

# **QUALITY OF LIFE AND THE ETHICS OF HEALTH**

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*Edited by :*

ELIO SGRECCIA

IGNACIO CARRASCO DE PAOLA

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*Presentation (H.E.R. Msgr. ELIO SGRECCIA, Msgr. Prof. IGNACIO CARRASCO DE PAULA)*

*Discourse of the Holy Father GIOVANNI PAOLO II*

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## **JOHN PAUL II**

### **ADDRESS TO THE PRESIDENT OF THE PONTIFICAL ACADEMY FOR LIFE 19 February 2005**

To my Venerable Brother Bishop Elio Sgreccia

President of the Pontifical Academy for Life

**1.** I am pleased to send my cordial greetings to those who are taking part in the Study Congress that the Pontifical Academy for Life has sponsored on the theme: "Quality of life and ethics of health". I greet you in particular, venerable Brother, and offer you my congratulations and good wishes on your recent appointment as President of this Academy. I also extend my greetings to the Chancellor, Mons. Ignacio Carrasco, to whom I also wish success in his new office. I next address thoughts of deep gratitude to eminent Prof. Juan de Dios Vial Correa, who has retired from the presidency of the Academy after 10 years of generous and competent service.

Finally, a word of special thanks goes to all the Members of the Pontifical Academy for their diligent work, especially valuable in these times, marked by the manifestation of many problems in society related to the defence of life and the dignity of the human person. As far as we can see, the Church in the future will be increasingly called into question on these topics that affect the fundamental good of every person and society. The Pontifical Academy for Life, after 10 years of existence, must therefore continue to carry out its role of sensitive and precious activity in support of the institutions of the Roman Curia and of the whole Church.

**2.** The theme addressed at this Congress is of the greatest ethical and cultural importance for both developed and developing societies. The phrases "quality of life" and "promotion of health" identify one of contemporary society's main goals, raising questions that are not devoid of ambiguity and, at times, tragic contradictions. Thus, they require attentive discernment and a thorough explanation.

In the Encyclical *Evangelium Vitae*, I said regarding the ever more anxious quest for the "quality of life" typical of the developed societies: "The so-called "quality of life" is interpreted primarily or exclusively as economic efficiency, inordinate consumerism, physical beauty and pleasure, to the neglect of the more profound dimensions - interpersonal, spiritual and religious - of existence" (n. 23). These more profound dimensions deserve further clarification and research.

**3.** It is necessary first of all to recognize the essential quality that distinguishes every human creature as that of being made in the image and likeness of the Creator himself. The human person, constituted of body and soul in the unity of the person - *corpo et anima unus*, as the Constitution *Gaudium et Spes* says (n. 14) -, is called to enter into a personal dialogue with the Creator. Man therefore possesses a dignity essentially superior to other visible creatures, living and inanimate. As such he is called to collaborate with God in the task of subduing the earth (cf. Gn 1: 28), and is destined in the plan of redemption to be clothed in the dignity of a child of God.

This level of dignity and quality belongs to the ontological order and is a constitutive part of the human being; it endures through every moment of life, from the very moment of conception until natural death, and is brought to complete fulfilment in the dimension of eternal life. Consequently, the human person should be recognized and respected in any condition of health, infirmity or disability.

**4.** Consistent with this first, essential level of dignity, a second, complementary level of quality of life should be recognized and promoted: starting with the recognition of the right to life and the special dignity of every human person, society must promote, in collaboration with the family and other intermediate bodies, the practical conditions required for the development of each individual's personality, harmoniously and in accordance with his or her natural abilities.

All the dimensions of the person, physical, psychological, spiritual and moral, should be promoted in harmony with one another. This implies the existence of suitable social and environmental conditions

to encourage this harmonious development. The social-environmental context, therefore, characterizes this second level of the quality of human life which must be recognized by all people, including those who live in developing countries. Indeed, human beings are equal in dignity, whatever the society to which they may belong.

**5.** However, in our time the meaning which the expression "quality of life" is gradually acquiring is often far from this basic interpretation, founded on a correct philosophical and theological anthropology.

Indeed, under the impetus of the society of well-being, preference is being given to a notion of quality of life that is both reductive and selective: it would consist in the ability to enjoy and experience pleasure or even in the capacity for self-awareness and participation in social life. As a result, human beings who are not yet or are no longer able to understand and desire or those who can no longer enjoy life as sensations and relations are denied every form of quality of life.

**6.** The concept of health has also suffered a similar distortion. It is certainly not easy to define in logical or precise terms a concept as complex and anthropologically rich as that of health. Yet it is certain that this word is intended to refer to all the dimensions of the person, in their harmony and reciprocal unity: the physical, the psychological, and the spiritual and moral dimensions.

The latter, the moral dimension, cannot be ignored. Every person is responsible for his or her own health and for the health of those who have not yet reached adulthood or can no longer look after themselves. Indeed, the person is also duty bound to treat the environment responsibly, in such a way as to keep it "healthy".

How many diseases are individuals often responsible for, their own and those of others! Let us think of the spread of alcoholism, drug-addiction and AIDS. How much life energy and how many young lives could be saved and kept healthy if the moral responsibility of each person were better able to promote prevention and the preservation of that precious good: health!

**7.** Health is not, of course, an absolute good. It is not such especially when it is taken to be merely physical well-being, mythicized to the point of coercing or neglecting superior goods, claiming health reasons even for the rejection of unborn life: this is what happens with the so-called "reproductive health". How can people fail to recognize that this is a reductive and distorted vision of health?

Properly understood, health nevertheless continues to be one of the most important goods for which we all have a precise responsibility, to the point that it can be sacrificed only in order to attain superior goods, as is sometimes demanded in the service of God, one's family, one's neighbour and the whole of society.

Health should therefore be safeguarded and looked after as the physical-psychological and spiritual balance of the human being. The squandering of health as a result of various disorders is a serious ethical and social responsibility which, moreover, is linked to the person's moral degeneration.

**8.** The ethical relevance of the good of health is such as to motivate a strong commitment to its protection and treatment by society itself. It is a duty of solidarity that excludes no one, not even those responsible for the loss of their own health.

The ontological dignity of the person is in fact superior: it transcends his or her erroneous or sinful forms of behaviour. Treating disease and doing one's best to prevent it are ongoing tasks for the individual and for society, precisely as a tribute to the dignity of the person and the importance of the good of health.

Human beings today, in large areas of the world, are victims of the well-being that they themselves have created. In other, even larger parts of the world, they are victims of widespread and ravaging diseases, whose virulence stems from poverty and the degradation of the environment.

All the forces of science and wisdom must be mobilized at the service of the true good of the person and of society in every part of the world, in the light of that basic criterion which is the dignity of the person, in whom is impressed the image of God himself.

With these wishes, I entrust the work of the Congress to the intercession of the One who welcomed the Life of the Incarnate Word into her life, while as a sign of special affection, I impart my Blessing to you all.

From the Vatican, 19 February 2005

## JAVIER LOZANO BARRAGÁN

### TEN YEARS AFTER “EVANGELIUM VITAE”. THE QUALITY OF LIFE

I believe that the best homage which we can offer to commemorate the tenth anniversary of the Encyclical “Evangelium Vitae” is a tentative to reflect on the meaning of the true quality of life. Very interesting themes are often considered in an erroneous sense and subsequently, we try not to discuss them any further, leaving behind a very great treasure. In this Assembly a deeper reflection on the theme will be presented and, given the importance which it has for the Pontifical Council for Health Pastoral Care, it seemed appropriate to me to express some ideas on the subject here as well.

In talking about the quality of life, we refer to an evaluation of life and to the ability to say that the life of one person has a better quality while that of another has less quality. It is obvious that in order to measure we need a measure, a yardstick; therefore, at once a problem presents itself: what is this yardstick, and where can it be found?

When this problem was proposed in the history of humanity, and more concretely, in the history of human thought, one arrived at the very nucleus of human existence, as the answer cannot be different from that which one gives on life itself: what is life?

On a previous occasion, in this same location, I had the opportunity of presenting a reflection of mine on this question: what is life? My answer was “it is the total giving of love which is possible in the relationship between the giver and the one who gives and who, by divine paradox, while both giving to each other, live longer and better.

It appears to me that this thought is alien to the way of viewing things nowadays according to the mentality of postmodernism, which has very strange concepts with regard to the quality of life. In addition to the yardstick of life mentioned, many other distinct measures are used, according to the way which we adopt to conceive life. In order to comprehend each other better, let us refer to some concepts which appeared emblematic to us.

### A PSYCHOLOGICAL AND QUANTITATIVE PROSPECT OF THE QUALITY OF LIFE

The technological computerised school of thought

For some people, who are dominated by the technological computerized school of thought, the quality of life is perceived in a curious way. The human person is imagined, half-way between metaphor and reality, to be a computer which comes directly from the brain. The brain is, as it were, the “hardware” and the mind corresponds to the “software”. The quality of life is measured according to the quantitative increase in both: according to the greater or lesser capacity to receive information and to the amount of information actually received. Sickesses which, like “viruses”, aim to destroy both the “software” and even the “hardware”, oppose the quality of life. Such sickesses are like many other “bugs” which destroy the harmony of computer technology and take leave of the intricate world of “internet” or the great global motorway of the world.

This measure of the quality of life would appear unthinkable, but it is not far from the modern school of thought, according to which the manner of measuring is only of a quantitative mechanistic style, or else of a psychological nature, where life and people are valued by their level of awareness, that is, quality is measured by wellbeing or by the presence of self-awareness and psychological health.

Similarly, this concept of the quality of life has already been the goal from the time of the W.H.O.’s definition of health of a long time ago at Alma Ata (1948), interpreted as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”, in which the measure is quantitative or even, in the best of cases, mental or social.

## The psychological perspective

In fact, today, especially in the new paradigm of the United Nations, the mental and social aspect is emphasized more; indeed, the quality of life was defined as “the individual’s knowledge of his position in life, in the context of the culture and system of values in which he finds himself, as he makes for his goals,

There are also the theories of preference: they propose the role of an individual’s autonomous choice in guiding their own choices as being central to the quality of life, and there are also the theories of perfectionism which identify the promotion of the quality of life with the exercising of some capacities that are entirely human. What is essential for the promotion of the quality of life is the presence of an effective capacity to develop in areas which belong in a particular and universal way to human beings, as in relationships of affection, the capacity to reflect on things, creativity, etc.

Others interpret the quality of life as the relationship between needs and desires, that is, the society which wants to develop and make progress once its basic needs are satisfied, that seeks the satisfaction of its desires and aspirations, achieving an ever greater well-being, which is the quality of life. This is equivalent to understanding the quality of life as being exclusively or predominantly economic efficiency, consumerism, beauty and joy in life in its physical and corporeal dimension[1].

## The pragmatic utilitarian perspective

According to the pragmatic utilitarian perspective, a life has value only if it possesses a certain level of “quality”; it is evaluated in relationship to the minimization of pain and often of economic costs.

According to this perspective, based on an ethic of consequentiality, the value of human life depends on different levels of “quality”, independent of any value greater than life itself. There are lives whose qualities render them worth living and there are others which are not worth living. The measure has been fixed in different ways. Some people adopt the following criteria: a minimum intellectual capacity (I.Q. greater than 20-40), self-awareness, self-control, orientation in time (past, present, future), capacity to relate to others, interest for others, capacity to communicate, control of one’s (own) existence, curiosity, capacity to change, balance of rationality and feeling, neocortical functions[2].

There is also a hedonistic perspective for measuring the quality of life; according to this yardstick, the quality of life depends on the presence of pleasurable states of mind and on the absence of unpleasant or painful states of mind; therefore the quality of life should be considered positive if unpleasant or painful states of mind are absent.

## The socio-biological perspective

According to the socio-biological perspective, it is necessary to deal with the protection of the environment as an urgent remedy in order to reach an acceptable quality of life. The balance between the (various) forms of life in the world, their reciprocal relationship in order to defend the health of the living environment, are factors considered to be indispensable for the quality of life. In this system of interdependence between these forms of life, people are the main users, the guardians of resources and, at the same time, the major agents responsible for their deterioration[3].

There are also other perspectives according to which the quality of life is represented by the sum of economic goods necessary in order to live, which, in turn, are measured with reference to the gross national product. However, some people do not accept this standard, as the GNP cannot become the criterion because of the environmental pollution which provokes its growth; thus, they prefer to speak in terms of the NEW, that is the net economic well-being, which takes into account not only production but also respect for the environment, work conditions, use of free time, etc. Nevertheless, the influence

of the family and of society should be added as essential data to the NEW, in order to be more comprehensive[4].

In these descriptions of the quality of life there is a standard which remains at a mechanistic or psychological level. Curiously, even the post-modern school of thought does not go beyond the Cartesian foundation of reality, considered to be a projection, and of the person, considered to be a consciousness. The standards used are yardsticks which are entirely of a human nature and commit the fatal error of confusing the way of measuring with what is measured. It has often been said that man is the measuring stick of his life, but insofar as he is a person, not as in an abstract human being; but as this concrete person dies, how can death be the yardstick of the quality of life?

Awareness of this absurdity in the last century brought, in a tragically logical manner, to existentialism and to finding palliatives for disguising the misfortune in stereotyped phrases like “having the courage to live for death”, “to live absurdity with dignity and courage”. Meaningless phrases which do not solve anything. On the other hand, in Marxism, survival in the future community was discussed, although, insofar as it was of the future, it did not solve the misfortune of the present. Nowadays, in post-modern times the old solution of burying one’s head in the sand is preferred, drowning oneself in a culture of desires, consumerism and of all types of freedom, creating a society of pleasure, power, instinct and bestial force without regard for the hunter, death. However, as we said, these yardsticks are not yardsticks but exactly the opposite of a measuring stick, they are defeat in a battle against a reality which is always present and close by: death.

## LOOKING TOWARDS AN AUTHENTIC QUALITY OF LIFE

I believe that the quality of life, the namely the best life, could logically be no other than that which conquers death and gives us a continuous life, growing until the definitive victory. This quality should be physical as much as mental and social. Nonetheless, here the facts contradict us, even from a physical point of view, as the ageing of cells is in contrast with their continual growth.

### The quality of life as universal harmony

Some people, on arriving at this point, confronted by the inevitability of death, have deemed that the quality of life should not be measured from a physical point of view, but that transcendence should be achieved through virtue. So it was in the former stoical manner of conforming oneself to the harmony of the universe and feeling oneself to be a particle of Nature. It has also been considered in this way in the concepts of the Renaissance in the organic model of Nicola di Cusa or Paracelso and in present times, in the Buddhist model which also includes the extinguishing of desires. However, our experience of this quality of life, cold and impersonal, is that it does little to satisfy our needs and leaves us in the darkness of death.

### The quality of life seen as values

Nowadays, it is said that we have lost the quality of life just because we have lost our values. Values such as justice, honesty, truthfulness, respect for others, sincerity, industriousness, etc. In actual fact, there is no doubt that these values depict one’s life in a positive light, and in some ways, may be considered a measure of the quality of life. Nevertheless, the values themselves, in spite of being so noble and improving one’s life, are not an adequate measure of the quality of life, for the additional reason that a life studded by such values does not escape from death in any case.

### The quality of life seen as a giving of oneself

In the reality of history we know that, beyond the desire for immortality present in every culture, a wonderful event has happened, the only event, we can say, that characterizes life, because it is one that has conquered death: the resurrection of Jesus Christ. And this event does not remain external to men and women but can be applied, in this form, to those who wish to accept it, being transformed in everyone into true life in all its fullness. The way in which we can acquire this life is only through the personal all-powerful love of the Father and of Jesus Christ Himself, which is the person of the Holy Spirit. Thus the Father gives us life that never ends. This life follows all the tracks of the life of Jesus Christ, who is in fact “the way/path, the truth and the life”. The measure of life in Christ is the measure of the gift of life itself and the measure of this gift is the love of identifying oneself with Christ, namely the Holy Spirit.

### The quality of life seen as creative divine and human love

Therefore, the quality of life has only one measure: love. However, it is not just any form of love that is transient, but a personal divine love which falls in love with our human love and renders it eternal. The measure is the divine human love which the Father sends us with His Spirit. This Love which breaks the limits of mortality is love because it identifies us with Christ, the conqueror of death.

This infinite love has a creative power. At the beginning of all things, “the Spirit hovered on the waters” and God created everything from nothing, from the confusion. Nowadays, we have the obscure nothingness of death. The Spirit returns once more to hover on the destructive turbulent waters of death, and creates, from death and destruction, new life that never ends, the Spirit creates the Resurrection. Christ, on the cross, commended His Spirit to the Father, and the Father, with the infinite loving strength of His Spirit, raised the Son from death. Therefore, the true measure of the quality of life is the measure of the gift of the Spirit.

For this reason, the quality of life is to be measured with the “yardstick” of Christ Himself who is the total gift of self to others unto death. It is a love which leads to death in its fullness of love, and only in this way does it transform the darkness of death into light, the end into a beginning, the tomb into a crib, and defeat into victory.

### The quality of life seen as the most Holy Trinity

If we elaborate what has been said, the quality of life becomes more of a motor than a measuring stick. The motor is the presence of the most Holy Trinity in a man or woman. Thus, the quality of life is the quality of life of the most Holy Trinity that consists of a complete and loving self-giving of each other. The Father gives all of Himself to the Son, and the Son gives all of Himself to His Father; from this mutual self-giving comes the Holy Spirit. Therefore, the quality of life is an ontological entity before being a gnosiological entity: the presence of the Trinity in us through Christ who dies and rises from the dead. Consequently, the greater the measure of one’s love - the more his or her giving of self, the better life each one of us has.

This self-giving reaches its peak when we take our whole life in our hands as we die, and offer it all lovingly to the Father through the love of the Holy Spirit. It is possible only when we let ourselves be penetrated by the love of the Spirit. It is a gift, the greatest gift. Thus, the Spirit presents us with the penultimate step of the quality of life which is death that is like an abundant ripening which bears the fruit of resurrection.

Therefore, an authentic quality of life conquers the fear of death and becomes transformed, with the trustful hope of love, into a song of victory. In this case, the quality of life is transformed into pure spirituality, since it is the task of the Spirit of Love.

#### The quality of life seen as well-being

This manner of conceiving the quality of life would thus appear to be very far from the initial descriptions of the quality of life as well-being, or else, opposed to the quality of life as fullness of life, physical, mental and social, here in the world. However, it is not so; in fact, physical, psychological and social well-being shall be the fullness of the quality of life in the resurrection, and obtaining it now means having a foretaste of the same resurrection, especially with regard to the treatment of sickness, although we are aware that such well-being is only relative, and merely points the way to the definitive resurrection.

#### The quality of life seen as awareness

While referring to the quality of life as self-giving, perhaps it could be said that if someone is not capable of giving himself or herself, he or she does not have quality of life. Consequently, those who are not conscious, at the beginning (of life), permanently or transiently, as in the case of embryos, mentally handicapped people, or sick people who are unconscious, who cannot give of themselves, would (supposedly) not have quality of life.

We said that the self-giving is not a human gift but a divine and human giving, that is, it is the measure of the acceptance of the gift of the Holy Spirit. And this gift is found in some way in all people from the moment of their conception. Therefore, it can be found in embryos and in people who, for whatever reason, are unaware or unconscious in a given moment. Self-giving characterizes a person, since the latter can exist only if it is the result of self-giving. The same quality of life is the foundation of dignity in a human being, and thus he or she identifies himself or herself with this (model). It is certain that the quality of life is not static, but can grow according to the circumstances and the actions of each person. Nevertheless, there is always an essential quality of life which is applicable to every person from the beginning of his or her existence and which gives rise to his or her original dignity.

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[1] JOHN PAUL II, *Evangelium Vitae*, No. 23; CDF, “Instruction Declaration on voluntary abortion”, 18th of September, 1974- 11.

[2] FLETCHER J., *Four Indicators of Humanhood-The Enquiry Matures*, HastingsCenter Report 1975, 4:4-7.

[3] SGRECCIA E., *Bioetica, società, sanità e qualità della vita*, in ID., *Manuale di Bioetica*, vol II, Milano: Vita e Pensiero, 2002: 15

[4] Cfr. LOZANO BARRAGAN J., *Teologia e Medicina*, Bologna: Ed. Dehoniane, 2001: 12-13.

## **MAURIZIO FAGGIONI**

### **The Quality of Life and Health in the light of Christian Anthropology**

With the simple use of the word "and", our title makes a tenuous connection between two expressions having complex and varied meanings, placing them in the light of the Christian vision of the human person.

In this introductory discourse we will examine concisely the semantic weight of these two expressions, so recurrent in the bioethical debate of our time, and thereby seek to confer upon them a determined meaning that roots itself in the Christian vision of man.

#### **HEALTH**

The categories of health and its mirror image, illness, refer to two realities that seemingly have simple definitions. In effect, however, their precise delineation proves to be quite complex and far from unambiguous, since they depend on diverse and not always clearly explained[1] anthropological models.

The traditional category of health was typically spoken of in medical terms, defined as it was as the "absence of illness". It took as its point of departure the understanding that illness was a deviation from the conditions normally required for the ideal functioning and integrity of an organism. In the 20th century a new vision was set forth that sought to overcome the "medicalization of health" - to use the effective phrase of Illich[2] - and that expanded the study of health to include a consideration of social structures and structures of labor, recreation, education, housing, and food.

