubts whether this process could continue to proceed in a balanced way. Accelerated progress which is indifferent to the particular socio-cultural reality must be controlled in all possible ways. The adverse effects of not doing so have already been seen in those non-European societies which have imitated the European model.

In Islam the principles which must be at the base of legislation regulating the use of medical and biological technologies are two:

1. Respect for the human person
2. The duty of taking care of oneself.

On the basis of these principles Islamic culture condemns disease and struggles against it. However any means which does not respect the person is considered to be more harmful than the disease itself. Human dignity is indispensable to faith and is the fundamental precondition for a correct social life. It is the only possible objective of medical practice, otherwise this would become oppressive.

Islam considers the body to be a good which is shared by man and God. The two complementary rights exist: that which belongs to the individual and the exercise of his private interests, and that belonging to God which involves the general good and that of the collectivity. The right to life and health of the body is based on the balance of these two rights. It was easy to connect these two principles in the past; today the new horizons which have been opened by biological research have given rise to grave and complex questions which confound the human spirit. Legislation has an important normative function but is inadequate. One can perceive the enormous social and political implications of these questions, the problems can therefore only find their solutions in a cultural context especially within the domain of ethics, which for those countries in the South must take into account development.

### ***BRIEF COMMENTS OF EVALUATION***

The different focus on Quality of Life present in various countries in the region of the Mediterranean, which is evident from the many reports of this conference, seem

to reflect the different socio-economic realities of these nations, differences in the political situation, health needs as well as criteria adopted for ethical reflection and judgement. At times these criteria are conflicting rather than different.

### *The Socio-Economic situation*

It is interesting to note that in the industrially developed countries represented, such as Spain, Italy and Portugal, the most pressing problems discussed on the Quality of Life have to do with caring for old people, the progressive growth in material wealth, the search for a just allocation of financial resources for different health care projects, and the environment. On the other hand developing nations, such as Egypt are more concerned with ensuring existence itself, and more with basic human needs such as housing and urban development.

### *The Political situation*

It is evident that the political scene has its influence on the problems of Quality of Life in the various countries represented in this Conference. The clearest example is Croatia which was suffering a terrible war, in which the very existence of its population and culture was under threat. Another example would be the corruption of the political class in Italy which has brought with it social injustice and a lack of political stability. The size of the nation concerned as well as its age as an independent country also affect concerns on the quality of life. It is no coincidence that concepts such as the "Common Heritage of Mankind" have originated in small countries such as Malta. Small nations more than any other nation depend on the development of International Law that would protect their stability which is so necessary for the development of their quality of life.

### *Culture and Religion*

The different cultures and religious beliefs, or lack of them, also influence the ways of thinking of the participants as well as the ethical starting points of bioethical debates, controversies and decisions taken in their countries. Clear examples of this point are the contrasting views, even within the same country, concerning issues like practices of artificial means of reproduction, objection of conscience, the way in which scientific progress of western origin is perceived in the Muslim world.

### *Contrasting Ethical Criteria*

After reading the different presentations of this conference it is revealing to reflect on the two conflicting types of ethical criteria which are used by the various authors to define Quality of Life and to justify means of attaining what is considered to be a better quality of life. The first set of criteria I would call *utilitarian*. These would define as good a quality of life without pain, and with the maximum amount of life and pleasure for the greatest number of people. A clear example of where this type of ethical reasoning used is in the article on the the thalassaemia programme in Cyprus. The elimination of this disease is perceived to be the highest value. So that the termination of pregnancy for fetuses diagnosed to be homozygous for this condition is justified as long as there is the informed consent of the parents.

The other set of criteria are governed by a belief in the dignity of the life for every human being. This principle is considered to be the starting point of any consideration on the meaning of Quality of Life. No human life may be sacrificed for any end. Not even the elimination of terrible diseases. This ethical view is perhaps most clearly presented in the last presentation by Ennifer Hmida.

### *Conclusion*

I believe that this conference has gone a long way in presenting the various problems connected with the Quality of Life in the Mediterranean. However there is need for more dialogue to take place on the two conflicting ethical starting points just alluded to. A further point which is evidently in need of more dialogue concerns the causes and possible remedies for the unequal distribution of wealth, and for the various armed conflicts of the region. It is only when these problems are faced seriously that the quality of life of the region would be able to progress in an integrated way.

Department of Moral Theology  
Faculty of Theology  
University of Malta  
Msida