To this enlarged understanding may be added the famous definition of health from the World Health Organization (WHO) in 1946: "Health is a state of complete physical, psychological, and social well-being and not merely the absence of illness or infirmity"

The promotion of health, then, is much more than the removal of pathogens or the restoration of an ideal organic normality; it is also the promotion of behaviors and standards of living that afford the person the attainment of full psychological, physical and relational well-being. If health is to become a global reality, it must be promoted through the efforts and cooperation of all those fields that embrace physical, psychological, and social well-being. It cannot fall solely under the scope of medicine. Rather, medicine and health politics must be integrated. The same field of medicine that at one time almost exclusively laid claim to curing illnesses now feels ever more beholden to efforts aimed at prevention and at the promotion of healthy lifestyles. Health becomes ever more understood as a goal that is to be pursued collectively, as an index of progress for a society, and as a proving ground for those who have been given public responsibility.

Because health is an essential good of the person, it is reasonable and right that society should devote itself to recognizing and promoting the "right to health" of every person. Only with such societal involvement can health, in a more expanded way, be adequately protected. The precise meaning of this "right to health" can often be misunderstood. The expression "right to health" is not synonymous with a "right to be in health," since the attainment of good health is often not achievable through medicine or other human means. There does exist, however, the right to be aided by society through some sort of socialized medicine in order to regain or conserve one's health. This assertion - seemingly indisputable - is nevertheless in practice challenged by many distressing questions. Can we truly guarantee all means to all people in the area of health services? Can we really put all biomedical technologies at the disposal of every person? Rather, perhaps an expanded notion of health could content itself to furnish to everyone only a "decent minimum?" And finally, what must "minimum" mean; what must "decent" mean?

The theme of health intertwines itself necessarily with the theme of justice. Questions of health justice arise at both the global and local levels. At the global level for example, one discerns how to ensure equitable distribution of health resources, complicated by the fact that the level of health care deemed minimal by Northern countries would often be deemed excessive by Southern countries. At the local level, one discerns whether the treatment of patients in public hospitals should be based upon a fixed budget or rather upon the patients' real clinical needs. Or again at the local level, one discerns whether or not to provide therapies to a patient who can no longer enjoy even a minimal level of well-being, realizing that in thus holding back such "futile" therapies one is also denying the patient's abiding right to have access to treatments. It is bewildering to think that a fundamental right of a person, like the right to health, can vary so significantly depending on one's cultural, social, political and existential contexts. A paradigmatic modern example regards the treatments to counteract AIDS; the availability of such treatments varies dramatically depending on one's location on the globe. Similar examples could be offered ad infinitum. The slogan "Health for all" and the definition of health as a "state of complete well-being" ring hollow to the millions of poor in the world, evoking an empty rhetoric of nice words rather than describing a project that has been initiated and that can be brought to completion.

It would be good to now consider the definition of health offered by the WHO as "a state of complete well-being". This definition has merit in that it proposes a multidimensional or holistic vision of health, yet it also reveals the subjective aspect of health, for it makes "health" dependent on the perception of culture.

Two points should be made here regarding the definition. First, it favors a crudely utilitarian reading of health by establishing a strict connection between personal well-being and one's capacity to respond to social and cultural expectations. The same WHO, in another less famous but not less significant affirmation, linked the meaning of existence to productive capacity, defining health as "the state of physical and mental well-being necessary for living a pleasant and productive life, and one rich in meaning." The duty of medicine, according to this perspective, is to counteract and - if possible - to eliminate illness with its symptomatic progression in a way that reintroduces the sick person to the so-called active life or, at least, that reduces the burden on society by ending one's need for assistance and treatment.

Second, the conception of health as a state of complete well-being offers, in fact, a secularized vision of salvation and an illusory promise that man can procure for himself by his own means the fullness of well-being in this life. As a consequence, an unrealistic expectation is created that medicine will be able to respond to all needs and desires of persons. In such a "medicine of desire" the subjective dimension of health becomes emphasized to the point of confusing the right to health with the right to see satisfied one's desires. The medicine of desire, which promotes the idea of medicine as a business and which increases the requests for pharmacological and medical-surgical treatments, seems to be now absorbing public resources beyond reasonable levels.

## QUALITY OF LIFE

The lights and shadows contained in the concept of health as a state of well-being became more focused and clearly expressed, beginning in the 1950's, in the newly coined category of "quality of life". We can say that this category of quality of life has become the standard way of referring to health in terms of well-being, with an emphasis on its subjective dimensions.

In the literature of bioethics the notion of quality of life is a constant theme, though it is not always adequately articulated. It is easy to verify that, in general, the defenders of the so-called "quality of life bioethics" offer many approaches to making quality of life calculations, and seriously attempt to refute the rival paradigm, represented - according to many of them - by the "sanctity of life bioethics", though their attempts to ground and rigorously define "quality of life" itself are less convincing.[3]

From the theoretical point of view there are various attempts to define this concept,[4] though certain common themes can be singled out. First of all, it is said that quality of life refers to a person's

agreeable or disagreeable state of mind in response to his psychosomatic and social conditions. From this it follows that obtaining a good quality of life consists in creating the conditions for a gratifying life and in removing painful or distressing conditions. According to this approach, for example, health-care politics should be used to allocate resources in order to advance quality of life by providing helpful products and by removing disagreeable conditions. The insistence on the subjective dimension of quality of life, taken to the extreme, can introduce a certain relativism that, in the end, denies any objective evaluation of it at all. Different subjects, in fact, will often identify different things that make up a good quality of life, and this variability, if it is not tempered by objective criteria, results in an absolute indeterminism, vitiating any attempts to evaluate the value of life based on rational foundations and on verifiable and constant criteria.

Many authors, attempting to overcome the difficulties deriving from an exclusive emphasis on the subjective components of quality of life, try to ground it objectively by measuring it against certain capacities said to be properly human. Some, like H. T. Engelhardt, identify these capacities with the integrity of cerebral functions, self-awareness, and rationality. Others, like Flettcher, identify quality of life with a level of human life that has at least a minimum level of intellectual capacity, self-awareness, self-control, sense of time, capacity for relationships, interest in others, capacity to communicate, capacity to change, balance between reason and sentiment, and neocortical functions. Such attempts to identify the meaning of quality of life do have an important goal, for it is admittedly necessary for us in society to share a clear and common vision of what the typical human capacities ought to be. Yet such attempts leave unresolved the question of whether or not a human life that is incapable of expressing such capacities retains its value or - which amounts to the same thing - if the duty remains to protect and care for such a life. In other words, whether one evaluates a person's quality of life by measuring the level to which goods are enjoyed and happiness attained, or whether one evaluates it by measuring the level to which typical human activities and capacities are manifested, the quality of life category ultimately disregards the most profound, ontological, and non-utilitarian dimensions of the human being.[5]

In this vein a collaborative international group of the WHO defined quality of life as "individuals' perceptions of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concern"

The notions of quality of life always reflect the anthropology that sustains and grounds them. In fact, it is anthropology, often implicit and not articulated, that provides a frame of reference for what is intended by "a good life", "a happy life", "a pleasant life", or "a life worth living". More radical still, anthropology indicates what is intended by "human", that which we are obliged to protect and promote. Normally, in the anthropological field, defenders of "quality of life" in this sense assume a highly simplified anthropology. Similarly, in the neocontractualist approach, there are authors who tend to recognize as truly human, in an ontological sense, only those beings who actualize the capacities or qualities held to be typically human, and exclude from citizenship in the moral community those who no longer display, or who do not yet display, clear indications of human self-awareness or a capacity to establish interpersonal relationships.[6] For such authors the person is constituted, rather than revealed, by the signa personae. The value of each human life, and of the same human life in the different conditions and times of its history, depends on the presence of some minimum characteristics or qualities that are held to be relevant. There is, moreover, a correlation between the level of such qualities and the strength of the person's right to exist and to receive care and assistance.

We can recognize here the "short-circuit" logic of much secular bioethics. These notions of quality of life are supported by an anthropological framework that tends to identify as truly human only those subjects who are already living or are able to live a good quality of life. The notion of quality of life, in other words, is not only an ethical criterion to establish the right to protection and the duty of society to care for someone, but it also contributes to a definition of the human being. There are lives which do not

adequately reach standards of performance, and which are therefore held to be unworthy of protection or of the same protection that lives of good quality enjoy.

The quality of life ethic, understood in this way, leads inevitably to discrimination toward human beings regarding their dignity and rights. Equality among all human beings is the common foundation and presupposition for our mutual life on this planet, and the essential foundational principle of the modern democracy. The quality of life category, however, when used as a criterion for determining the value of human life, denies the natural and cultural foundations of equality and introduces an ethic of inequality. Even if it is true - as Adriano Pessina argues - that "the thesis of (ontological) equality among men, and thus the equality of their intrinsic worth, is historically indebted to philosophy or the Judeo-Christian religion, . . . these origins do not rule out an approach to recognizing the dignity of man in a way which does not depend on these foundations."<sup>[7]</sup>

Tragically, this ethic of inequality purports to be highly reasonable, and pretends to prove with objective facts (acts, psychosomatic conditions, phases of life, behavioral performance...) an inequality which is a pure cultural construction.

#### HEALTH AND QUALITY OF LIFE IN THE CHRISTIAN PERSPECTIVE

The quality of life ethic is often contrasted - in an overly simplified manner - to a sanctity of life ethic. The contrast between these two expressions can be overcome, as we shall see, but it is comprehensible if we keep in mind that the two expressions, in the bioethical debate, are used in certain anthropological and ethical contexts and thus their notional content is determined by a certain philosophical framework<sup>[8]</sup>.

The "quality of life" bioethic presupposes that life is ethically defined by its quality and posits that there is an inequality of value among different human lives. The "sanctity of life" bioethic, on the other hand, refers to the fundamental idea that the value of a human life does not depend on an appreciation and evaluation of its accidental qualities, but rather on the very fact that it is a human life. To affirm the sacredness of every human life and to posit the equality and intangibility of human dignity does not mean that one denies that there is a diversity of qualities among humans, some desirable and some undesirable. Nor does it deny that for some people, perhaps for many, life is not happy, complete, and fully realized. It does strongly deny, though, that such fragile and suffering existences have any less value or dignity.

The moral agent is called, therefore, not to attribute value, but rather to recognize the intrinsic value of every human life in virtue of its very humanness. Monsignor Carrasco De Paula has rightly noted that the expression "value of human life" is actually an abbreviated form "of the more precise phrase value of the living man in virtue of being alive."<sup>[9]</sup> Life is not a good that one possesses and that can be abandoned or extinguished once it no longer seems to be a desirable or useful good, but rather is the complex experience of existence. I do not have a life; I am a living being.

The category of sacredness is much misunderstood and is much criticized by secular bioethics, which often has an anti-religious and anti-metaphysical point of departure. Many view the category of sacredness as having a quasi-magical intonation and accuse Catholic morality of a crude vitalism or of an absolute and unconditional exaltation of biological life, deriding it for its supposed attachment to a pre-scientific vision of life. Others, such as H. Kuhse in a celebrated essay, speak of the intangible nature of the sanctity of life and justify such intangibility by the divine command: "Do not kill." Others seek to find a new category of sacredness; sacredness that is detached from the religious context in which it was born and through which it becomes fully intelligible; sacredness that is demythicized. One would then attribute a value to human life based on a sanctity of life that is understood in an evocative, emotive, and parenthetical sense, and would push people to respect it based on this understanding. Some look to science, above all in the theories of evolution, in the neurosciences, in etiology, and in sociobiology for evidence of an interrupted continuum between human and animal life, in order to overcome the ontological difference between man and animal and to deny any special value, not to

mention sacred value, of human life. Anthropological reductionism is the true underpinning of much of the secular bioethics and anthropology that is so diffused in culture today, and carries in itself an incapacity to grasp the multidimensionality of the human person, the value of the person's life, and the ultimate meaning of the person's existence.[10]

On the other hand, the deep conviction regarding the dignity, value, and autonomy of the person represents one of the very characteristic elements of the Christian anthropological proposal. In substance, in order to respond to the challenges of anthropological reductionism, one must reaffirm the difference between the human being and every other being and therefore its excellence, as one reads in the famous passage of *Gaudium et Spes* that describes the constitutive aspect of man:

Being a unity of body and soul, humanity concentrates in its physical dimension the elements of the material world . . . Humankind is not mistaken in recognizing its superiority over bodily things . . . By its interior life it far exceeds the totality of things.[11]

Christian thought, from the very first attempts to ponder the faith on the part of the Fathers, has maintained as undeniable the affirmation of the exceedence of man; he exceeds his biological and material components. Christianity has found it convenient to express this exceedence by returning to the term *theologoumenon* of the soul. It is precisely in this context that the ethical category of "sanctity of life" is traditionally situated.

For Catholic bioethics "human life is sacred because, from its beginning, it carries the creative action of God and remains always in a special relation with its Creator, its unique end." [12] This createdness of man is a fundamental fact of Christian anthropology. Man is a creature and so, like every other creature, is understandable only in relation with God. The human creature's relation with God, however, is absolutely unique, because it is a constitutive and exclusive relation. It is a personal relation that makes of man a person, a reality disposed to transcending all things and to opening itself outwards, with a dynamic motor and force that leads it toward an ever greater actualization and fulfillment.

The value of human life therefore is not derived from that which a subject might do or express, but rather simply from its existence and from its being constituted in relation with God: the roots of the value and of the inviolability of every human life rests ultimately in God. Young or old, healthy or ill, embryo or neonate, genius or idiot, the value of every human being is above all independent of the quality of its performance or life; that which counts is the fact of its being in relation with God. The teleological roots of this fundamental value were beautifully described in the instruction *Donum Vitae*: Physical life, with which the course of human life in the world begins, certainly does not itself contain the whole of a person's value, nor does it represent the supreme good of man, who is called to eternal life. However, it does constitute in a certain way the "fundamental" value of life, precisely because upon this physical life all the other values of the person are based and developed. The inviolability of the innocent human beings' right to life "from the moment of conception until death" is a sign and requirement of the very inviolability of the person to whom the Creator has given the gift of life.[13] The Christian vision of the person and of the value of his life brings us thus to develop an understanding of the categories of health and of quality of life that does not reject the constructive contributions of secular thought, but rereads them from an original perspective.

Christian anthropology, thus attentive to stressing the unity of the person in his multidimensionality, proffers a holistic notion of health and illness, in which bodily, psychological, and spiritual elements interact with one another, without denying or neglecting the necessary relational aspects. Just as human life cannot be reduced solely to its biological dimensions, but rather involves the multidimensionality of the human person, so too human health cannot be reduced to any one of the dimensions of man, but rather involves the harmonization and integration of all of a person's energies: physical, psychological, and spiritual. Health, in this much fuller sense, can be considered, as defined by Karl Barth, "the power to be man." [14]

The right to health does not encompass establishing a standardized level of quality of life. Health does consist of the equilibrium and harmony of a person, but not an equilibrium and harmony given for all

and to all in the same manner. Promoting the health of a subject, then, means helping him to live his life in the most authentic manner starting from the concreteness of his psychological-physical state. Each person must be helped to find his own harmony and equilibrium in his particular state of life, for the right to health is not realized only by those who enjoy some predetermined or fixed quality of life. The right to health of each person is derived from his or her right to life, a right rooted in the very life of God Himself, out of who comes all other life. The right to health is a right that logically precedes its recognition by society because health, though defined by culturally conditioned categories, is not purely or simply a socio-cultural construct. Rather it stems from one's most basic right to life and is the very capacity to live that life.

While the exaltation of the value of the body today is leading to an extreme health craze, to a kind of idolatry of bodily appearance and vigor, and to a neopagan hedonism that is unable to accept the realities of illness and of the progressive decline of mind and body as authentic experiences, Christian anthropology makes it possible to discern between a reasonable care for health on one hand and the emergence of a modern, infantile desire for omnipotence on the other. In this same light it is possible also to grasp the value of life, even after it declines in physical, mental, or social health and is reduced to a minimal quality. Even there, where human life is judged to be of the lowest quality, the essential quality of life still remains, that which depends solely upon the intrinsic value of human life itself. Protecting a subject's health then, signifies helping him to actualize the intrinsic goodness of his own existence along a journey that continuously unwinds from his first rising, at the moment of conception, until his final extinguishing, in death. It is never good for another to act against his incarnate existence (such as in euthanasia or assisted suicide) because doing so negates the value of his existence instead of affirming it. Neither can it ever be good for one to care for health in such a way as to negate other truly essential dimensions of one's human being, such as freedom or love (such as in the area of so-called reproductive health).

Taking care of one's own health or that of another signifies that one recognizes the value of the human person's existence in all of its aspects and articulations. Taking care of the health of another is my fundamental ethical responsibility through which I welcome his existence as my neighbor and as one like myself. Taking care of the health of another signifies that I accept his appeal to my conscience; that I accept the human reality of dependence; and that I accept my own dependence on others. Each of us comes from others; each depends for his existence on others; this truth is the key that enables us to grasp our own original dependence as creatures. In fact, in the moment in which I welcome my relation to another and accept that he or she depends on me, my mind is opened to grasp the mysterious, natural, original limitedness and the radical creaturely dependence of the human being. Taking care of the life of another signifies, therefore, that I affirm that God does in fact exist and that man is in his image.

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[1] ENGELHARDT D. VON, Health and Disease. History of a Concept, in REICH W. T. ed., Encyclopedia of Bioethics, vol. 2, New York 1995, 1085-1092; SCHOCKENHOFF E., Etica della vita, Brescia 1997, 219-242; VIAFORA C., Malattia, in COMPAGNONI F. ed., Etica della vita, Cinisello Balsamo 1996, 81-116.

[2] ILLICHI., Medical Nemesis. The Expropriation of Health, London 1975.

[3] From the available literature, see for example: BOWLING A., Measuring disease: a review of disease-specific quality of life measurement scales, Philadelphia 2001; DAUM M. The quality of life report, New York 2003; LECALDANO E., Questioni etiche sui confini della vita, in DI MEO A., MANCINA C. curr., Bioetica, Roma-Bari 1989, 19-39; SHAW A., Defining the Quality of Life: a Formula Without Numbers, "Hastings Center Report" 7 (1977), 5-11; ID., Q1 Revisited, "Hastings Center Report" 18 (1988), 10-12.

[4] Cfr. SANDØE P., Quality of Life – Three Competing Views, "Ethical Theory and Moral Practice" 2 (1999), 11-23.

[5] In this sense the affirmation of Evangelium Vitae n. 23, according to which “the so-called quality of life is interpreted primarily or exclusively as economic efficiency, inordinate consumerism, physical beauty and pleasure, to the neglect of the more profound dimensions – interpersonal, spiritual and religious – of existence.”

[6] Typical of this approach is H. T. ENGELHARDT, *The Foundations of Bioethics*, Oxford 1996, 239.

[7] PESSINA A., *Bioetica. L'uomo sperimentale*, Milano 1999, 74.

[8] For fuller treatment, see various perspectives: CHODI M., *Tra cielo e terra. Il senso della vita a partire dal dibattito bioetico*, Assisi 2002, 45-94; FERNgren G. B., *The Imago Dei and the Sanctity of Life: the Origins of an Idea*, in MCMILLAN R. C., ENGLEHARDT J. R., SPICKER S. F. eds., *Euthanasia and the Newborn*, Dordrecht (ND) 1987, 23-45; KEENAN J. F., *The Concept of Sanctity of Life and its Use in Contemporary Bioethical Discussion*, in BAYERTZ K. ed., *Sanctity of Life and Human Dignity*, Dordrecht-Bosotn-London 1996, 1-18; KUHSE H., *The Sanctity of Life Doctrine in Medicine. A Critique*, Oxford 1987; SPINSATI S., *Qualità della vita o santità della vita? Oltre il dilemma*, in VIAFORA C. cur., *Centri di bioetica in Italia. Orientamenti a confronto*, Padova 1993, 212-224.

[9] CARRASCO DE PAULA I., *Dignità e vita umana nell' etica medica*, "Medicina e Morale" 45 (1995), 213-222 (here p. 220).

[10] Cfr. FAGGIONI M. P., *La sfida del riduzionismo tecnico scientifico al progetto uomo*, "Studia Moralia" 38 (2000), 437-473.

[11] ECUMENICAL VATICAN COUNCIL II, *Past. Const. Gaudium et Spes*, n. 14 (EV 1/1363).

[12] CONGR. DOCTR. FAITH, *Instr. Donum Vitae*, 22-2-1987, Introduction. 5.

[13] CONGR. DOCTR. FAITH, *Instr. Donum Vitae*, Introduction, n. 4.

[14] BARTH K., *Kirchliche Dogmatik*, vol. 3, tom. 4, Zollikon-Zurich 1951, 406.

## **JEAN-MARIE LE MÉNÉ**

### **HEALTH ETHICS AND WORLD HEALTH MANAGEMENT**

We all know the definition of health proposed by WHO: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". This definition has the advantage of taking both the body and the soul into consideration, which is more accurate than a merely organicist view of health. However, by mentioning complete well-being with no time limit, this definition also has the drawback of giving an idealistic conception of health that does not include the reality of the person who is called to live, but also to die.

Health around the world is far from meeting this ideal, and the ways of managing health in order to attain it are not uniform. In the developed countries, health management is conditioned to a great extent by demand, while in the developing countries it is mainly conditioned by supply. Supply and demand are the basis of all economics theories, which are in turn conditioned by ideologies. The question is whether or not there is a place for ethics in this concert of influences around world health.

### **IN THE DEVELOPED COUNTRIES DEMAND PREVAILS IN HEALTH MANAGEMENT**

In most of the industrialized countries with thriving economies, the health care situation can give rise to three observations. First, the era is over of the great epidemics of an infectious nature that ravaged entire peoples. Medical advances are responsible for the disappearance of these scourges. Next, the nature of the pathologies to take care of has evolved. The pathologies that were once microbiological and acute have often become chemical and chronic (cardio-vascular diseases, cancer, rheumatism, etc.), but the States and health care systems have generally taken the necessary measures so that the great majority of citizens will benefit in an equitable way from prevention and care, even though this could always be improved. Lastly, a shift in the demand for health care towards new needs is taking shape. Although these needs are not specifically medical, they are still addressed to the world of health. They are passed on in a powerful way by new requestors. They are leading to ever higher costs, which are (poorly) regulated by the payer's solvency.

### **FROM HEALTH TO WELL-BEING: NEW NEEDS PROMOTED BY NEW REQUESTORS**

Health care in the developed countries is tending to leave "the repair shop" of the human body (body and soul) in order to enter a dream-like sphere, an ideal space, and become a luxury item, a consumer product for the privileged of the planet.

The new needs: only one criterion, desire

The shining symbol of this evolution is the explosion of medically assisted procreation techniques that have no other purpose than to respond to the desire to have a child. But by treating the lack of a child as an illness that should be cured with every means, even the most dangerous and costly ones, just as one would do for a "real", life-threatening illness, the developed societies have accepted a shift from health towards well-being. The medical metaphor is effective. One acts as if the suffering of not having a child was a symptom within the competence of medicine that refers to an illness that could be treated and taken care of by the collectivity. All things considered, the situation is paradoxical inasmuch as the techniques proposed only treat the symptoms (the lack of a child), not the cause (a couple's hypo fertility or sterility). Let's not forget that a couple continues to be sterile after an in vitro

fertilization! The variety of procreation methods offered is presented as a response that is fine-tuned more and more each day, to the requestor's desire which is ever more demanding because it is spurred on day by day.[1]

The need to have a child is the inverted reflection of another equally radical need that came earlier historically: the desire not to have a child. This rejection of the child has also been medicalized and taken care of by health insurance for a long time. Free, reimbursed contraception is undoubtedly the first stage in this shift in health care allowed by the developed countries towards what they imagine comfort to be. But even more than the desire to have a child, it is unacceptable to include the rejection of a child within a so-called health care policy, as if life could be considered an illness and death a remedy.

Desire is enshrined once again when a health care system accepts, organizes and finances, in the name of health, the elimination of abnormal unborn children as a means of "preventing" handicaps. In the terminology employed, the therapeutic or medical interruption of pregnancy--the illusion of always staying within the world of health care--is a kind of moral security that is maintained deliberately. And yet, we cannot see what health care systems or health care professionals have in common with actions that deliberately cause death. In France, until the present, only the so-called medical interruptions of pregnancy were reimbursed by the national health organization, whereas abortions of convenience were charged to the State budget. One of the first measures taken by the Minister of Health, Prof. Jean-François Mattei, was to make the national health organization also bear the economic burden of abortions of convenience.

This desire of power is also manifested in our contemporaries' need to stay young forever. This is how the demands to use the human embryo for cell therapy are popularized as infallible means of conquering the illnesses of old age like Alzheimer's or Parkinson's disease. The illusion of eternal rejuvenation -- and in the end of defying death -- reverts back to fantasy and mythology. Moreover, this desire seems so irrepressible that if the embryonic stem cells taken from the surplus embryos, after their destruction, should turn out to be incompatible with the receiver organism, the possibility of having recourse to so-called therapeutic cloning has already been heralded as the cure-all. Once again, the term 'therapeutic' links us -- erroneously -- to the universe of health. Some countries like Belgium and Great Britain have authorized so-called therapeutic cloning. Others, like France or Germany, have forbidden it for the moment in their national legislation, but they are becoming its proponents internationally in view of a condemnation by the United Nations only of reproductive cloning.

For the record, the desire of power also extends to physical beauty and sexual performance. Just think of the recurrent efforts to make credible the power of the DHEA youth hormones popularized by Prof. Etienne Beaulieu (the inventor of the RU 486 abortifacient pill) and to make this one of the necessary components of health... in order to feel good. Just think of the luxurious advertisements in medical journals for products like Viagra... about which nothing indicates that they should be covered as health expenses.

The list could be longer, but what is important to remember is that the solvent part of humanity is obviously replete with ordinary health products. From now on, the developed countries will be expressing new demands related to the creation of life, eternal youth and beauty, and to avoiding death, which all have the enormous advantage for the market of never being satisfied. This is because rank and file citizens do not claim these unattainable horizons. These new demands are brought, promoted and popularized by new requestors.

A characteristic of the new requestors: they are not "spontaneous" sick persons

In front of the immense prospects opened up by these new needs, an enthusiastic view is strictly required. Anyone who does not subscribe to it without reservations is excluded from the inexorably happy march towards the new Promised Land of health. This view is held in an authoritative way by

scientists whose status has undergone a real metamorphosis. Whether they are doctors, biologists or geneticists, scientists have been promoted to the rank of experts, dispensers of truth and hope. When public opinion is uneasy, when the media ask questions, or when politics are on the blink, the experts are called in to express their opinion. Very often they are asked to define rules, set limits, and give meaning, all tasks that go beyond their mission and competency. This ideology of expertise whereby scientific knowledge alone can give foundation to a political choice is an illusion that allows political power to relieve itself of a responsibility that it no longer wants to assume. This results in an over-representation of the scientific or technological viewpoint in deliberative or decision-making bodies, ethical committees or parliamentary commissions. In France, after the national consulting committee on ethics has been functioning for more than twenty years, it stands out clearly that the role of the experts gathered together in that committee, most of whom are scientists, has practically been to get public opinion and the media accustomed to transgression. There are almost no examples where the committee on ethics has not been a laboratory and then a recording chamber for transgression in order to make it digestible for public opinion. It has even been called an “acclimatization garden” for what is “still unacceptable” in scientific innovations. One geneticist wrote, “The public is not afraid of progress, but the speed of progress. The work of the ethical committees is to act like a brake to slow down the application of technology to a speed acceptable to the public.”[2]

Whether this has to do with extending the legal deadline for abortion, various medically assisted procreation techniques, the use of embryonic stem cells, the manufacture of “babies as medicines” after a double preimplantatory diagnosis, the so-called therapeutic cloning, or the exception of euthanasia, the dialectics have often been the same. At first, the principle of respect for life is firmly recalled; subsequently, as an exception, some derogation is foreseen that will soon replace the principle. If some dejected persons display any qualms, the official position of expertise responds out of the need for a certain “ethical disenchantment”. In other words, scientific and medical progress has always had to go through transgressions. Three examples are cited traditionally: the dissection of corps, blood transfusions and organ transplants. These practices never constituted moral transgressions. At most, they were social transgressions at the time when they appeared. On the other hand, the purely utilitarian, industrial imperative is often called in for support. It is out of the question for any country to be delayed in the biotechnological race, and especially not for ethical reasons. The brain drain towards even more liberal countries is a sword of Damocles that is often brandished: the countries that care less about ethics benefit from a competitive bonus and a comparative advantage. Falling in line with the “cheapest ethics” becomes the only rule for ethical committees. In these conditions, it is not difficult to call for and obtain consensus. As a result of this imperialism of techno-scientific expertise, paradoxical slogans are produced that go along with the drifts in health towards well-being or comfort. In this way, medicalized abortion is a factor of women and children’s health. In the same way, preimplantatory diagnosis becomes a way of avoiding abortion. The use of the embryo for research would be the opportunity to develop intergenerational solidarity: the “baby as medicine”, after a double selection in vitro, will be promoted to the rank of “baby of hope”, etc.

Parallel to the diktat of expertise, the role of associations of the sick has developed as stakeholders in the demand for health, but in reality as a pressure group. The new forms of solidarity woven around patients afflicted with AIDS or myopathies are some of the major illustrations of this. Regarding AIDS, in the early 90s, some militant associations considered the experimental trials as a means of access to hopeful drugs and expressed strong criticism of the classic testing methodology. In addition, the associations intervened with pharmaceutical companies, governments and prescribers to speed up the circulation of new drugs before they were authorized to be put on the market. In the name of compassion for the sick who had to die, and using means that were sometimes terroristic (bursting into TV panels, threats...), the associations demanded that the patients should get the chance to have access to molecules on the margin of controlled tests, which were not completely evaluated or validated. Since the AIDS epidemic has received great media coverage, the associations have played an important role

in public discussions. The evaluation of the facts provided by science has not remained in the hands of the specialists; it has been appropriated by a lobby. The financial arbitration has also been influenced by this to the detriment of other health choices.

A mixed formula that brings together experts and pressure groups has arisen to guide research on genetic diseases and now on cell therapy. With the significant funds collected and distributed each year by Telethon, some management associations have become key actors in the choice of research topics and teams in public bodies. But the ends pursued and the means used are not without criticism. It was in this way that authorization for preimplantatory diagnosis was the direct result of the lobbying done by Telethon. The birth of the first child after preimplantatory diagnosis was made possible through funding from Telethon, which was very pleased about it. In the past, some Telethon TV broadcasts had already presented "babylathons": that is, children born free from disease through prenatal diagnosis. The next stage began when Telethon took a position in favor of embryonic stem cell research and therapeutic cloning.[3]

## EVER HIGHER COSTS POORLY REGULATED BY THE MARKET

To a great extent, the increase in health costs is linked to the increase in health activities for illnesses that could be described as 'civilizational', resulting from the demands for comfort and well-being described earlier. Until now, the recommended policy had been to let the responsibility fall upon the medical profession, which has been accused of inflating its treatments and prescribing too much. In reality, the increase in health care activities is the result of the change in the nature of health and its shift towards relieving the so-called 'civilizational' illnesses. It is the fatal result of an alliance between scientism and the market.

### The appearance of new ills: sicknesses related to civilization

It has to be noted that the liberty taken with a certain number of moral, environmental and societal rules is manifested in the emergence of many illnesses or "malaises" that were rarer or even unknown in the past, as they still are in the poor countries. And yet the health care system takes care of these illnesses solely from a curative viewpoint without considering their causes, which remain untreated.

It is in this way that the main problem of public health for the elderly is to reduce their number of hospital stays because of the secondary, treatment-derived effects of taking too much medication. For young girls, the goal of public health consists in preventing socio-emotional deprivations and their consequences: anorexia and obesity. For children, it is a question of preventing the major family-related disorders, identifying and taking care of mistreatment. Young college and high school students are followed up so that they will refrain from adopting addictive behaviors (alcohol, tobacco, drugs). It is already planned to develop education to contraception and recourse to emergency contraception (abortifacient) to reduce the prevalence of abortions. To this young trainees will also add protection against the risks of suicide and exposure to HIV and STDs.

The medicalization of life, which has become a general phenomenon in the developed countries, raises a particular problem for mental disturbances and behavior disorders. The notions of comfort and dependency are at the heart of the question. It seems that there has been a shift from medication for the sick, to medication for those in good health with problems, and then to medication for healthy people in order to make life easier. However, it has to be known if the role of medication is to give these patients that constant "joie de vivre" thwarted by technological advances detached from any ethical principles. Don't patients tend to expect from antidepressants what they used to expect from vacations? Personal development, self-reconquest, the appearance of happiness, and the need for action and performance in work, studies and sports[4] all have a high cost. In a society guided by moral principles,

the question is to know whether or not something is permitted and if it conforms to the common good. In the individualistic and hedonistic societies, the question is rather to know whether or not each one will be able to go to the limit of what he/she desires and what is possible to achieve. Reference to what is permitted gives way to reference to what is possible, but the collateral damages are costly for the societies concerned.<sup>[5]</sup> The market is not only powerless to give meaning, but also to rationalize this evolution. It seems to be forgotten that the natural law cannot be violated with impunity without paying a heavy price for human health.

#### A lack of regulation by the market

Is health in the developed countries going to go bankrupt under the prevailing economic interests? The illusions brought by the biotechnologies seem to accompany the beginning of the millennium. Soon one should be able to buy additional years of life, renewed youth, improved sexual performance, flawless offspring, and constant euphoria before an unperceived end of life, thanks to embryonic stem cells and human cloning. From this viewpoint, is health a means or an end? Aren't health as well-being, and health as comfort identified with individual health, Paradise regained, in a parody of the beatific vision? The liberal view, which is invested with a legitimacy that no other position can claim, assures us that unrestricted market freedom is our best chance for increasing collective wealth, and that we owe our comfort, well-being and health to it. Guaranteeing consumption implies guaranteeing the permanent reconstitution of the work force so that the system will not be paralyzed by breakdowns in the workers' health. In this way, health has also become an individual right proportional to the duty to give oneself entirely to economic progress. Health has also been identified with the ability to earn one's livelihood. Accidents and illness are considered like tributes that individuals pay to economic growth. This is why society must take care of them. But now that the solvent part of humanity is replete with primary health care products, it has to push back the horizon. The fantasies associated with the development of genetics and cell therapy today assign a new goal to economic liberalism in order to get it out of its crisis. Isn't this the "new paradigm of health"? Fifty years ago, we spoke about expenditures for health. Tomorrow won't we talk about the riches made available by health? Economics have overtaken ethics.

#### IN THE DEVELOPING COUNTRIES HEALTH MANAGEMENT IS PENALIZED BY SUPPLY

It is obvious that all the possibilities offered by the health market in the huge consumer system we described, will be reserved for a minority. An offering of this kind will never be made to all the humans on the planet who are not solvent. In the countries of the South, the first sectors sacrificed are health and education. But the setbacks of these countries do not come from a scarcity of world resources -- they exist -- but rather from their unequal distribution, or even their confiscation by the rich countries. It is not an exaggeration to say that the international development institutions have made the Third World pay for their ideological hesitations, while the health management of these countries is now a victim of various forms of piracy.

#### The health of the developing countries at the risk of ideologies

For the past fifty years, the international organizations have recommended the implementation of vast health programs in the developing countries that are likely to ensure access of the population as a whole to a minimum level of care. The different approaches proposed have only achieved their goals in a very unequal way. The ideologies underlying them are not unrelated to this failure.

## The Alma-Ata Declaration: the socialist illusion

The international conference organized by WHO and UNICEF in 1978, represented a real turning point in implementing health programs in the developing countries. The solemn declaration proclaimed on that occasion invited all the countries to make the promotion of primary health care the cornerstone of the development of health systems. It was a question of ensuring all peoples' access to a satisfactory level of health by the year 2000. The slogan, "Health for All in the Year 2000", became the catchword for health policies in the developing world in general, and in Africa in particular. The developed countries did not take part in this movement that was in fact intended for the poor countries of the planet.

The state of mind in the 70s, which followed in the wake of the events of May 1968, was influenced by progressive images of disadvantaged peoples liberated from the power of the rich, popular knowledge that is wiser than the illusions of the modern world, and traditional culture that is healthier than alienation through money... The particular feature of this choice for primary health care was thus found in the peoples' participation in improving their health through activities that could be carried out in the villages and outlying urban neighborhoods without requiring the presence of qualified persons. The great media coverage of China's popular communes and the success of the Vietnamese fighters against the US army were for a whole generation the striking demonstration that the key to the development of the poor countries was found in the people's commitment to common objectives, and that it was possible for them to get out of their underdevelopment by mobilizing their own energies. On the contrary, the appropriation of medicine by the health professionals, the qualified hospitals and the perfected technologies were reserved for the most advantaged minorities and denounced as a source of exclusion of the poor countries. There was a revolutionary illusion in imagining that there could be health care for all within a short term using models like the barefoot doctors of China that were spread around by Third World militants. This great movement in favor of health for all was joined by the NGOs, the UN specialized agencies, the World Bank, the European Union, and most bilateral organizations. And so hundreds of thousands of first-aid hygienists, village midwives and traditional therapists were trained, and tens of thousands of village pharmacies were set up. But a great number of programs or projects ended in failure. The funds were insufficient, the health workers were insufficiently trained and equipped to solve the problems confronting them, and the quality of care was poor. In a general way, the illusion of Alma-Ata was to manage the health of the poor countries on the basis of a health care scheme that was formatted ideally, but in reality inappropriate and insufficient. The error on the part of the international organizations was to invent ideological "models" and impose them on the beneficiary States, without taking the good of persons into consideration sufficiently.

## The Bamako initiative: the liberal disenchantment

In the mid-80s, after noting the loss of impetus in the primary health care services, a consensus was reached among the international institutions regarding the need for the users themselves to take charge of at least part of the health costs. It was James Grant, the Director of UNICEF, who launched the idea with the name "Bamako initiative". This initiative was adopted in 1987 by the WHO 37th Regional Committee. Its founding principle was the following: the direct sale to users of generic drugs bought at a low price and resold with a margin of profit should ensure the renewal of medical supplies and the financing of the health centers' functioning costs. Because of this, the Bamako initiative led to abandoning gratuity and the historical preference for the budgetary financing of health. Willingly or not, all the countries came around to this in the mid-90s. In comparing the objectives with the developments observed during these past ten years, a mixed assessment can be made of this initiative. Although the funds obtained within this framework have made some recovery possible for the less advanced countries, most of the problems have not been solved.

At the same time, the 80s brought a period of global economic crisis in Africa, to which the industrialized countries responded with a series of adjustments known as “structural adjustment programs” set up by the IMF and the World Bank. This is how the international institutions carried out a global transformation of the Third World economies in order to adjust them to the needs of the world market. At the time, most of the highly indebted developing countries had no other choice than to submit to the conditions tied to the loans granted by those institutions. It was in this context and to compensate for a lack of public financing of health that the Bamako initiative was born.

In fact, the financial system set up was destined to collapse: since the rate of attending health centers did not improve and the expenses were increasing, the rate of collection for the services decreased. But above all, from the people’s viewpoint, the principle of recovering costs -- extended to all health services -- led to the exclusion of the most disadvantaged from the health care system. So it can be seen that the poorer a country is, the more its inhabitants are obliged to pay for health care themselves. Moreover, the improvement in the quality of health care services, the supply, which was supposed to go hand in hand with the principle of paying for these services, has not always been achieved. Nothing indicates a notable improvement in the health of the peoples of reference that is due to the Bamako initiative.

The 90s were marked by sectorial approaches in the countries where foreign aid contributes to a large extent to financing the health system. Beyond the obvious advantages of the sectorial approaches, they are exposed to the risk of a coalition of backers in which one of them can play a predominant role in determining the offer. It was during this period that the World Bank became the first public backer in the area of health. As a matter of fact, there was a transfer of competencies and responsibilities from WHO to the World Bank for health matters, with WHO suffering a crisis of confidence and credibility. However, the sectorial projects financed by the World Bank had difficulty getting implemented. The effectiveness of the World Bank’s interventions in the area of health could be increased by facilitating partnerships with many other actors in health.<sup>[6]</sup> In its latest report, moreover, WHO expressly calls on the denominational associations to implement the sectorial approaches.

When all is said and done, economic aspects are not the only factor of exclusion from access to health care, except for the peoples who have a very low income or none at all. It appears that the exclusion of users can be attributed first of all to the quality offered by the health structures. Neither the Alma-Ata declaration, nor the Bamako initiative, nor the sectorial approaches have been able to structure and strengthen the quality of the health care offer. The ideology underlying the different interventions by the international organizations in favor of the Third World, whether they were of a socialist or a liberal inspiration, have never sufficiently put the person at the heart of health management.

## THE HEALTH OF THE POOR COUNTRIES AT THE RISK OF PIRACY

Control over the planet’s biological treasures is also the subject of a historical conflict between the developed and the developing countries. The struggle to control biological resources has dominated the agenda of FAO meetings for a long time. The fact that life is becoming patented is a characteristic of the biotechnological era and it is at the origin of a fierce competition between the firms that want to enlarge their share of the market and strengthen their competitiveness, sometimes to the detriment of the poorest countries. The possibility of authorizing so-called therapeutic cloning, which is currently the object of attempted legal piracy at the UN, is not likely to reassure these countries.

## Biological piracy: privatization of the biological patrimony of the countries of the South

The conflict setting the multinationals of the North against the countries of the South over control of the world biological patrimony promises to be one of the main economic and ethical battles of the biotechnological era.

Multinationals finance expeditions throughout the whole Southern hemisphere in search of rare genetic or biological characteristics likely to acquire a commercial value. What is at stake in this research -- whose goal is to lead to new drugs -- is considerable. It is not a question of being hostile to issuing patents for procedures or technologies, but the ability to patent life itself or any fragment of a living organism is unacceptable. The countries of the South feel that these discoveries are really an act of piracy of their patrimony, even if the firms produce a certain added value by manipulating the coding genes for some particular proteins. In this way, a drug manufactured by a pharmaceutical firm on the basis of a biological resource from Africa, for instance, a resource that is already known and used as such locally, can become the property of the firm and resold -- in the form of a licensed patent -- even to the country from which it came.

In their desire to allay the increasingly fierce opposition, the multinationals are trying to impose a uniform regime of industrial property that will have legal force all over the world, and give them access to all the biological and genetic resources of the planet, while guaranteeing them protection for the products of their manipulation.

Of course, these new forms of colonialism are regularly denounced in the major international conferences dedicated to patents. Moreover, the attempts to appropriate living matter are the subject of negotiations before the international institutions (WTO, IMF, UNDP), despite the assurances of wanting to "humanize" internationalization and its consequences. The developing countries are beginning to understand that the raw materials of the past will no longer be the object of appropriation, but rather the genetic and cellular patrimony of man himself. According to information from the world organization of intellectual property, in 1996, private persons and firms from the industrialized countries, with all fields mixed, hold 95% of the patents of Africa and 70% of those of Asia.

This attitude is particularly harmful when it is held by the pharmaceutical industry and through the law of patents, leads to penalizing the countries of the South's access to drugs or screening for illnesses. The conflicts are growing which set some poor countries against industries that have a monopoly over drugs (especially against AIDS) or certain genes (breast cancer).

The outcome of this ethical battle around one of the greatest challenges to natural law obviously has some immediate repercussions on the economies and consequences for the health management of the poor countries.

## Legal piracy: the attempts to authorize cloning at the UN

On November 6, 2003, after animated discussions, the UN Sixth (legal) Commission decided to postpone the examination of proposals aimed at drawing up an international convention against the cloning of human beings, even though the majority of the countries present is against cloning and the vote on that convention is urgently needed.

Some developed countries really hope to authorize the cloning of human embryos (so-called therapeutic cloning) in order to continue experimentation cheaply and free themselves from any ethical rules, even though there are really very slight therapeutic prospects. Fortunately, the great majority of the world's countries -- in particular, the developing countries, the Islamic countries, the United States, the Vatican -- hope for the pure and simple prohibition of any form of human cloning. And yet, the small lobby of the rich countries and those who care less about ethics managed to put off the discussion hoping to gain some time, to buy the votes of the poor countries, and to change the balance of power.

Human cloning, regardless of its objective, is an extremely disturbing evolution in biotechnology. In all its forms, it is intrinsically contrary to ethics and constitutes a dangerous precedent. The most disadvantaged countries are not the ones least exposed to its dangers for several reasons.

First, if the so-called therapeutic cloning is authorized, it risks transforming women's bodies into merchandise. It will be necessary to abuse and pay many female candidates to submit to medically dangerous treatment in order to produce the enormous amount of ova needed for cloning. Obviously, for economic reasons, women from the poor countries will be the priority targets of this foreseeable exploitation.

Next, these same poor countries, whose regulation and control capacities are often deficient, will be chosen in order to delocalize biotechnology firms dedicated to the so-called therapeutic cloning on a large scale. Once cloned embryos are made available in this way, it will be practically impossible to control their use. Stocks of embryonic clones can be built; they can be bought and sold, even trafficked, and no one will know. The illicit implantation of these embryos, which is easy to carry out, will be practiced clandestinely, with no consequences for the perpetrators of these crimes.

Lastly, let's not forget that cloning is dangerous because the transplanted embryonic cells cannot be controlled by the receiver organism and that they produce cancers in it. And so on what organisms, in what conditions, and against what false promises will attempts to transplant cells from clones be practiced in the poor countries?

Then, above all, the funds invested in these techniques will not be invested elsewhere. On the one hand, the ousting effect of funds will penalize research on cell therapy based on adult stem cells, which does not raise any ethical problems and includes real therapeutic possibilities. This will also penalize the implementation of sectorial aid programs concerning the primary health needs of the developing countries.

For all these reasons, it is important to accompany the decision-makers from the developing countries in resisting this attempted legal piracy at the United Nations.

In conclusion, it seems difficult not to see that two considerations are almost always absent from health concerns around the world: namely, the integral good of the person, on the one hand, and death on the other.

It is never asked what man's good means. On the contrary, one gets the feeling that both the health systems that respond to demands and those which impose the supply, do not include what is due to the human person, why it is due and how. Altogether, the health systems propose or impose solutions, but they have forgotten what the question is.

The consideration about death is no longer included in the discussion. How can a coherent, viable health system be built that is not a headlong rush if its conceivers are afraid to speak about death? Isn't the truth about death likely to give meaning to a health care system and guide its choices?

"We are born and we die: we are born to die because we start by dying in order to be born". [7]

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[1] I took part in a conference several years ago where I was at the podium with a famous French gynecologist, the former President of the Academy of Medicine. While calling himself a practicing Catholic, he stated that he was ready to offer the reproduction technique through cloning to any woman who would ask him,. The doctor supported his “compassionate” position with one exact argument: ever since the medically assisted procreation technologies developed, their benefits have never been refused to any woman who requested them.No one has ever risked judging the women’s requests.

[2] Nature, March 1997.

[3] I was present when consensus on this subject was drawn up in France.First, representatives of the sick were chosen to receive information about cell therapy from experts behind closed doors.All the scientific experts were in favor of using the embryo.Next, the representatives of the sick and the experts met in the presence of the public and the media.The animator of the discussion asked the representatives of the sick if they wanted to be cured.At their affirmative response he turned towards the experts and asked them what they proposed: the use of embryonic cells. Since everyone agreed, he invited the representatives of the sick to write up recommendations addressed to the government and parliament along these lines. The press commented on the Recommendations with this headline: “The sick demand that....”.A few months later, the vote on the law of bioethics gave them satisfaction.

[4] The spread of the notion of “doping” expresses this perfectly: the use of substances that enhance the ability to measure up, conforms to a lifestyle characterized by constantly surpassing oneself.

[5] Without mentioning contaminated blood and AIDS, the mad cow and Creutzfeldt-Jacob disease.

[6] This is what emerges from a conversation I had with the President of the Republic of Senegal in Dakar last August 4th.With regard to HIV/AIDS, President Abdoulaye Wade confirmed to me that Africa had no need for additional financing but that it needed assistance with the concrete implementation of projects in the field.

[7] Saint Bernard de Clervaux, Treatise on the different degrees of humility and pride.

**MICHEL SCHOYANS**

**“REPRODUCTIVE HEALTH” AND DEMOGRAPHIC POLICIES  
THE CASE OF WHO**

Within the limits of this communication, it is obviously impossible to explore the countless documents in which international bodies, public or private, take up the question of "reproductive health". We will concentrate our analysis on one dossier dedicated explicitly to this question that was published by the World Health Organization in 2004.[1] The text is entitled, Reproductive Health.[2]

The term reproductive health, which is usually translated into French both as santé reproductive and santé générésique, appeared nearly forty years ago in texts of different UN agencies like WHO, the United Nations Population Fund (UNFPA), the United Nations Children's Fund (UNICEF), the United Nations AIDS Program (UNAIDS/ONUSIDA), the United Nations Development Program (UNDP), the World Bank, etc. We will stay with the term "santé reproductive". This has been widely disseminated since 1994 on the occasion of the Cairo Conference dedicated to the theme of Population and Development. It was also at the center of the Beijing Conference on Women in 1995.

One might think that the term means essentially the preventive care and cures available to mothers during pregnancy or during and after childbirth, as well as the treatment offered in cases of sterility or sexually transmitted diseases. In reality, the term 'reproductive health' is a typical product of verbal engineering and it takes in many meanings. While it can refer to the care we have just mentioned, it also refers to contraception, safe abortion, a certain kind of sex education for adolescents, and a change in laws and mentalities.

In the first part of our presentation, we will take the report we have already mentioned on Reproductive Health as our guide. We will present some significant extracts from that text literally.[3] Next, we will analyze some political aspects of reproductive health. Lastly, we will go on to make a moral qualification of this view of health.

**PRESENTATION OF THE DOCUMENT**

**A strategy for reproductive health according to WHO**

The report highlights the definition the Cairo Conference gave to reproductive health. Here is the English text of that definition:

"Reproductive health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition are the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law [...]." [4]

**Responding to needs**

The report tells us first of all that the 55th WHO Assembly resolved to develop a strategy in view of making progress in reproductive health. The resolution also recalls the objectives and commitments made in Cairo and Beijing (1), as well as the objectives stated in the year 2000 in the Millennium Declaration (4). It is specified that there are many discrepancies between the goals to be attained and the

realities observed. Therefore, a strategy needs to be defined and disseminated among a very large audience of decision-makers (3).

Admittedly, since 1994, remarkable progress has been made, but the global situation still displays some deplorable characteristics. In Sub-Saharan Africa, for instance, 1 woman in 16 is exposed to the risk of maternal death (11). In the poor countries, the lack of qualified personnel acts in such a way that avoidable or treatable gynecological and obstetrical complications are not taken care of (12). In the developing countries or those in transition, the need for safe contraception has not been met by 120 million couples and many adolescents (15 s). Each year 80 million women have an undesired pregnancy. Some of these pregnancies are due to contraceptive failure because no contraceptive method is 100% effective (16).

The estimated number of abortions per year is 45 million, 19 million of which are unsafe. 40% of these abortions are performed on women between 15-24 years of age. Unsafe abortion kills approximately 68,000 women each year, representing 13% of all pregnancy-related deaths (17).

Each year an estimated 340 million new cases of sexually transmitted bacterial diseases occur (18), which especially strike young women between the ages of 15-24. These infections can lead to sterility (21).

### Obstacles to progress

Disparities are striking between men and women in health (23). Women are often victims of violence, rape, sexual aggression, even by their own companions. Women and girls are often victims of human traffic and prostitution. It is easy to imagine the consequences of such disparities on reproductive and sexual health (24).

Female adolescents are particularly exposed to risks in the area of reproductive and sexual health because of taboos and norms that impede their access to information. In or out of marriage, the sexual activity of adolescents is often risky. These adolescents are rarely in a position to resist the pressure to have sexual relations, negotiate a safe sexual relation, or protect themselves against pregnancy and infectious diseases. Meeting the needs and protecting the rights of the planet's 1 billion 200 million male and female adolescents is essential in order to preserve the health of the future generations (25). Is it also necessary to recall that poverty goes hand in hand with inequalities when dealing with access to health services, especially maternal health (26)?

These different obstacles to reproductive health are made even worse by an overall decline in development. It is true that some new funds have been created to fight AIDS, tuberculosis and malaria, but a sustainable health system needs to be set up that includes reproductive and sexual health services (28).

One of the major obstacles to the expansion and improvement of these reproductive and sexual health services in many regions has to be sought in adequate human resources. Strategic planning to build and maintain a trained medical workforce is crucial for progress in the area of reproductive and sexual health care (29).

In addition to the difficulties related to poverty, there are others that are derived from taboos, women's weak decision-making power, as well as negative attitudes and prejudices of family members or health care providers. A holistic examination of beliefs, attitudes and values provides an important starting point for overcoming these fundamental obstacles (30).

Lastly, in some countries, laws, policies and regulations may hinder access to services, unnecessarily limit the roles of health care personnel, bar access to some services (for example, supplying over-the-counter emergency contraception), or restrict the importation of some drugs or essential technologies. Removal of such restrictions is likely to contribute in a significant way to improving people's access to these services (32).

## The strategy to accelerate progress

The supreme objective is to accelerate progress in view of reaching an agreement on the highest level regarding the objectives to be attained in the area of reproductive health for all (33).The WHO strategy to achieve this acceleration is based on international instruments on which there is agreement, and declarations about human rights achieved through global consensus.[5] For these rights to be respected, policies, programs and interventions must promote equality of the "genders", that is, the sexes, in order to give priority to the poor and underserved populations, especially adolescents (34).

The major entry point of access to reproductive and sexual health will be through prenatal, childbirth and postpartum services (36).

Unsafe abortion must be treated as part of the Millennium Development Goals[6]concerning maternal health and other goals and targets.Family planning services must be strengthened in order to prevent undesired pregnancies, and to the extent that the law permits, to ensure that services are available and accessible.Also to the extent that the law permits, it is necessary to improve the formation of health care providers who are trained in modern techniques and equipment.It is also necessary, to the extent that the law allows, to provide abortion services on the primary health care level (37; cf. 40).

The overarching actions to be undertaken are: strengthening health care systems capacity, improving information for priority setting; creating supportive legislative and regulatory frameworks; a three-fold reinforcement of monitoring, evaluation and accountability for actions (42).

The strategy also requires strengthening sustainable financing mechanisms of which a significant part will be allocated for training health care personnel (45-49).

Quality information should make it possible to set priorities.In defining these, all the parties concerned will have to be involved: governments, bi and multilateral agencies, professional associations, non-governmental organizations, women's groups and other sectors of civil society.By bringing together the parties concerned, a consensus will be built (53).

The creation of a strongly supportive climate on the international, national and local levels, and the initiatives based on law in the area of reproductive and sexual health will help to overcome inertia, galvanize investment as well as set high standards and mechanisms for performance accountability (55).

The removal of unnecessary restrictions in policies and rules, in order to create a supportive framework for reproductive and sexual health, is likely to contribute significantly to improving access to services (57).For this purpose, it will be necessary to review and, if necessary, change laws and policies (59), and include the "human rights" dimensions of reproductive and sexual health.

In order to bring this strategy to a successful conclusion, the WHO will continue to strengthen its partnership with other organizations within the United Nations system (especially with UNFPA, UNICEF and UNAIDS), the World Bank, the associations of health care professionals, NGOs and other partners (64).

## ANALYSIS OF THE DOCUMENT

### The real objective: population control of the poor Countries

In relation to many other earlier documents, the 2004 document we have just presented hardly contains any surprises or new elements.Its essential elements can already be found in previous WHO publications[7] and the CairoPlan of Action (1994), which is often mentioned.The same themes are taken up again and organized following similar structures.

These same themes are found again in the documents released by other UN bodies, but with different emphases.While WHO highlights reproductive health,[8] UNFPA puts the emphasis on population

control, UNICEF on adolescent education, and UNAIDS on AIDS. The World Bank takes up the same problems from the economic and financial viewpoint.[9]

Admittedly, these documents, especially those published by WHO include recommendations that are so acceptable that we get the impression we are dealing with truisms. Who, as a matter of fact, would not undersign programs aimed at reducing maternal morbidity and mortality, infant mortality, sexually transmitted diseases and, in a more general way, making all basic health care accessible to the greatest number of persons? Who would not support prevention campaigns for illnesses of all kinds?

In reality, however, these declared good intentions are not enough to conceal the strong ideological tenor of the WHO document dedicated to reproductive health. We are dealing with a typically Malthusian document. Everything converges towards one focal point: the alleged need to control the population growth of the poor countries. Now, it has never been demonstrated that it is necessary to control this population in order for the poor countries to develop. This central question is never mentioned, much less discussed, in the WHO reports, nor in those of UNFPA, UNICEF the World Bank or in the Cairo Program of Action. The Malthusian postulate is accepted as self-evident and hence requires no demonstration and so one proceed to act directly.

The ideological character of this Malthusian prejudice is confirmed by the total absence of any disturbing references, such as the fact that the drop in the fertility rate is a world phenomenon today recognized by the Population Division, which is also a UN body. This drop does not spare the poor countries. It is sufficient to point to the figures on the 2003 Data Sheet of the Population Reference Bureau (Washington, DC) to see that one third of the world's countries have a fertility rate equal to or less than 2.1 (the threshold at which a population heads inevitably towards aging).

There is a desire to strike public opinion, medical personnel and decision-makers by mentioning real needs, but these needs are used as a decoy to hide the true objective which is to control the poor populations through the most effective means.

Since it has been decided to ignore or hide these realities, the document concentrates on three recurring themes that are considered means to attaining the real Malthusian objective: safe abortion, contraception, changes in laws linked to the mobilization of leaders.

## FIRST MEANS: ABORTION

Abortion: undesirable if unsafe

The reproductive and sexual health program is silent about the question of protection for the human being before birth. On the other hand, it is very interested in abortion. It is stated several times that it is necessary to end unsafe abortion. Only unsafe abortion is undesirable, precisely because it is unsafe - for the mother, naturally - and not because it eliminates a human life.[10]

This position is confirmed very clearly by other UN and WHO documents. Let us report the definition of reproductive health that appears in the Cairo Plan of Action cited above. This definition includes the "regulation of births" in reproductive health. As we noted, in French this corresponds to the English term regulation of fertility. But what does this regulation of fertility, this 'regulation of births' include? The answer appears as clear as can be in the Definitions and Indicators in Family Planning & Child Health and Reproductive Health, of which a revised edition was published by the WHO in March 1999 and in January 2001:

Fertility regulation

Is the process by which individuals and couples regulate their fertility. Methods that can be used for this purpose include, among others, delaying childbearing, using contraception, seeking treatment for

infertility, interrupting unwanted pregnancies, and, in the case of mothers with an infant or small child, breast-feeding.

Source: Working definition used by the Special Programme of Research and Research Training in Human Reproduction, and the Division of Family Health.[11]

If the words have a meaning in English as they do in French, the interruption of an unwanted pregnancy means abortion. Therefore, abortion is included in the concept of reproductive health disseminated by WHO and other UN agencies.

#### Early abortion

Furthermore, since reproductive health includes abortion, then it is one of the means to be implemented in order to control births in the developing countries. In 1992, in its report on Reproductive Health, the WHO stated: "Developing countries need strong national capacity to solve the reproductive health problems of their fast growing populations".[12]

### SECOND MEANS: CONTRACEPTION

Together with abortion, contraception appears to be an essential means for controlling births in the poor countries. Indeed, one is impressed by the significant financial and human resources allocated by WHO for research on what that organization calls "contraception". Together with abortion, the massive inclusion of contraception in reproductive health gives confirmation that the central objective of the strategy defined by WHO is truly birth control.

#### Contraception and abortion

This brings us to point out one important explanation regarding the relations between contraception and abortion. Here, in fact, we are looking at another case of verbal engineering. What does the word abortion mean in the WHO vocabulary? The answer is given to us in the Definition and Indicators already cited:[13]

#### Abortion:

Induced: or the voluntary termination of pregnancy is used to end an already established pregnancy (i.e. a method that acts after implantation has been completed). [...] Division of Family Health and Special Programme of Research and Research Training in Human Reproduction. International Conference on Population and Development, Cairo, Egypt, 5-13 September 1995.[14]

According to that definition, there cannot be a question of abortion until after implantation.

The Secretary General of the Cairo Conference, Mrs. Nafis Said, confirms this way of presenting abortion with regard to "emergency contraception":

"EC [Emergency contraception] does not interrupt pregnancy or cause abortion. How does EC work? EC pills work by interrupting a women's reproductive cycle. Depending on when in the cycle the pills are taken they can prevent or delay ovulation, interfere with fertilization or block implantation".[15]

The World Health Organization and the former Executive Director of UNFPA thus have a rather particular way of presenting abortion. According to their reasoning, in order for there to be an abortion, the fertilized egg has to be implanted in the uterus. This is why everything that blocks implantation is called contraceptive. So let us take note of this scholastic example of a vicious circle:

Major premise: There is no abortion before implantation.

Minor premise: The contraceptive pill acts before implantation which it in fact impedes.

Conclusion: The contraceptive pill is not abortifacient.

In his well-known Manual of Bioethics, His Excellency Bishop Sgreccia, the Vice-President of the Pontifical Academy for Life, provides all the necessary clarification of this question:

"[...] We are referring to some birth control techniques improperly called contraceptive that do not impede the encounter between the gametes, i.e. fertilization, as the term contraceptive would lead to suppose. Their mechanism really consists in impeding the already fertilized egg cell from becoming implanted in the uterus. Those who make propaganda for these techniques are very careful not to call them abortifacient (the term 'abortion' still means something dramatic for many people). They are thus described as interceptive if they intercept the zygote by impeding it from becoming implanted, or contragestative (from contragestation in analogy with contraception) if they impede the continuation of the pregnancy once the embryo is implanted in the uterus".[16]

### The anti-pregnancy vaccine

It is striking to note that much of the research supported by WHO has been and still is destined to perfecting methods of early abortion,[17] especially research on "long-term contraceptive implants", [18] vaginal rings, etc. Research on embryo implantation is also under way to perfect an "anti-implantation or menses-inducing agent", to be taken once per cycle to bring on menstruation and impede possible implantation if conception has taken place.[19]

Special mention should be made of the immuno-contraceptive preparations, that is, the anti-pregnancy vaccine, often designated as immuno-contraceptive hCG.[20] Once this "vaccine" is perfected, it will be an early abortifacient. A mother will no longer recognize the embryo as a body she must not reject. A vaccine of this kind thus eliminates the deep physiological roots of motherhood because a mother is made hostile to her own child.

## THIRD MEANS: CHANGING LAWS AND MENTALITIES

### Removing legal restrictions

In the text we presented in the first part of this communication, as well as in many other WHO texts, reference is made to laws or regulations that could hinder the reproductive and sexual health programs. This is why the text recommends that efforts should be made to eliminate the restrictive laws regarding contraception and abortion and in this way favor the development of the poor countries. These countries can use the model of the industrialized countries that have already changed their laws to adapt them to the goals of reproductive health.

In this regard, this is what Mrs. M. Berer writes in the WHO Bulletin, one of the widely disseminated, authorized organs of the WHO:

"Making abortion legal is an essential prerequisite to making it safe [...] To make abortion safe, restrictive laws need to be annulled, amended or replaced; traditional and, in some cases, religious laws may also require attention when legal change is being contemplated. Countries have three main routes to this end: liberalizing existing law within penal or criminal codes; partially or fully legalizing abortion through a positive law or a court ruling; and decriminalizing abortion by taking it out of the law altogether. These changes have already occurred in almost all industrialized countries and are happening in a growing number of developing countries as well".[21]

Invoking "new human rights" obtained through consensus will facilitate these changes in laws. In this way, in the name of the gender ideology, abortion will be presented as a "new right of women". In the

same way, it will be said that adolescent boys and girls have a "right to complete freedom of decision and choice" in the reproductive and sexual area. Parents should not interfere in these matters.

### Involving influential persons and religious groups

Obstacles to the plans of action for reproductive health also come from certain religious beliefs or "laws", as it appears from the preceding quotation. But these obstacles can come from religious organizations and thus from persons who exercise a position of responsibility and influence in one of these organizations.[22] These resource persons, preferably religious leaders, have to be reached and won over without reservations to the objectives of reproductive health.[23] This is what we find in a WHO document entitled Key messages for communicators, where we read the following:

"Culture and Religion Influence IEC [Information, Education, Communication] Messages and Strategies. Culture and religion play a major role in people's decisions to use family planning and in the acceptability of specific methods. Successful programmes make an effort to learn about the cultural and religious beliefs of their clients and adapt IEC messages and strategies in response to those beliefs. In general, the cultural and religious beliefs of clients should be respected by programmes unless they are harmful (as is female genital mutilation, for example). Communicators should consider involving key community and religious leaders in their IEC programmes".[24]

Therefore, it is necessary to target the population that one wishes to influence:

"Decide exactly who in the population you are trying to influence. While the main target audience for family planning messages may be women of reproductive age, consideration should also be given to other groups whose knowledge, values, and attitudes may have a strong influence on a woman's beliefs and actions. These secondary target audiences may include husbands, partners, parents, grandparents, religious and community leaders, schoolteachers, traditional birth attendants, and local government officials".[25]

## WHICH ANTHROPOLOGY? WHICH MORALITY?

### An individualistic concept of man

What is striking in the WHO document is the total absence of any reference to the institution of the family in a text that deals with reproductive and sexual health. Words like 'family' and 'motherhood' only appear in contexts dealing with sexuality. Reproductive health is at the service of individuals who are considered great consumers of sexual activities. The discreet allusions to the gender ideology truly make it possible to state that in the WHO view individuals choose their "gender", their sex, and that the reproductive health programs have to be at the service of these choices.

In this way the family is not just ignored but also destroyed. Sexuality is separated from love. The WHO text is a dead text because it overlooks conjugal love. A human being is thus no longer a person, a relational being, capable of commitment and fidelity who aspires to love and be loved. He is sexually "tutored". He is the object of a new kind of paternalism of technocrats who know what is good for everyone, especially the poor.

Hence the insistence on monitoring, checking up on the execution of the programs, and the convocations directed at countries and regions to appear at conferences and make an account of their performances in applying the Program and respecting the deadlines.

Individuals and couples are alienated in this way from their own responsibilities. They have to be educated, formatted, and mentally reprogrammed, in order to practice a politically correct sexuality. Their consent must be "informed". The same will go for medical personnel. The emphasis on

the need to train this personnel and set them up within the UN reproductive health services indicates clearly that in carrying out the plans of action, there will be no place for conscientious objection. As to law, it will have to be put at the service of the programs of action. The ad hoc laws will be purely positive ones: that is, they will reflect the will of the reproductive health strategists. Whenever necessary, national laws will be abolished or modified. Legislation will have to be validated by an international law the lynchpin of which will be the supreme standard theorized by Kelsen. In this way, the key question emerges that is raised with regard to reproductive health: What legitimacy can WHO and its allies claim in carrying out programs that escape any control of parliaments, and in requiring sovereign nations to account for applying programs that come to them from abroad?

### The viewpoint of Christian morality

The critiques we have just made are of a purely philosophical nature. As we have seen, they border on anthropology, the philosophy of law and political philosophy. Christian morality subscribes to these critiques suggested by reason. Moreover, the corpus of Christian morality is constituted to a great extent on the basis of discernment of the facts accessible to reason and integrated into that corpus.

It is no less true, however, that the WHO program on reproductive health calls for some specifically Christian critiques.

From the Christian viewpoint, man was created in God's image and likeness. From this he gets his incomparable dignity. From this he gets his rights and duties. For this reason he can have knowledge, because as a unique creature in creation, he shares in divine intelligence and can freely conform his will to God's will. Enlightened by the grace God offers to all those who seek him, man can recognize in his fellow man one who has also received his existence from God and for whom Jesus also shed his blood. This is the foundation of Christian fraternity. For all men, life is a divine gift, and so I must respect it in myself and in others. The Lord will bring this duty to its highest expression in the "new commandment": "Love one another just as I have loved you". [26]

It is sufficient to read the instruction leaflets accompanying boxes of contraceptive preparations or the protocols drawn up by pharmaceutical companies to realize that love of one's neighbor is really not honored when one knows, or ought to know, that prescriptions given to women consumers can cause early abortions, and that they themselves are exposed to various serious risks.

But man is not called to live alone. In the same way that the Three Persons of the Trinity do not keep anything jealously for themselves and love one another without reservations, Christians are also called to live together in mutual love. This love has one of its exemplary expressions in human sexuality where a man and a woman are invited to love one another without reservations or soul-searching, and to give life just as they have received it from those who gave them life. Through this ordinary vocation to marriage, a man and a woman are associated in a unique way to divine creation: they procreate. They exercise a divine power through delegation, through divine proxy: the power to give life to another human being who, like them, will not be a mere individual biologically delimited by his mortal coil, but a person open to relations that will allow him to grow and assert himself. [27]

In this regard, we can see how grave it is from the Christian viewpoint to use knowledge, which ought to be at the service of life, to impede it by blocking implantation, or to impede a mother from recognizing the embryo as a being she cannot reject because like her, it is in God's likeness.

Moreover, it should not be forgotten that poverty is neither a sickness nor a fatality. Poverty is not remedied by the hormonization of women or by abortion. In the same way, the alcoholism of husbands is not cured by sterilizing their wives. The international agencies that propose false remedies based on erroneous diagnoses would do well to get familiar with recent studies that debunk the commonplaces about poverty. The capital that is most in danger of being scarce is human capital, that is, man who is well prepared physically, intellectually and morally to face life and serve his fellow men.

Here we are touching on a problem of social justice. It would be necessary to substantially revise the scale of appropriations destined for development. This distribution ought to be made to benefit education and moral formation. As John Paul II writes in the Encyclical *Centesimus Annus* (No. 32), "today the decisive factor is increasingly man himself, that is, his knowledge, especially his scientific knowledge, his capacity for interrelated and compact organization, as well as his ability to perceive the needs of others and to satisfy them". And in speaking about human ecology, the Pope adds, "Not only has God given the earth to man, [...] but man too is God's gift to man" (No. 38). This idea appears again in the Encyclical *Evangelium Vitae* where the Pope writes, "God entrusts man to man" (No. 19).

## CONCLUSIONS

First, it has to be said that the WHO has done and continues to do worthwhile things around the world in research, prevention and therapeutic care. The eradication of smallpox is one remarkable achievement, and we have every right to expect renewed success in the fight against malaria and perhaps AIDS.

In the same way, in the area of reproductive health - provided this term is used in a broad sense--, it must be acknowledged that the WHO makes efforts to take care of women struggling with gynecological and obstetrical problems, to treat sterility, to lower infant mortality, and to prevent and cure sexually transmitted infections and diseases.

But when this formidable medical potential is deviated to a great extent and put at the service of the Malthusian ideology focusing on population control of the poor, then, unfortunately, it is necessary to warn WHO about the manipulation of which it is also the object. Poverty is not eliminated through medical means, especially when these do harm to bodies, minds, consciences and societies.

If the WHO does not go through a process of self-criticism in such serious areas, it will soon come under attack for eugenics, in this case a kind of eugenics that targets the weak and poor peoples. Sooner or later, it will then be the victim of disrepute that will adversely affect its partners and cast suspicion on the whole UN institution.

But perhaps there is still a ray of hope. We have pointed it out from the beginning. The document we analyzed takes up the same themes, even the same structures we already found in the reports from the 80s and earlier. The human price paid by generations of poor people only confirms once again the failure of the diagnosis and the therapy recommended by Malthus and his ideological heirs. It certainly would have been preferable if the Malthusian ideology had not been adopted by large, public international organizations.

Therefore, it is hopeful in the more or less short term that the demographic facts will ultimately win out over the Malthusian vulgate. Programs of public health, especially with regard to reproduction, cannot be indefinitely based on the systematic disregard for unquestionable scientific data regarding two generalized phenomena: namely, the drop in fertility and the tendency towards aging.

In conclusion, I would like to emphasize the crux of my communication.

We Christians are too often paralyzed by our hesitations, our ambiguities and our compromises when it comes to defending life and the family. Our firmness to defend them both is often encroached upon by the concessions to which we agree. The strength of the adversaries of life and the family comes from their success in weakening us and the ease with which they divide us.

During the twentieth century, Christians, Catholics, played the role of useful innocents by making alliances with totalitarian ideologies and movements. Similar disparate alliances can be found again in our times. Today, the presence and action of useful innocents of a new kind can be seen: those who make alliances and collaborate with movements that do not respect life or the family. In a document published in September 2004, Working from within, UNFPA congratulates itself, for instance, for its good partnership with the "Pastoral Care of Children" in Brazil. "Despite the end of this partnership (in

1999), one important lesson came out of it for UNFPA: the most powerful religious institutions are not monolithic" (p. 26).

What is needed, according to WHO and UNFPA, is to practice infiltration, to infiltrate the Christian milieus, to change the leaders' mentalities. This is why the publication we just cited is completed by another: 24 Tips For Culturally Sensitive Programming (UNFPA, September 2004). What UNFPA and the agencies associated with it recommend is a new cultural revolution, a change of hearts and minds. And in view of this change, it is necessary first of all to target the religious leaders who are traditionally resistant and even in opposition, but who are giving signs of division today called euphemistically "schools of thought" (loc. cit., p. 15).

Through their secret or public dissent, through their partnerships with unacceptable programs, Christians are weakening the unity of the Church from within and making it run the risk of a schism. This de facto dissidence is made even worse by the silence of many pastors who fail to say, "at the right time and the wrong time", the prophetic words that call for the protection of life and the promotion of the family. In turn, this fearful silence contributes to reinforcing the schismatic drift. Christians of all categories, however, cannot be unaware that there are human and Christian values which are not negotiable, and that their defense is gravely compromised when disregard for the truth is accelerated by the decline of courage.

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[1] We will use the abbreviation WHO for World Health Organization. This organization is based in Geneva.

[2] This document is dated April 15, 2004 and numbered A57/13. It can be found at the following address: [http://www.who.int/gb/ebwha/pdf\\_files/WHA57/A57\\_13-en.pdf](http://www.who.int/gb/ebwha/pdf_files/WHA57/A57_13-en.pdf)

This will be completed by the communiqué released by the WHOMediaCenter, dated May 22, 2004, accessible at: <http://www.who.int/mediacentre/releases/2004/wha2/fr/index.html>

[3] The figures in parentheses that appear in the body of our text refer to the numbers in the report Reproductive Health.

[4] Cf. Report of the International Conference on Population and Development, Cairo, September 5-13, 1994: document numbered A/CONF.171/13, October 18, 1994. The quotation is found in Chapter 7, No. 7.2 See the Report Reproductive Health, No. 1.

[5] See the text published by the WHO:

[http://www.who.int/reproductive-health/publications/RHR\\_01\\_5\\_advancing\\_safe\\_motherhood/RHR\\_01\\_05\\_abstract.en.html](http://www.who.int/reproductive-health/publications/RHR_01_5_advancing_safe_motherhood/RHR_01_05_abstract.en.html) : Advancing Safe Motherhood through Human Rights.

[6] Cf. <http://www.un.org/millenniumgoals/>

[7] All the themes already appeared, for example, in the Seventh Annual Report concerning the Special Program of Research and Research Training in Human Reproduction, mimeographed document OMS/WHO, 1978.

[8] See in particular: UNDP/UNFPA/WHO/World Bank: Special Programme of Research, Development and Research Training in Human Reproduction (HRP): Internet

page: <http://www.who.int/reproductive-health/hrp/index.html>

[9] See <http://www.worldbank.org/wbi/reprohealth>

[10] See in particular the WHO publication (2003): Safe abortion: Technical and policy guidance for health systems, on the Internet page: [http://www.who.int/reproductive-health/publications/safe\\_abortion/safe\\_abortion.html](http://www.who.int/reproductive-health/publications/safe_abortion/safe_abortion.html)

[11] The underlining is ours. This text is found in page 6 of the Definitions and Indicators in Family Planning & Child Health and Reproductive Health used in the WHO Regional Office for Europe, published by the Reproductive, Maternal and Child Health European Regional Office and the World Health Organization (WHO), s.l., edition revised in March 1999 and in January 2001. Available on: <http://www.euro.who.int/document/e68459.pdf>

The source indicated right after the definition was prepared in view of the Cairo Conference. You will note that the same definition is found on the website of the International Planned Parenthood Federation /IPPF): <http://www.glossary.ippf.org/GlossaryBrowser.aspx>

[12] The underlining is ours. See: Reproductive Health: A Key to a Brighter Future, Biennial Report 1990-1991 of the Special Programme of Research, Development and Research Training in Human Reproduction, Geneva, World Health Organization, 1992. Our quotation appears on page 127.

[13] See the above reference in note 11.

[14] The underlining is ours in the passage in parenthesis. The text cited actually mentions the date 1995, whereas the Cairo Conference took place in 1994,

[15] The underlining is ours. Cf. the IPPF and Cairo+5 document, Issue 9, May-June 1999, Prep Com Special on: <http://www.ippf.org/cairo/issues/9906/emergency.htm>

[16] Cf. Elio SGRECCIA, Manuel de Bioéthique. Les fondements de l'éthique médicale, Montreal, Ed. Wilson & Lafleur, 1999. A new edition of this reference work was published in Paris, Ed. Mame-Edifa, 2004. Our quotation comes from page 506 of the Canadian edition. See also what the same expert writes on page 431 sqq.

- [17] See a good summary on the Internet page (text dated 1997): [http://www.who.int/reproductive-health/hrp/progress/44/news44\\_1.en.htm#4](http://www.who.int/reproductive-health/hrp/progress/44/news44_1.en.htm#4) Contraceptive methods are mixed with methods of early abortion.
- [18] See in particular what the WHO says about the Norplant implant: [http://www.who.int/reproductive-health/publications/rhr\\_02\\_7fr/rhr\\_02\\_07q12.html](http://www.who.int/reproductive-health/publications/rhr_02_7fr/rhr_02_07q12.html)
- [19] See the text in the report: [http://www.who.int/reproductive-health/publications/atr\\_2002/Section\\_1.PDF](http://www.who.int/reproductive-health/publications/atr_2002/Section_1.PDF)
- [20] In 1993, for example the WHO published in collaboration with the UNDP, UNFPA and the World Bank a report on the Fertility Regulating Vaccines (WHO/HRP/WHO/93.1). On page 15 of that report we read: "HCG is a hormone produced by the egg a few days after it has been fertilized. This hormone is needed to complete the process of implantation (embedding of the fertilized egg in the lining of the uterus). It is still not clear exactly how immunity to hCG prevents the establishment of pregnancy [...]. However, its effect must be exerted after fertilization has taken place since no hCG is present until after this has occurred". Research is still under way and we can follow its progress in the "Annual Technical Report of the UNDP/UNFPA/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction" published on Internet: [http://www.who.int/reproductive-health/pages\\_resources/listing\\_programme\\_reports.htm](http://www.who.int/reproductive-health/pages_resources/listing_programme_reports.htm)
- [21] The underlining is ours. Cf. M. BERE, Eliminer les risques liés à l'avortement: le devoir d'une bonne politique de santé publique, Thème spécial-Santé génésique, Dossiers thématiques, published in the Bulletin de l'Organisation Mondiale de la Santé, Recueil d'articles N. 3 2000, pp. 117-128. Our quotation is found in p. 119sqq, accessible at: <http://www.who.int/bulletin/volumes/en/Document> available at: <http://www.policyproject.com/pubs/occasional/op-06fr.pdf> Other works by M. Berer can be researched on Google.
- [22] The fact that the UNFPA's position is hostile to the Church appears in a statement by Nafis Sadik, at the time Executive Director of UNFPA, dated January 1998. See in this regard: <http://www.c-fam.org/FAX/fax1998/faxv1n16.html>
- [23] In 2000 a study was published by Justine TANTCHOU and Ellen WILSON entitled "Le Project POLICY", in which there is a curious honors list of support given to the reproductive health programs in five African countries. The support of religions is rated "very low" in Benin, "low" in Burkina Faso, "medium" in Cameroon, "low" in the Ivory Coast, and "medium" in Mali. The document is accessible at: [sante\\_reproductive\\_Afrique.pdf](http://sante_reproductive_Afrique.pdf)
- [24] The underlining is ours. Cf. Communicating family planning in reproductive health. Key messages for communicators, a 1997 document listed as WHO/FRH/FPP/97.33. It can be found at: [http://www.who.int/reproductive-health/publications/fpp\\_97\\_33/fpp\\_97\\_33\\_7.en.html](http://www.who.int/reproductive-health/publications/fpp_97_33/fpp_97_33_7.en.html)
- [25] The underlining is ours. See: [http://www.who.int/reproductive-health/publications/fpp\\_97\\_33/fpp\\_97\\_33\\_2.en.html](http://www.who.int/reproductive-health/publications/fpp_97_33/fpp_97_33_2.en.html)
- [26] Jn 13:34.
- [27] See the Encyclical *Evangelium Vitae*, Nos. 43 and 92.

## **ALFONSO GÓMEZ-LOBO**

### **QUALITY OF LIFE AND POST COMA UNRESPONSIVENESS**

In this article I shall try to answer three questions: (1) What is quality of life, (2) Whether quality of life should play a role in difficult end-of-life decisions, especially those affecting patients in post coma unresponsiveness (PCU), and (3) Whether the conclusions reached are consistent with the directives of Pope John Paul II's allocution of March 2004.

My approach will be primarily philosophical and I am very much aware that, to be truly satisfactory, it should be enriched by theological arguments.[1]

#### **QUALITY OF LIFE**

The expression “quality of life” can be used in different senses.[2] The words themselves evoke the idea that lives can be better or worse, i. e. that lives can be evaluated in a manner similar to the way we evaluate, for example, works of art, instruments and institutions. The idea that lives can be judged according to their quality goes back to the ancient Greek philosophers and their efforts to discover which is the good (or the best) life. The highest quality life they identified with the happy or flourishing life, a life lived in the enjoyment of the basic human goods.

A poor quality life, by contrast, is the life of an individual who lacks certain goods that can be of different kinds, for example, mental, physical, social, or instrumental. A mentally impaired person who suffers from a chronic disease, doesn't have relatives or friends, and lacks financial resources can be said to have a low quality of life.

Quality of life, in this sense, is a holistic notion that covers different dimensions and is therefore open to different assessments. Can there be unanimity about the quality of the life of a person who lacks certain goods (e. g. mobility) but has others (wealth)? In fact, the assessment of quality of life will vary across traditions, cultures and social groups, with some people regarding certain forms of dependency (e. g. having to be fed and cleaned) as abhorrent while others would regard them as tolerable.

One should also distinguish from quality of life a narrower concept that also admits of degrees, the concept namely of physiological condition. One's health can be better or worse. This determination of the condition of a patient is a diagnostic judgment reserved to the medical profession and is a necessary condition for effective therapeutic intervention. Without a reliable assessment of the patient's pathological condition it is hard to see how a physician could cure her illness or alleviate her suffering, but this assessment is surely different from an over-all quality of life judgment.

Low quality of life and pathological condition are two different concepts that do not coincide and should be distinguished.

#### **QUALITY OF LIFE IN END-OF-LIFE DECISIONS**

Should quality of life be a central consideration when making difficult end-of-life decisions, especially in the case of patients in PCU? The reference to this class of patients is included because they can be taken to be at the lowest possible level in terms of the quality of their lives. We shall address their condition after some general remarks.

It is well known that the expectation of a low quality of life has become a standard rationalization to justify euthanasia, especially among representatives of contemporary utilitarianism. I have in mind here poor quality due to a wide variety of impediments and handicaps short of PCU. Since utilitarians

consider pain and the loss (or diminution) of the capacity to experience pleasure among the worst evils, and since they measure quality of life by reference to pleasure and pain, it is not surprising if they claim that by intentionally killing a patient with low quality of life expectancy they are benefiting him. This manner of thinking is today deeply embedded in the Anglo-American culture and is spreading swiftly in the wings of globalization, first to continental Europe, notably the Netherlands, and then to other areas of the world.

In order to understand what is deeply wrong with this pattern of thought, it is useful to remember some basic notions of traditional action theory. In any action, an adequate philosophical analysis would distinguish between (a) what is done and (b) why it is done.[3] The former is the action itself (which may consist in an omission), the latter is the motive the agent has for engaging in the action, and usually consists in the expected consequences of the action. In traditional terminology these are called the *finis operis* and the *finis operantis*, the objective of the action itself and the further purpose of the agent.

Utilitarianism is a consequentialist position, and as such derives its moral judgments not simply from what an agent intends, but rather from the actual results achieved. In the case of euthanasia, the consequence is that all pain, of course, is eliminated, but we know that there are many actions that may lead to good results and yet are seriously objectionable, like obtaining peace by wholesale destruction of cities.

An agent aiming at euthanasia can perform different kinds of action or engage in different kinds of omission that will have as a consequence the death of the patient. Can the expected low quality of life ever justify such actions and omissions? I think there are good philosophical reasons to give a firm negative reply and to assert, on the contrary, that a person in such a condition should never be denied care and respect.

In fact, although a person may be affected by a serious lack of goods, she is still enjoying the basic good of life, a good that is distinct from any evil that the person may be undergoing. Moreover, from the perspective of the person herself, life even under those conditions can be desirable although for an external observer it may appear almost unbearable. It would therefore be an intolerable presumption to judge from the outside that that is a life “not worth living.”

The universal prohibition of intentional killing of the innocent is grounded on respect for the dignity of a person, and human dignity is logically independent of, and not reducible to, the quality of a person’s life because dignity is an intrinsic property that does not admit of degrees. Dignity expresses the value of persons, and unlike the value of things, it does not vary. A severely handicapped person is as valuable as anyone else, and consequently should be respected like anybody else.

There are good reasons to extend special care to people whose lives are of poor quality (they need the care more than others), but there are no good reasons to justify the obliteration of their lives because of their poor quality. Quality of life considerations, paradoxically enough, do not measure the quality of life itself (for it remains an invariable basic good), but rather of other goods that may be sustained by life or be lacking from it.

To assert that life is a basic human good is not equivalent to what can be called “vitalism.”[4] This position holds that human life is an absolute good that takes precedence over all other goods, and that should be preserved at all costs. The dominant value of life would thus ground stringent moral rules that should govern all end-of-life medical decisions. For vitalism the preservation and prolongation of life is the sole action-guiding goal in matters pertaining to medical practice once health can no longer be restored.

In rejecting vitalism, I would affirm the traditional principle that it is rational to pursue, foster and protect goods (chiefly, though not exclusively, human life), but that it is also rational to forgo goods (in certain circumstances and in light of other goods) as long as one does not turn intentionally against them. By “forgo” I mean “to give up”, “rinunziare”, “renoncer”, “aufgeben”. An example of this attitude would be that of someone who affirms that to have children is an important human good, and

yet gives up the enjoyment of this good by entering a monastery. A further case would be that of a person who, because of an insurmountable impediment, cannot enjoy the good of progeny. Such a person would not be giving up a good. He or she would be accepting the fact that circumstances have placed this good beyond his or her reach. This acceptance (“accettazione”, “acceptation”, “Hinnahme”) is not irrational and is perfectly compatible with a strong affirmation of the value of the corresponding good.

For vitalism, due to its faith in technology and its frontal resistance to the forgoing of life, the idea of the acceptance of death is a source of anger and rebellion. This is an attitude that is sometimes found, I am told, among relatives of cancer patients who want the physician to continue chemotherapy after it has ceased to be effective and long after it has begun to show its devastating effects on the dying patient. Illusionary hopes or the arrogant determination to defeat illness and death replace the deeply human attitude of acceptance of the inevitable ending of our lives.

For those who stand on the middle ground between vitalism and thanatism, between the will to preserve life at all costs and the will to cause death when deemed convenient, an intractable dilemma arises in certain difficult cases, most notably in the case of patients in PCU.

Let me first give an explanation about terminology. The standard way to refer to this condition is “PersistentVegetativeState” (PVS) or more generally in a “VegetativeState” (VS). These labels are remotely based on Aristotle’s distinction of faculties or powers (*dunameis*) in living things.[5] In these patients the rational and sensitive powers of the soul can no longer be activated in the normal way and thus what is left exercising its activity is only the *threptikón*, the “vegetative” power, that is independent of consciousness and the will. However, the term “vegetative” easily leads people to think of these patients as “vegetables”, and thus as non-human. In order to avoid this terrible misunderstanding, a new label has been proposed “Post Coma Unresponsiveness” (PCU) which is free from the misleading associations, and I am happy to adopt it.[6]

The Aristotelian framework, on the other hand, provides apt conceptual tools to reject the view that patients in CPU have ceased to be persons.[7] Aristotle expresses the common sense view that each of us is a single organism, a single, fully unified substance, and that the loss of the higher faculties is not the passing away of a substance, called “the person” residing in a different substance called “the body”, as contemporary dualists hold. The loss of consciousness and reason is the loss on the part of a person of his capacity to activate his higher powers due to physiological impairments, but is not equivalent to the death of the person.[8] Although a patient in PCU may show no sign of responsiveness to his environment, this is not a reason to deny that he is the same person that was conscious before he suffered the trauma that led to PCU. It follows that he now deserves the same respect he deserved at earlier stages of his life.

The difficult dilemma I mentioned earlier arises out of the fact that most PCU patients cannot swallow because of their pathological condition and hence require assisted nutrition and hydration (ANH), also referred to as medically assisted nutrition and hydration (MANH). What can moral philosophy say about the proper way to decide whether to provide, withhold or withdraw such assistance?

There are many factors that should help us realize that it is very difficult to provide a univocal answer that would apply to all cases. There is in the first place the difficulty involved in deciding whether nutrition and hydration by means of a nasogastric tube or a gastrostomy tube constitutes normal care or medical treatment. Once a tube has been inserted, the feeding can be done by an untrained person, but the decision to insert a tube, the insertion itself (especially when surgery is required), the prescription of the food and liquids to be provided, the monitoring of the patient and of any side-effects (aspiration, infections, etc.) clearly require the skills of a physician.[9] Since the day-to-day feeding, which is the ordinary care part of the process, is only possible because of the prior, medically accomplished insertion of the feeding tube, it seems to me, as matter of logic, that the procedure as a whole should be deemed to be “medical treatment.” In fact, a medical intervention provides the necessary conditions for

the inception of the ordinary care, and medical monitoring is part of a responsible continuation of the care. In a village without doctors, ANH of patients in PCU is impossible.

The classification of ANH as medical treatment does not, by itself, resolve the ultimate moral question whether its provision is obligatory or optional. It does help to sharpen the issue by inviting us to consider the traditional criteria for inception, continuation or cessation of treatment, namely its benefits and burdens.[10]

In order to discuss the application of these criteria to MANH I would like to consider an extreme hypothetical claim, the claim that withholding or withdrawing MANH is always and necessarily euthanasia by omission. In order for this claim to be true there would have to be a logical or conceptual connection between the *finis operis* and the *finis operantis* in this case, in other words, the action would have to be such that it could only be performed by an agent with a specific further intention. There would be no room for exceptions.

I submit that such a connection exists between an act of active killing and the intended goal of euthanasia. A physician who gives a patient a lethal injection surely intends the death of the patient. The act of itself would not be performed were it not for the intention of the agent. That further intention is a necessary condition for the performance of an action that directly causes the intended effect.

Omissions are different. They do not actively cause death. They usually remove an impediment for the operation of a different cause. When a respirator is turned off and a patient dies, what causes the death is the prior acute pathological condition, not the actual unplugging of the machine. A patient in a less serious condition who has been put temporarily in a respirator would go on living. Turning off a life sustaining machine, by itself, does not cause death.

Due to the manner in which causality operates, an omission may or may not be linked to a specific intention. If the connection between the omission and the intention were not contingent but necessary, then every withdrawal of treatment or of artificial life support would have to be considered euthanasia. In traditional language this would entail that all means should be considered ordinary means. If a doctor withdraws antibiotics from a patient who has been in PCU for several years, the doctor could be suspected of intending the death of the patient. If a doctor halts chemotherapy at the request of a patient, he could be accused of engaging in physician assisted suicide.

These clearly unacceptable accusations are meant to show that the connection between the *finis operis* and the *finis operantis* in the case of omissions is indeed contingent. That there are legitimate forms of letting die is central to the position that values life and yet accepts the forgoing of life, that strives to care for the sick but rejects excessive medical treatment.

It is true that certain omissions can be the result of intending the death of the patient, but they need not be. For an external observer there may be no perceptible difference between euthanasia by omission and legitimate letting die because the intention with which similar actions are performed cannot be judged from the outside. If a dedicated physician examines carefully whether a treatment is futile or burdensome or both, and decides in good conscience to halt it with the intention of letting the patient die of her underlying illness, it would be presumptuous to impute to him the intention of causing the death of the patient and thus of engaging in euthanasia.

The same holds, I conjecture, for certain cases of PCU.[11] There are instances in which an underlying pathological condition prevents the patient from taking food normally so that it is precisely the pathology that calls for the surgical insertion, for example, of a gastrostomy tube. Again it would be presumptuous to blame a physician if, after a lengthy period of time and after considering the burdens on the patient herself and her family, on the surrounding community, as well as a host of other factors (such as lack of health insurance), he recommends that the medically assisted nutrition and hydration be forgone.[12] We cannot know what his real intentions are, but we should not assume that he is necessarily intending the death of the patient. As I have argued, from the point of view of action theory, there is no such necessity. His intention may be a case of letting die for legitimate reasons because he has concluded that it would be disproportionate to continue. This does not presuppose that the patient is

considered somehow “worthless” or “unproductive” or lacking in dignity. Futility and the burdens on the patient, the family and the community would be the only legitimate reasons to decide.

In summary, I have argued for a minimal claim. I acknowledge the advance made by “the culture of death” in its efforts to legitimize euthanasia and also the dangers derived from the progress of medical technology that allows for the virtually indefinite prolongation of life.[13] I have tried to steer clear of both thanatism and vitalism. My conviction is that care for the handicapped and the unconscious should always be the primary concern, an obligation that requires no justification because it is deeply rooted in our very humanity. The suffering and the weak have a special claim on us. The quality of the life of the patient should not affect this primary obligation. Life continues to be a basic good to be protected. But I have also argued that we cannot assign morally unacceptable intentions in those cases in which conscientious physicians and families, after careful deliberation in light of the traditional criteria, opt for the withholding or withdrawal of nutrition and hydration of a PCU patient. I have tried to show that there is room for legitimate instances of letting die.

## CONSISTENCY WITH THE PAPAL ALLOCUTION

In March 2004 His Holiness Pope John Paul II delivered an address in which he spoke of the obligation to provide nutrition and hydration to patients who are said to be “in a persistent vegetative state.”[14]I cannot reproduce here the rich content of this document, nor am I competent to offer an authoritative exegesis of its teaching. What I shall do instead is to refer, without commentary, to a few passages from a “Briefing Note on the Obligation to provide Nutrition and Hydration” published by the Australian Catholic Bishops Committee for Doctrine and Morals and the Committee for Health Care in which they provide pastoral guidance by explaining the background and implications of the Papal statement.[15] I quote:

“2. The provision of food and water, even by artificial means, is not in itself a medical treatment that may be forgone or withdrawn solely on the grounds that it is medical treatment. (...) In itself, the provision of food and water (by whatever means) is the ordinary way of sustaining a patient’s life and a minimal part of the care we owe to others. (...)"

“3. In particular cases, however, the provision of nutrition and hydration may cease to be obligatory, e.g. if the patient is unable to assimilate the material provided or if the manner of the provision itself causes undue suffering to the patient, or involves an undue burden on others. (...) in Australia tube feeding is not normally too burdensome to others. (...)"

“4. The Pope’s statement does not explore the question whether artificial feeding involves a medical act or treatment with respect to the insertion and monitoring of the feeding tube. While the act of feeding a person is not itself a medical act, the insertion of a tube, monitoring of the tube and patient, and prescription of the substances to be provided, do involve a degree of medical and/or nursing expertise. To insert a feeding tube is a medical decision subject to the normal criteria for medical intervention.”

“5. Whenever medical treatment or the provision of nutrition and hydration is withheld or withdrawn for legitimate reasons (futility, burdensomeness), this is not euthanasia. As the Pope wrote in *Evangelium Vitae*, ‘Euthanasia must be distinguished from the decision to forgo...medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family... To forgo extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death’ (EV 65)”

The Australian Bishops conclude their remarks with a set of conclusions that I take to be consistent with the views advanced in the present article.

“In summary, the Pope’s statement is an application of traditional Catholic teaching, and says neither that nutrition and hydration must always be given, nor that they are never to be given, to unresponsive

and/or incompetent patients. Rather, the Pope affirms the presumption in favour of giving nutrition and hydration to all patients, even by artificial means, while recognizing that in particular cases this presumption gives way to the recognition that the provision of nutrition and hydration would be futile or unduly burdensome.”

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- [1] Cf. SGRECCIA E., *Manuale di Bioetica*, I. Fondamenti ed Etica Biomedica, Milano: Vita e Pensiero, 1988: 40 – 42.
- [2] For a collection of documents and studies see WALTER J. J. SHANNON T. A. (eds) *Quality of Life. The New Medical Dilemma*, New York: Paulist Press 1990.
- [3] This analysis is further developed in GOMEZ-LOBO A. *Morality and the Human Goods. An Introduction to Natural Law Ethics* WashingtonDC: GeorgetownUniversity Press 2002.
- [4] This use of the label is relatively new and should not be confused with vitalism as a doctrine in philosophy of biology upheld by Bergson, Driesch and others. Cf. BECKNER M. O. *Vitalism in EDWARDS P. Encyclopedia of Philosophy* New York 1967, 8: 253-256. On the importance of considering vitalism I owe much to KEOWN J. *Euthanasia. Ethics and Public Policy. An Argument against Legislation* Cambridge: CambridgeUniversity Press 2002.
- [5] ARISTOTELIS *De Anima* recognovit brevique adnotatione instruxit W. D. Ross Oxford: Oxford University Press 1956. See especially Book II Chapter 3.
- [6] BOYLE J. et al. *Reflections on Artificial Nutrition and Hydration* [www.utoronto.ca/stmikes/bioethics](http://www.utoronto.ca/stmikes/bioethics) 2004. PCU could be confused with Minimal Consciousness State (MCS) and hence its correct diagnosis is of considerable importance.
- [7] For a succinct expression of this widely shared view see BRODY B. *How much of the brain must be dead?* in STEINBOCK B. ARRAS J. D. LONDON A.J. *Ethical Issues in Modern Medicine* New York: McGraw Hill 2003: 281: "...life support could in these cases be unilaterally withdrawn when the organism no longer composes a person because the cortex no longer functions."
- [8] See ARISTOTELIS *DeAnimali*. 4. 408b 18-25. It should be kept in mind, however, that Aristotle does not think in terms of the later concept of personhood.
- [9] See also AMERICAN ACADEMY OF NEUROLOGY Position of the AAN on Certain Aspects of the Care and Management of the Persistent Vegetative State *Neurology* 1989, 39: 125-126 especially II.C.1 in WALTER J. J. SHANNON T. A. (eds) *Quality of Life. The New Medical Dilemma*, New York: Paulist Press 1990.
- [10] POPE PIUS XII *The Prolongation of Life* (Nov. 24, 1959) in O'ROURKE K. *Medical Ethics: Sources of Catholic Teachings*, Third Edition, WashingtonDC: GeorgetownUniversity press 1999: 213-214.
- [11] In this short (and insufficient) treatment I am assuming that the will of the unconscious patient is not known. For Pope Pius XII the presumed will of an adult patient was the foundation of the rights and duties of the doctor and of the family. Cf. POPE PIUS XII *ibid.*
- [12] Apart from the direct physical risks to the patient, such as risk of perforation of the bowel, infection or aspiration, etc. the emotional strain on the caregiver, especially if he or she is a close family member should not be minimized. The burden can be increased considerably if the family resources are limited and the same persons has to carry the whole weight of paying for the hospitalization, nursing home services or home care in countries where there are no adequate public health services.
- [13] The longest recorded instance of survival in coma in the US is that of Elaine Esposito who lived in an unconscious state for more than 37 years. See WALTER J. J. SHANNON T. A. (eds) *Quality of Life. The New Medical Dilemma*, New York: Paulist Press 1990: 86 n. 8.
- [14] See [www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march).
- [15] This document can be obtained from Catholic Health Australia, PO Box 330, Deakin West Act 2600, Australia.

## **FAIRNESS, RATIONING AND THE RIGHT TO HEALTH CARE**

### **INTRODUCTION**

The crisis – in the etymological sense of ‘move’ or ‘transition’ – of the welfare state is the crisis of a specific model of its management, namely the statist model, which tends to accompany the attainment of the objectives of social security with the reduction of the margins of personal choice of citizens. However, this crisis is not a crisis of the values that have supported the welfare state since its birth, nor does it involve a denial of the fact that the advances of the welfare state are one of the highest expressions of the democratic and civil progress of western civilisation. In addition, the roots of the crisis of the statist model are not of a fiscal character – which is more an effect than a cause – but are to be found, rather, in the incapacity of this model to conjoin fairness and freedom in a sustainable way. The citizens of our advanced societies no longer accept giving up their freedom in order to achieve higher standards of defence against risks. When the pursuit of social security enters into collision with the expansion of areas of freedom it is efficiency itself that is affected, hence the fiscal crisis, and thus the financially unsustainable situation of the welfare state.

What lies at the basis of the diversity of the requests of today’s citizens compared to yesterday’s citizens in relation to the welfare state? As A. Giddens (1997) has observed, in the move from the Fordist to the post-Fordist society, the specific nature of the risks that the welfare state has sought from the outset to combat has changed and is changing. Protecting the citizens from the adversities connected with the erratic developments of the business cycle and acts of nature (loss of employment; loss of health; a sad old age and so forth) has always been the proprium of the various institutions of welfare. The new feature is that whereas during the previous stage of development security was threatened by factors that were exogenous to the life plans of individuals to-day uncertainty has become, to a great extent, endogenous, that is to say attributable to the way in which society is organised and above all to the way in which the sphere of the production of wealth is structured.[1] That part of the welfare state that deals with the defence of health very clearly illustrates this inversion in the nature of uncertainty. Whereas the ‘old’ national health service could assume (not completely plausibly) that illness was something accidental and not correlated with ways of living, such an assumption would certainly not stand up in an age when people to a certain extent choose their own lifestyles and their health is a ‘function’ (in addition to health care) of factors such as the environment, eating habits, condition of work, family relationships, and so forth. One may think here, to take a banal example, of pathologies involving cancer. Bio-medical research tells us that most of these are to be attributed to specifically environmental factors. Whereas the old welfare state could confine itself to the search for effective therapies, in addition to ways of alleviating consequences, a new welfare state that meets the expectations of citizens cannot but allocate resources so as to act at the source – the fight against smoking; the abolition of toxic substances in the workplace; health promotion policies; limiting of dietary disorders requirements (not so long ago, it was nature and the seasons, in addition to poverty, that effectively determined people’s diet).

In the presence of changes of this kind, the idea of conserving the scaffolding of the old model of welfare, albeit in an up-dated and rationalised version, would only serve to accelerate the transformation that is already under way of the welfare state into a ‘transfer state’ (to use the colourful expression of Assar Lindbeck): this would involve large and distorting transfers of income not so much from the rich to the poor but from one segment to another of the middle and upper middle classes. The impulse to conflict in order to win the support of various sections of the electorate that would spring from transfers of this kind would certainly not be compatible with the stability requirements of an advanced democracy. To put it another way, as long as risks can be seen as exogenous it is feasible to

try to meet them through a direct management by the state. Such is not the case, as we will see later on in this paper, when the risks become in large part endogenous.

The new model of the welfare must place the category of freedom (in its positive sense) at the centre of political decision-making. Needs that are held to be essential cannot be met by distributing goods and services to citizens in a paternalistic way, leaving aside, that is to say, their preferences and their identity. This is because, as A. Margalit (1998) well observes, it is not sufficient to aim for a just society: what one should search for in addition is a ‘decent society’, a society, that is to say, that does not humiliate its members by distributing benefits to them but at the same time denying their autonomy. The welfare society posits that one thinks of citizens as responsible agents and therefore it is an inescapable task of a civilwelfare state understood in civil not only to assure the supply of goods and services but also to promote all those forms of collective action that have public effects; it posits, that is to say, going beyond the erroneous approach that identifies the sphere of the public with the sphere of the state. It is for this basic reason that the new model of welfare needs civil society to organise itself so as to become an actor in the various institutions of welfare.

It is against such a background that the pages that follow should be read, to which I assign two objectives. The first is to explain why an optimal system of the health care sector - a system, that is to say, that is able achieve at one and the same time the objectives of fairness, efficacy and efficiency in the production and provision of health care services.– is practically impossible to achieve. Such a perception is important because, while freeing us from the illusion of being able to secure, the elimination of the pervasive ethical dilemmas that entangle health care activity, it also directs us to search for a way to escape from the multiple trade-offs that, afflict the sector in question. The second objective is to supply arguments in support of the thesis according to which a health care universalism that seeks to be sustainable can only be, at the present time, a universalism that provides essential services to all.In order to defend this thesis, it is necessary to develop its two parts. On the one hand, I have to defend the idea that it is a good thing for the health care service to remain a universalistic service. Indeed, those who choose the approach of selectivity can certainly solve, at the outset, the problem of financial sustainability, but at the same time they have to demonstrate the political and social sustainability of such an approach. On the other hand, I have to propose criteria on the basis of which it is possible to establish a packet of essential health care services for every citizen.

## **WHY HEALTH CARE MUST REMAIN UNIVERSALISTIC**

The question immediately presents itself: what arguments can be adopted to support the thesis in favour of universalism in the health care sphere? There are two kinds of arguments: –general (that is to say those that also apply to other spheres of welfare), and specific, (that is to say those that apply to health care). Let us begin with the first.

The first argument is well evoked by the idea of J. Buchanan[2] according to whom a stable democracy can only survive if its welfare programmes are based upon principles of ‘generality’, that is to say universalism. The argument, in short, is as follows: welfare programmes that discriminate between social groups by subjecting citizens to means test or acting on the taxation front or on that of transfers end up by weakening the support of society for the whole political process. This is because, programmes of this kind generate incentives amongst the population to invest resources to ensure favourable treatment or to obtain protection against penalising treatment. Although on the one hand it fosters the waste of resources used in rent-seeking activities by groups that can count on the fact that in systems of government based on parliamentary democracy once a privilege has been acquired it is practically impossible for it to be eliminated even by an opposing political coalition, on the other hand it ends up by fragmenting society by eroding the pact that is the cement of a stable democracy.

This is the point that W. H. Beveridge, in his famous report of 1942 ('Social Insurance and Allied Services') had already foreseen when he wrote that the adoption of 'universal schemes' had to work for the 'solidarity and unity of the nation', given that, as one can read in the preface to the report, 'misery generates hate', that is to say civil war. Indeed, the experience of the Second World War had taught that everyone, irrespective of their social position, ran the same risks, and that it was neither worthwhile nor opportune to engage in a policy of discrimination. It was therefore with the Second World War, the people' war, that the arguments framed in terms of freedom from need were flanked by another argument – that of the equality of social citizenship. Now, if the founding principle of freedom from want can be compatible with selectivity – services are provided to those who have specific needs – the other founding principle necessarily postulates universalism.

It should be observed that the validity of this argument is not undermined by the more recent neo liberal position which argues that because the well-being of citizens is a function of economic prosperity that, in turn, is anchored to the extension of market relations, the real priority for political action is that of ensuring the full meeting of the conditions for the prosperity of markets. From here, the move to seeing the welfare state (which, redistributes quotas of wealth irrespective of the mechanisms involving the production of wealth) as an impediment to economic development is a short step. Hence the suggestion that the welfare state should be concerned solely with those who are left at the margins or are left behind by the competitive race. The others, those who manage to remain within the virtuous circle of growth, will defend themselves through the system of insurance.

Why does such a line of argument not hold up? For the simple reason that it is not true that the full extension of the area of the market increases well-being for everyone. Thus the legend according to which "a raising tide raises all the boats" is not in fact true. But quite apart from this, the problem of freedom remains. If, following A. Sen, we define freedom as the ability to exercise a function – for example the function of meeting one's own needs from the utilisation of the services that are offered – then it is not enough to pay attention solely to the sum of goods and services available to the individual. An individual, indeed, may not have the capability to take advantage of them. A form of welfare that takes the category of rights seriously must be a form of welfare that is empowering: there is a level of needs shared by everyone because everyone belongs to that human condition that must be met before individuals enter the market. If the opposite held, citizens would not be given the freedom to decide either the composition of the categories of goods to be produced (more private goods or more public goods or more relational goods) or the ways in which these are supplied. On this last point let it not be forgotten that the benefit that we gain from the consumption of a good does not depend solely on its intrinsic characteristics but also on factors connected with the way in which that good is provided. If the market were a democratic institution, the problem raised here would be solved with the usual methods. Yet, as J.S. Mill grasped, the market is an arena in which votes are weighed and not counted. What arguments, specifically applied to the health care sector, support universalism? The first and most immediate argument relates to the difficulties encountered in managing systems of selection: how can one arrive at a correct identification of those who have the right to services and how can control and monitoring procedures in relation to the platform of beneficiaries, which is clearly destined to change its composition over time, be implemented? As Toso well illustrated (1998), an expenditure programme with selective bases requires both the establishment of criteria of choice by which the limits at the level of categories of the programme are established (the right to use certain services is conditioned by the possession of characteristics of deserving such services that delineate the boundaries of the categories of those who have such a right) and the operational character of the criteria of allocation by which the real ability to enjoy services is sanctioned – for example, the identification of the monetary variables on which such enjoyment depends. Clearly, modifications of the rules relating to allocation extend or reduce the platform of actual beneficiaries according to the requirements of the decision-maker.

However, the pervasive phenomena of asymmetric information, which, indeed, are massively present in the health care sector, and the difficulties that are encountered in gathering and managing necessary information, means that the errors in the identification of potential beneficiaries are more the rule than the exception. And it is readily seen that in the case of health care protection the errors of exclusion (those who in conditions of perfect information would be the recipients of services are excluded) are much more serious than the errors of inclusion (those who do not have rights, that is to say the false positives, are included). In the field of social assistance, on the other hand, the errors of exclusion are less serious given that in this case it is easier to remedy the injury caused to the false negatives, for example, with various forms of compensation.

The above can be summarised in the following way. The health care sector is a sector that is inexorably dominated by phenomena that involve asymmetric information. (It may be interesting to recall, in passing, that the phrases ‘adverse selection’ and ‘moral hazard’ – phrases that describe the problems attributable to asymmetry at the level of information – were coined for the first time by K. Arrow in his famous article of 1963, specifically with reference to health care protection). On the other hand, whereas the problems of efficiency attributable to moral hazard (the aim of medical insurance is to provide care irrespective of its costs) and at the level of agency (the agent does not have to meet the costs of the treatment he provides) are still unresolved at a technical level, for those attributable to selection there is a ‘natural’ solution and it is called universalism. It is self-evident that this does not mean that where health care protection is offered on the basis of universalism all individuals, manage in reality to have access to it. Indeed, although the technology of enjoying health care services requires, in addition to access to them, also the availability of other inputs (an adequate level of education; minimum conditions of income etc.), it is not enough to establish a universalistic system for all citizens to actually benefit from it. But this does not go against universalism; indeed, it adds a further argument to support it.

There is a second argument on which I will dwell. It is connected with a special characteristic of the process of the production of health care services: the person who uses such services attributes importance, and thus a positive value, not only to the securing of health – something that is obvious – but also to other outcomes, such as respect for personal autonomy, the relational dimension, and fairness. This point may now be clarified.

Respect for the autonomy of the patient, understood as the concrete possibility that he or she has to take decisions, in one sense or another, as regards his her own state of health, is something more than the well known principle of the sovereignty of the consumer. The values of the agent should count in the decision-making process and that this is a matter for him/her.

Autonomy, i.e. the capacity to explain one’s own choices with reference to one’s goals, implies that the patient has the right not to choose. This means that the act of choice itself enters as a positive argument into the utility function of the subject, leaving aside the effects that the exercise of the choice will then produce. (This is what is implicit in the notion of consumer empowerment). And yet in the vast literature on health economics the exercise of the choice is almost always an option of the medical doctor, who works either directly as an agent of the commanding patient or indirectly as a supplier of information that is relevant to the choice.<sup>[3]</sup> Obviously enough, this reflects the utilitarian approach to which this literature belongs: whereas the principle of the consumer sovereignty is compatible with the philosophical matrix of utilitarianism, the notion of personal autonomy does not manage to find a position within that matrix.

The modality of the provision of health care services is also an element that is assessed positively by the user. As a myriad of empirical research studies confirm – and in particular the research carried out on the state of implementation of the Charters of Health Care Services and mixed consultative committees – the patient is increasingly interested in what is termed ‘relationship medicine’. Discretion in the carrying out of certain diagnostic examinations (one may think here of rectal endoscopy); the decency of waiting rooms for clinical tests; access to information that is not deformed as regards the

patient's own state of health; and the forms of interaction between the medical doctor and his/her patient – all these are examples of relational goods that are asked for by individuals, but to which it appears that sufficient attention is not paid on the supply side.

In general terms, a relational good is one that generates utility not only because of its intrinsic properties, as occurs in the case of all other goods, but also because of the modality of the process of consumption. Relational goods have a dual meaning. With respect to the production side, the relational dimension requires the co-participation of all the members of the organisation without its terms being negotiable. This means that the incentive that induces subjects to take part on the production of a relational good cannot be outside the relationship that connects those subjects: the identity of another person counts. As regards the consumption side, the function of a relational good postulates some involvement of the subject of supply because the direct relationship with another person is a constituent part of the act of consumption. This explains why in the process of consumption of such goods communication becomes an element that is not secondary.

Lastly, fairness as equality of opportunity in access to health care services is also a result sought after by the process of production of such services. As is known, the question of fairness in health care is a question that is still broadly debated in the literature, and one cannot see signs of a convergence towards solutions that are sufficiently shared. Of the three principal notions of fairness in health care – equality in health; equality in the use of care in line with need; and equality in access to care, it is this last which is normally adopted in documents dealing with health care policy, with the exception, perhaps, of those of the World Health Organisation, which seem to favour, inexplicably, the first definition.<sup>[4]</sup> It is easy to understand the reasons why preference is given to the notion of fairness as access. This belongs to the approach of 'process-oriented' assessment, according to which it is to the process rather than the final state that should be considered when one has to assess alternative institutions or policies. (The other two notions of fairness belong, on the other hand, to the 'end-state' approach: only the final result of the process counts). For this reason, a defendable health care system must seek to have an impartial approach to the aspirations of all potential patients, as required by the celebrated principle of neutrality, which lies at the heart of liberal thought.

Now, although it is true that at least two different versions of this notion of fairness are possible – should access refer to the actual use of services or to the opportunity costs that the patients have to meet to benefit from such services? – and that different results are obtained according to which one of the two notions is adopted, it is nonetheless undeniable that this notion well expresses the idea that an acceptable health care service in an advanced democracy is one that assures all its citizens equal opportunity as regards the use of certain specific services. Indeed, the goal is not the levelling of services but the empowerment of citizens with regard to health care. Usher (1977) coined the phrase 'the socialisation of goods' to describe a situation in which a society decides to appropriate the whole available quantity of a good and to redistribute it amongst its citizens on the basis of criteria that are not rooted in the market, and identifies the health care sector as a typical sector in which such a situation is encountered. In other words, health care services are said to belong to the category of social goods, that is to say those goods that are consumed on the basis of need, quite apart from the extent to which the beneficiary contributes to their financing.

It has been demonstrated that universalistic systems, *coeteris paribus*, mitigate the existing correlation between people's socio-economic status and their state of health. Indeed, it is known that poor people and people with a low level of education suffer from higher levels of illness and worse death rates. In a recent study, S. Decker and D. Remler ('How much Might Universal Health Insurance Reduce Socioeconomic Disparities in Health?', NBER, Aug. 2004) compared the present situations in Canada and the United States of America and found that having a below average income increases the probability that a middle aged person will be in bad health by about 15% in the United States of America and by about 7% in Canada (where a universalistic system exists). On the other hand, this eight percentage point difference between the two countries falls to four percentage points when people

over the age of sixty five are subjected to study (in the United States of America people over the age of sixty-five have access to the universalistic services of Medicare).

In conclusion, if one argues that attributes such as autonomy, the relational dimension and fairness have to be a constituent part of the patrimony of citizenry and are thus given to all citizens without distinction, one must agree that a selective health care system would be a clear pragmatic contradiction. Direct confirmation of this comes from the American experience. In 2002, in the United States of America, 15.2% of Americans – about 43.6 million people – were without health care insurance for the whole of the year. In 2001 the same percentage was 14.6%. For this category of individuals, the only hope of gaining access to care and treatment was connected with the availability of the offer of services by the safety networks of public hospitals, community health services, and the various non-profit organisations working in the sector. It is evident that for people without insurance, access to health care is in fact rationed (see C. Gresenz, J. Rogowski, and J. Escarce, ‘Health Care Markets, the Safety Net and Access to Care among the Uninsured’, NBER, Sept. 2004). Thus the country with the most researchers in the world, with the best forms of treatment against almost all illnesses, is unable to offer quality services to all of its patients, even though it spends more than double than other industrialised countries (about 16% of GDP) on health care.

## SUSTAINABLE UNIVERSALISM IN HEALTH CARE AND THE BACKWARDNESS OF THE DEBATE ON PRIORITIES

Does supporting universalism perhaps mean subscribing to a health care system that promises ‘everything to everybody’? Not at all. This would be a non sequitur. Indeed, from the realisation that a complete universalism, that is to say all-inclusive universalism, is in contemporary conditions simply not credible, two paths emerge that can be followed: to assure ‘everything to some people’, which is the pathway of the residual conception of welfare that postulates selectivity, or assuring ‘the essential to everyone’, which follows the redistributive conception of welfare, and which, I will now defend.

As one can understand, the heavy task that falls to those who follow such a path is to propose criteria that are coherent and ethically acceptable on the basis of which it is possible to define the health care basket to be assured to everyone – the ‘essential levels of care’. This is the subject of the great question of the establishment of priorities or to put it another way of ‘rationing’ in the health care sphere. It may be interesting to observe that it was the sentence of the Constitutional Court n. 356 of July 1992 that lifted the veil, in the Italian context, on the problem of priorities: emphasis was laid on the need for the ‘quantity and level of health care services, to be established on a prior assessment of priorities and compatibilities and taking account, of the fundamental needs connected with the defence of the right to health’ to be conditioned by the actual financial resources available.

The question presents itself: why has the critical debate about the question of priorities in health care remained on the margins, at the level of both experts and politicians?<sup>[5]</sup> Three different circumstances, which are not mutually exclusive, may be referred to. The first is that it is only in relatively recent years that the problem of financial compatibility has arisen in relation to this sector of social expenditure, as becomes clear when we observe the evolution of public health care expenditure in advanced Western countries. This fact has helped to spread the popular conviction, that health care is an activity that cannot be subjected to judgement based on efficiency. Specifically because the services that are produced have the characteristics of merit goods, the familiar economic criteria are not applicable to them. The medical doctor is therefore said not to have to take inefficiencies of various kinds (waste, and duplications of expenditure), into account. Episodes of this kind are at the most definable as minor evils or even inevitable evils. For an interesting analysis of the consequences at the level both of costs and of fairness in the allocation of resources in health care that come from the reluctance of medical doctors to take into account the fact that their own decisions are always in some

way influenced by the scarcity of resources see C. Alexander et al., ‘The Costs of Denying Scarcity’, Arch. Int. Med, 2004, p. 164. In essential terms, as long as health care expenditure remains at levels that are significantly low – in Italy, pro-capita health care expenditure was still \$600 in 1980, increasing, however, to \$1,236 in 1990– it is more than understandable that the question of priorities is not raised and therefore not addressed.

The second circumstance to which I referred above in a certain sense mirrors the first. It is not possible to launch a serene debate on priorities in health care in conditions of financial emergency. Indeed, the categorical imperative in Europe – to contain public expenditure in order come within the parameters laid down by the Treaty of Maastricht – has ended up by directing everybody’s attention and concern to one single priority: how to reduce health care expenditure. From the early 1980s a distinction begun to be made between the right to services (a right that had remained universal and thus unconditional) and the co-participation in health care expenditure: with the exception of those who are exempt, users are called to pay a fee for services such as a day hospital regimen, hospital emergency services, pharmaceutical costs, and specialist diagnoses. This kind of ‘neo-universalism’ made it believed for some time that in order to make the national health service financially sustainable it was sufficient to act – in addition to the rationalisation of the system – also on the category of those exempted from payment by intervening in a restrictive way through a suitable refining of the criteria enabling people to be treated free.

Finally, a kind of financial obsession has ended up pervading the process of reform of the national health service. As is well known, the focus of attention has in large measure been directed towards the financial structure of the system, with the result that the choice of the nature of competition and of the model of organisation of supply are seen as dependent variables. The result of this has been an overturning of the natural order of things: rather than engaging in a search for an organisational structure of the supply of health care services that most meets the requirements of efficiency and efficacy, it has been find out which organisation is most able to achieve the objectives of containing health care expenditure :the introduction of the new prospective system of funding of services that involve specialist and rehabilitative hospital care (the so-called ‘DRG tariffs’)[6] is the result of this approach.

I believe the time has come to realise that it is necessary to go beyond neo-universalism and to manage to define in a new way the principle of the comprehensive character of services. The innovation lies in the fact that a sectorial criterion must be introduced not in relation to beneficiaries (as is already the case) but in relation to the services that must be provided to everyone. But it is clear that this cannot take place when concerns about budget compatibilities take pride of place before all the others.

The third circumstance that has hitherto impeded an open debate on the subject of priorities in health care is connected with the special situation of the relationships that still exist between the economic disciplines, the medical sciences and moral philosophy. The wall of incommunicability that has always kept these three areas of study separate from each other has made difficult the identification of a space for encounter in which to address jointly the question discussed here. For that matter, priorities can never be established by any one of these three areas in isolation from the rest.

As regards my discipline, that of economics, things have developed, more or less, in the following way. With the rise within economics of the famous thesis of *avalutativity* (one of the central theses of the neo-positivist epistemological statute), the tendency spread to see economic knowledge as knowledge that is free of practical functions. Economic knowledge does not accompany and guide the action of decision makers, whoever they may be, but sees and predicts human actions as the physicist sees and predicts movements in nature. The adoption of the criterion of *avalutativity* once linked to the idea that only scientific knowledge can be said to be rigorously rational, leads *avalutativity* to be seen as the essential inherent character of economic thought. That is to say that in order to be scientific the economist cannot compromise himself by engaging in judgements of value. The gap that opens up in this way between analysis and decision becomes unbridgeable. Ends and motivations are declared to be

phenomena that cannot be provided with foundations by scientific analysis, which, indeed, has nothing to say about such entities. Hence the spread of relativistic, if not indeed sceptical, approaches, among a significant number of economists, and even among those who address themselves to questions that involve applied economics.

The concern at this abstinence from orientations is by now apparent to everyone, above all to those economists who love to ask themselves about the use of the results of their own scientific work. This is not difficult to understand. If one sees economics as one of the ways –certainly not the only way – of increasing our understanding of events in the social world and contributing to improving certain social structures and arrangements, such as, for example, the welfare system, the economist cannot limit his range of action solely to questions of efficiency. And above all he cannot pretend to ignore that the greater the importance of the decisions to be taken – as is the case with health care – the more necessary becomes the task of making explicit the criteria on the basis of which action is taken.

‘Although he knows all of this’, writes Jonas (1991), ‘the technician of economics still feels obliged to deny to his own science the power of providing such criteria for choices, and as a result the authority to say ‘yes’ or ‘no’ to any goal that is proposed, with the exception, of the decisions that involve mere practicability. In addition, to the question whether economic knowledge must be the judge of its objectives or a mere executor, the purist answers by choosing the second possibility. This is the answer of scientific asceticism, on which he draws in the name of the scientific purity of economics’ (p. 142). And yet we know today that scientific analysis can have the function of providing foundations for values, that is to say that values and scientific knowledge are not necessarily in opposition to each other, as indeed Pascal, in the modern age, courageously pointed out.[7]

The extent to which this ‘scientific asceticism’ has injured (through delay) the launching of an open debate on the subject of priorities in health care is evident to everyone. Indeed, an unreasonable and perverse of division of work between scholars has become established as a result of which the economist who is expert in the health care field must be concerned with judgements of efficiency alone; the medical doctor should deal with judgements on the efficacy (or appropriateness) of initiatives; and the (moral and/or political) philosopher should deal with questions of fairness. But it is clear that beginning with such a division of labour neither the dilemmas regarding the inter-sectorial allocation of resources (how many resources should be allocated to health care and how many to other sectors, as the environment, road safety, safety at work, etc.) nor the distributive dilemmas can ever be dealt with in a reasonable and above all politically acceptable way.

## APPROACHES TO THE ESTABLISHMENT OF PRIORITIES IN HEALTH CARE

a. What should be done in the area of priorities? The ethical crisis in which the health care systems of our countries are debated is rooted in this question. Such systems were created with the goal of reducing the suffering, and saving the lives, of individuals, without there being any a priori process of exclusion. On the other hand, the state of medical knowledge, and the low efficacy of medicine only allowed modest initiatives, and to such a degree that although access to medical care during previous periods had been limited to the prosperous classes, it was not at all certain that this would involve a disadvantage for the excluded, as the history of medicine well testifies. Today the situation has been overturned. Explicit rationing has become inevitable, but the exit route from this situation remains unknown. ‘Medical ethics’, writes M. Jori (1994), ‘is no longer only the ethics of the medical doctor[i.e. ethics concerned with the relationship between the medical doctor and his patient] – it has become the problem of the basic principles according to which resources are allocated to medicine at an overall level and are distributed within medicine’ (p. 80). Later on he adds: ‘the ethical paradox before us is, therefore, that the increase in power of medicine has increased rather than diminished the

number of tragic choices that ethics is faced with in the medical field' (p. 82). Indeed, this is the paradox that typifies the historical phase that we have entered.

There are two levels of analysis that are relevant to the goals involved. Beginning with the general objectives that the public decision maker intends to pursue, which criteria should be adopted to establish what a national health service should do? That is to say, in order to decide where the lines of responsibility should be drawn at the top of a public institution such as the national health service? New and Le Grand (1997) ask in provocative fashion: 'Should the National Health Services dedicate resources to the removal of tattoos?...Is it the task of the NHS to provide sterility treatment, physiotherapy for sporting accidents, sex changes...plastic surgery?' (pp. 231 and 238). We may also consider 'cosmetic pharmacology' and psychotropic drugs. As we know, the propensity to expand the field of therapeutic action to situations that are merely unpleasant is spreading. That is to say, pharmaceutical shortcuts are preferred to more demanding initiatives of an educational kind. The question of rationing in health care poses itself at this level of analysis. Contrary to what is commonly thought, the subject of rationing is the services provided and not the people to be selected to receive a specific treatment.

In order to understand how still widespread are the prejudices about the concept of rationing, it may be interesting to refer to the experience of the Ethics Working Group which was created by the Clinton administration in 1993 within the orbit of the Health Care Task Force. This body had the task of addressing the problem of the establishment of priorities as regards medical services. According to the summary of N. Daniels (1988), a member of this work group, during the opening sitting this work group had imposed on it that it would never employ the term 'rationing' in the documents that it produced, and this on the grounds that this term would have frightened people and endangered the future of the reform that was being carried out. And yet American society accepts, as has been pointed out above, that a rationing of medical care is carried out on the basis of people's ability to pay.

The second level of analysis is connected with the 'places' where what has been decided at the first level is applied. This second level is connected with the procedures to decide 'who gets what'. For example, should these decisions be left to a general medical practitioner or to a specialist? To mixed committees made up of medical doctors and patients or some public agency? Should rationing be applied solely to the high levels of the health care system (prevention and treatment, hospitals and basic help) or should it be pushed to the lowest levels, at the level, let us say, of the local health bodies? If there is only one bed available in the resuscitation unit of a hospital and two people have been admitted who both need that particular kind of treatment, which of the two should have the only bed available? And so on.

In what follows I will focus attention only on the first level of the analysis, which clearly prepares the round for the second.[8] Many approaches have been proposed in the literature. In part they have already been tried out in certain countries. The most popular approaches – that of establishing a target and that based on studies of the costs of illness – are also the ones that are the most unsatisfactory. Let us now see why this is the case.

The method of establishing targets in relation to health care underwent a certain growth in popularity following the publication of the white book of the World Health Organisation Health for All in the Year2000, in which the goals of greater fairness between countries as regards access to care, a more effective involvement of all the sectors of the economy in the promotion of health, and a more incisive presence in school programmes of subjects bearing on health, were established.

As Mooney (1994) observes, this is an approach based on the assessment of the total needs for care of the population where need is defined in terms of the presence of illnesses in that population: the higher the incidence of illness, the greater the need for care. The priorities are thus established on the basis of the epidemiological profile alone, leaving aside whether many or few possibilities of success actually exist. In addition, an approach of this kind, as a tool of health care policy, tends to favour the status quo

because it neither indicates the allocation of responsibilities nor suggests sources from which to draw the resources that are needed. In essential terms, this is nothing more than wishful thinking.

The judgement that one can express on the method based upon the studies of the cost of illness (the so-called ‘burden of illness’) is no better. This argues that the pathology that costs more must be given priority. (In general, the costs referred to are direct costs involving treatment and indirect costs attributable to the experience of illness, such as the costs of being absent from work). Davey and Leeder (1993) have rightly observed that the logic that underlies such an approach does not take into account either the benefits of actions involving treatment or the marginal cost of such actions, but focus instead on the total cost. It is therefore obvious that a proposal of this kind, if adopted, could never satisfy the efficiency criterion. And yet this is a rather widespread approach. For example the World Bank has suggested it to developing countries as a way of establishing their priorities in the field of health care. Its popularity seems to mirror, according to Mooney (1994), the idea that the resources should be allocated, as a matter of priority, to the ‘big problems’.

Let’s consider the approaches that are scientifically more rigorous: the approach of Qaly (‘quality adjusted life years’) tables; the urgency approach i.e. that of avoidable death; and the relevance approach. We will begin with the first one.

b.Qaly is certainly the most well known example of the application of the method of cost-utility analysis: priorities are established on the basis of a procedure that involves the creation of an algorithm that calculates the estimate of the prolongation of life following a certain service taking into account the possible level of deterioration in quality of life experienced as a result of the service itself. A Qaly[9] table is then created which arranges the various services on the basis of respective cost in terms of Qaly. Lastly, the rule is that the programmes of health care action are implemented and the respective services are provided in ascending order of cost in terms of Qaly. The basic idea is that health care resources must be employed so as to produce the greatest good and the Qaly are only a measurement of the good produced by a treatment, that is to say the benefit derived from it. A medical treatment can have two kinds of result. It can prolong the life of people and it can improve quality of life. The Qaly approach combines these two types of benefit in a single measurement. A year of life in good health amounts to one Qaly; a year of life passed in illness, on the other hand, receives a rating that decreases beneath one Qaly according to the level of compromise of health that is involved. The algorithm used to determine the Qaly associated with the various forms of therapeutic treatment thus serves to break the trade-off between the length and the conditions of a person’s life. If a given state of health receives an adjustment factor, let us say, of 0.5, this means that two years in such a state are equivalent to a year of full health.

Originally proposed by Torrance (1985) in Canada and by Williams (1985 and 1994) in Great Britain – authors who define Qaly as a ‘utility of state of health’ – this method achieved a wide resonance after the decision of the State of Oregon to use it as a criterion for the allocation of scarce resources: to assure primary treatment and care to many rather than assure an uncertain result from sophisticated forms of therapy for a few.[10] In addition, according to the report edited by Abel-Smith (1995) for the Ministers of Health of the countries of the European Union, the method in question is the one that has the greatest chances of success in the establishment of health care priorities.

However, the conflicts of a moral character – I will leave to one side the difficulties of a technical character[11] – that the adoption of such an approach would produce are not slight. Assuming that what matters in determining the basket of admissible services is the maximisation of the Qalys, this approach not only ends up by not taking into account the other outcomes of the process of treatment, but above all proves to be inadequate in addressing questions involving efficiency. The Qaly tables say nothing about the fairness – however that may be defined – of the treatment, yet that we know that with regard to the rationing of treatment the dimension of fairness plays a decisive role. If, let us say, a kidney transplant cost \$3,000 per Qaly and a hip replacement cost \$1,500 per Qaly, would we have to ration

kidney transplants more severely than orthopaedic operations given that the money spent on these last produces ‘more good’ than money spent on kidney transplants even though we knew that such transplants save more human lives? Is it morally acceptable to deny someone a chance of life in order to employ resources to improve the quality of life of other people?

However, it is in relation to the basic idea that Qaly measure the ‘good’ produced by a specific health care treatment that the most serious doubts are raised. The fact is that the method in question springs from a specific philosophical approach, that of Benthamite utilitarianism, an approach whose greatest weakness lies specifically in its inability to give meaning to the category of rights. As is well known, this leads to the rather narrow vision that utilitarianism has of the human person. ‘Essentially’, write Sen and Williams (1984), ‘utilitarianism sees persons as localisations of their respective utility...Once the utility function of a person has been considered, utilitarianism has no further direct interest in any information about the person’ (p. 9). Indeed, in putting together pieces of utility in a total sum that has to be maximised, both the identity of individuals and their separateness are lost, and these are indispensable requisites for the attribution of rights to people. And there are those who see such a failing in utilitarianism as particularly devastating when referred to a sector such as the health care sector where what matters is specifically the identity and separateness of individuals. If therefore one wants, as I believe one must want, public institutions such as the national health service to seek to achieve equal opportunities at a functional level for all citizens (illnesses and inabilities narrow the range of forms of functioning of people), one understands why utilitarianism is not an appropriate framework. But it should be stressed that this does not remove the fact that the Qalys approach can be used to good effect in specific circumstances. For example, in considering alternative forms of treatment for the same patient there can be no doubt that it would be both licit and suitable to choose the one that is most beneficial for that patient in Qaly terms.

c. The urgency approach encourages the decision maker to think that priorities should be established on the basis of the level of severity of the conditions of health of individuals: priority must be given to those services that, if applied in time, avoid fatal consequences (‘avoidable death’). A special committee of the European Union drew up so-called ‘health atlases’ in which those episodes of illness are indicated where early death could be avoided if treated rapidly as well as appropriately (cf. Holland, 1991).

The severity method is a refinement of the urgency method, where this last is understood as an ability to draw benefit from care and treatment: the higher the capacity of a group of people, the higher the need of that group. Obviously enough, this depends on the technology of care and treatment that exists in a given place and period of time: one can speak of avoidable death the more one has available effective examples of technology. And this is one of the strengths of the approach in question, a strength that is of by no means secondary importance. This is because the resources are rationed on the basis of the effective possibility of care and treatment that can be assured. In addition, and this is a second strength of this approach, it translates rather faithfully the idea according to which the urgency of a need matters more than both the ‘merits’ of various kinds acquired by the patient and the maximisation of aggregated utility.

Consider the case in which two people are waiting for a liver transplant but where there is only one liver available. According to the criterion in question, the transplant should be carried out for the individual who is in the most urgent condition – in Italy such a situation is defined as one that involves a person who would die within three days if he or she were not given a transplant. If the criterion were that of the greater good, such urgency should not enter the picture: the transplant would be carried out on the patient who had the greatest chances of success in Qalys terms, leaving aside the level of urgency that was displayed. It is easy to grasp the philosophy that underlies the avoidable death method. If the patient with urgent need does not obtain the transplant he or she loses his final possibility of being able to go on living. The person who is in a situation of non-urgency and does not

have the transplant, on the other hand, can always hope that a subsequent opportunity will present itself. It follows from this that in giving priority to urgent cases we operate in a way that equalises the life opportunities of people. And given that life is the first condition of freedom, in acting in this way we also increase the stock of freedom in the system.

However, there are two basic difficulties that make this approach criticisable. The first, pointed out by Abel-Smith (1995, p. 86), is that its application at a practical level tends to generate undesirable results: depending on the age of the population referred to, it selects certain pathologies rather than others. For example, if attention is focused on people in their fourties, priority is given to the prevention and treatment of road accidents; if people over sixty five are chosen precedence is given to cardiovascular diseases and so forth. In situations of this kind, either one has a plausible meta-theory that is able to justify why one should favour one age group rather than another – but in this case the problem of priorities is only postponed – or the urgency approach becomes susceptible to dangerous manipulations.[12] The other difficulty involved was brought out by the Norwegian Lonning Committee Report (cf. NOU, 1987). The circumstance of a person being near to death is a sufficient reason for his situation to be placed at the top of priorities, but this leaves aside cost levels (something that would appear obvious) and above all the level of efficacy of the intervention. This is to say that forms of treatment are carried out assuming that all of them have the same degree of efficacy, which is manifestly false.

The practical application of this method could lead to a lexicographical arrangement whereby all the pathologies of the first category would have precedence over those of the second category – the Lonning Committee identified five categories – even though the pathology that occupies the first position in the second category could deserve more attention and thus have priority over the pathology that has the lowest position in the first category.

d. The recent work of New and Le Grand (1996) on the principle of relevance seems to me to be more reassuring. In order to grasp what this means, it is helpful to begin with the observation that the methods examined above tend to disseminate a certain scepticism amongst scholars in the field about the possibilities of actually managing to define a basket of health care services that generally, are shared by the citizenry. The reason is, simply, that because every treatment always produces some positive effects for at least somebody, even though ineffective with other individuals, and because medical professional ethics require an acceptance of the ‘principle of therapeutic alliance’ – on the basis of which the medical doctor has the ‘symbolic’ function of being a guarantor of the preservation of the subjective right to assistance – it is practically impossible to manage to ensure that baskets of services on the basis of those methods become really implemented.

This explains, in particular, why the experiment of the State of Oregon did not have the envisaged follow-up. Indeed, the Supreme Court of the United States of America prevented this decision from being reproduced elsewhere and did so on grounds of principle.

The basic idea of New and Le Grand is essentially the following. All those health care services that cannot be provided through normal market transactions because of their characteristics come within the responsibilities of a health system that is publicly administered. The characteristics taken into consideration are three: necessity, asymmetric information, and uncertainty. It is their combination that confers upon health care the status of a special activity that cannot be subjected to the governing canons of market exchange.[13] To give an example, food as well, perhaps on the same level as health care services, is necessary to life, but the other two characteristics certainly do not apply to it. And indeed nobody would ever propose something like a national food service. Equally, the sector of automobiles also suffers from serious information asymmetries as New and Le Grand point out, and nobody would think of creating a sort of national automobile service. The tools available to the public authority to defend citizens in an adequate way in such cases are of a very different nature. At the same time, not all health care services are afflicted by the consequences of these three characteristics with the

same intensity. For example, home care for elderly people who are not self-sufficient is certainly necessary but it is not disturbed by phenomena involving asymmetric information or by high levels of uncertainty. For this reason, it should not come within the range of responsibilities of a national health service. And so on.

As can be understood, the notable advantage of this approach is that it can totally avoid judgements both of efficacy and efficiency in the identification of the basket of essential services. On the other hand, such judgements would be used at the second decision-making level, when, that is to say, one is dealing with deciding about the distribution of the resources that are available between the services that are deemed relevant. It can thus happen that a national health service may decide not to provide an anti-cancer pharmaceutical because its efficacy has not (yet) been demonstrated, even though anti-cancer treatment belongs to the basket of relevant services. Vice versa, cosmetic surgery operations, even though they are of great efficacy and appropriateness for people, let us say, who belong to the world of entertainment, would not belong, according to the line of reasoning described above, to the responsibility of a national health service. There are, certainly, difficulties to be encountered in the implementation of this policy – difficulties of which the authors in favour of such an approach are well aware. I do not believe, however, that these are particularly serious difficulties as to exclude an approach that, in fact, should be received with critical favour.

I will now move to a conclusion. It has always been known that establishing priorities in the health care field is an arduous undertaking. But this is something that has to be done. Not least because not deciding on the matter brings out a choice: the choice to allow the circumstances of the case or local power relations to govern allocations in the health care field. What has to be clear is that an attempt to arrive at a method that is, so to speak, optimal and incontrovertible would be in vain, and this for the simple reason that such a method does not exist. What, instead, must be pursued is the objective of achieving an identification of a procedure that on the one hand is able to incorporate the minima moralia of the civil society concerned, and, on the other, is able to function and above all to change by improving itself.

It is certainly the case that managing to obtain guidelines that can be perfected, even though they are not perfect, through a process of consent can never take the place of the philosophical debate between the visions involved and political mediation between the bearers of different interests. However, it will be helpful to ensure that the reflection now underway in our countries on how to make health care welfare that seeks to remain anchored in the principle of universalism emerge from the constraints of a certain form of economicism. I say ‘economicism’ in order to refer to the position of those who argue that it is sufficient to act on the front of efficiency alone, operating through rationalisations and incentive schemes of various kinds in order to obtain the desired result. I have found an authoritative confirmation of such a line of thought in a recent work by A.O. Hirschman (1997) in which one may read: ‘what is really needed in order to make advances in relation to the new problems that society meets on its pathway is the capacity for political initiative, imagination, patience here, impatience there, and still other varieties of ‘virtue’ and ‘luck’ (p. 305).

## WHAT WE CAN EXPECT FROM THE RAPID LAUNCHING OF A DEBATE ON PRIORITIES

What results is it reasonable to expect from a launching of a systematic reflection on how we can arrive at a basket of essential health care services? First of all, that of raising the level of debate on the question of health care. Today, in relation to the reforming process in health care there is an excess of opinions and a shortage of arguments about ways of implementing that ‘pact of solidarity for health’ which is spoken about in a strong way in various circles. The mass of opinions do not really justify themselves. In general, taken as a whole the opinions do not achieve much: it would be much more efficacious to move onto the terrain of dialogue between the arguments that underlie certain proposals.

As is well known, the transformations of institutional arrangements follow, with a certain delay, the emerging awareness by citizens of problems to which such transformations should provide an answer. It is therefore indispensable to involve organised civil society in the debate, that is to say the various forms of associations that already operate, with varying levels of success, in the health care sector. Efficiency is lost when a system of governance is designed that does not use to the full that extraordinary resource which is, the responsibility of the actors. And this is because looking after health is, in addition to being a right, also a personal responsibility towards life,[14] and because the ‘being well’ of people depends not only on the efficacy and the appropriateness of forms of health care and treatment but also, as has been observed above, on the quality of interpersonal relations.

A second important result would be that of preparing the ground for the non-traumatic acceptance of the rules relating to priorities that are adopted so that they can be implemented in the future. Obviously enough, those who intended to apply from the outset rules of rationing that decreed the ending of health care services that had been provided up to that moment would be engaging in imprudence (a lack of phronesis). The social conflict that would follow could lead to every effort being made in vain. Nobody is able to predict with an acceptable approximation how scientific and technological progress will revolutionise traditional ways of responding to the various pathologies. So a definition today of a procedure that identifies health care priorities would perform a function analogous to that performed by the famous metaphor of Rawls – a ‘veil of ignorance’. Just as the constituents of Rawls, protected by a veil of ignorance, come to agree through rational calculation on norms that define justice as fairness, in the same way today’s citizens, knowing the rules of access and the levels of provision of their national health care system will have all the time and the opportunities that are needed to prepare actions and measures of a supplementary character.

I thus come to a third practical result that could be achieved rapidly. Only if citizens have an opportunity to know about the differential health care services for which they make over payments or insurance fees can a significant system of supplementary health care mutual aid be set in motion. It should be observed, however, that supplementary – or ‘complementary’, as some prefer to call it – mutual aid cannot be confused with mutual aid that is substitutive or mutual aid that is additional (which covers the difference between the price of the service and the quota guaranteed by the national health service; the services connected with public provision such as those provided by hotels, and so forth). Whereas these last two forms of mutual aid, contradict universalism, supplementary mutual aid obtains what we have termed ‘health care universalism’ in relation to essential services.

It is certainly the case that there are many problems, ranging from the theoretical to the practical, that have to be solved if we want to launch a robust sector of complementary health care.[15] Amongst the problems of a practical character, I would like to point out here those bearing on financial management. Still today, the absence of legal provisions in relation to adequate asset guarantees for those who have the right to services forces the bodies involved and the funds to act according to a short-term approach. The consequence of this is that financial balance is pursued on an annual basis by recalculating the payments to be made on the basis of historical data. The extent to which this generates greater costs and reduces the quality of the services that are offered can easily be imagined. Moreover, direct management by the mutual aid associations diverts their attention away from their primary goal, which is the aggregation of demand. But one must see in supplementary mutual aid the most immediate and serious opportunity that we have to put civil society to work. If one believes that civil society is a place of concrete examples of solidarity and a premise for social pluralism one cannot prevent a flourishing of those expressions typical of the civil economy, namely forms of supplementary health care mutual aid, in such a sensitive area of associative life as health care.

In a recent empirical study, A. Castelli and A. Culyer (‘Rationing Health Care in Europe’, Dept. of Economics, Univ.of York, 2003) carried out a sample study of English citizens in order to record their point of view on the rationing of health care services. Contrary to what was expected, the results revealed an attitude that was largely favourable to the establishment of explicit criteria for rationing.

Different views emerge in relation to the individuals who should be asked to engage in rationing and to the value judgements to be placed at the basis of such a procedure.

## THE ROLE OF THE ORGANISATIONS OF CIVIL SOCIETY

The above allows us to understand why organisations of civil society are needed that work so as to ‘autonomise’ demand by ensuring that it directs supply. As is well known, a fundamental characteristic of civil society organizations is that they belong to a plurality of stakeholders, and this means that the owners of such organisations are not only the people who invest in them to gain a return on the invested capital. The objective function of an association of civil society is more than that of serving in some specific way the community in which it operates through the production of social externalities and the defence of the principle of fairness. (Technically speaking, an externality is created whenever the actions of a subject have a (positive or negative) impact on the well-being of other subjects, an impact that is not mediated or regulated by the system of prices. On the other hand, an externality is social when it involves the community as a whole).

Public health is a typical example of a social externality, like social cohesion or social capital. In the presence of social externalities, the overall benefits generated by the activity of a subject as regards supply are not only those attributable to the output that is obtained, but also those connected with the way in which that output has been obtained and above all the motivational system that animates those who promote that specific activity. It follows that the generation of positive externalities, although it discourages for-profit companies from increasing their own investments, constitutes the very mission of an organisation of civil society, the reason, why the members of such an organization come together to create an economic activity. It should be observed that I do not mean to say that a for-profit firm is not interested in taking social externalities into consideration or that it is not happy to produce them. I simply want to say that the objective of the maximisation of profit (or of some other indicator of profitability) does not allow the for-profit firm to ‘attribute’ a certain weight to such externalities within its own decision-making procedure, even though it remains true that other subjects (for example a local agency or an association of consumers) could induce the for-profit firm to do this.

The question spontaneously arises: what economic reasons speak in favour of the organisations of civil society as providers of health care services? The answer that is given today to this question by most people is the one based on the theory of comparative advantage, a theory on the basis of which firms – it does not matter if they are public, private or non-profit making in character – that show that they are efficient are entitled to provide health care services. It should be observed that such a theoretical stance has been, and remains, so influential and pervasive as to have formed the basis of, or at least influenced, the Treaty of Amsterdam, which, indeed, set in motion the process of European unification. As is well known, this treaty envisages that with regard to health care services that are directly connected with public health (for example the prevention of epidemics), the rules of competition should also be applied to this sector. In practical terms, this means that in a short time the local health authorities will have to follow the same rules that local government bodies now respect when they decide to entrust the provision of specific services to outside bodies. We will have, that is to say, to proceed to so-termed comparative assessment: the service will be entrusted to those providers that assure the lowest costs for the same quality. This means that those structures that are incapable of meeting the challenge of comparative assessment will sooner or later be swept aside by the winds of competition.

It should be borne in mind that the intensity with which such winds blow will be especially high when in the near future the principles upheld by the GATS (General Agreement on Trade in Services), which was signed in 1994, come to be applied. One of these principles is ‘national treatment’: foreign companies that are present in the market of a given country must receive treatment at least as

favourable as that enjoyed by the national companies that operate in the same market. As one can well understand, the GATS, because it involves a commitment to liberalise services through periodic negotiations, will have effects, of a relevant character as well, on the international trade in health care services. One need only think here of services involving tele-medicine and diagnoses across different countries; the health care services offered by foreign companies or multinationals; consumption abroad; and so forth.

What does it mean? It suggests a cogent reason for the inability of non-profit organisations to meet the competitive challenge of for-profit companies. The argument, essentially, is that advanced by H. Hansmann ('Economic Theories of Non Profit Organizations', in Anheir H.K. and Siebel W. (eds.), *The Third Sector: Comparative Studies of Non Profit Organizations*, New York, De Gruyter, 1990) with reference to the banking and insurance sector of the United States of America. Why – Hansman asks himself – has this sector undergone in recent years a marked transition from non-profit forms to for-profit forms in concomitance with massive intervention on the part of the government at the level of rules and regulations? The answer is that the introduction of sophisticated forms of regulation by the government considerably reduces the possibilities that a profit firm could exploit its own customers. One should not forget, in fact, that the non-profit firm, because it eliminates the incentive to act opportunistically to make profits by exploiting asymmetric information, acts as a signal of trust as regards customers. But when technological innovations, on the one hand, and careful vigilance by government, on the other, impede a for-profit company from exploiting to its own benefit advantages asymmetric information, it is specifically at that moment that the non-profit form loses its specific comparative advantage and thus its economic legitimation.

This argument would explain, according to Hansmann and many other authors (for example J. Forder et al., 'Competition in the English Mixed Economy', *Journal of Social Policy*, 25, 1996), the recent massive penetration by for-profit companies in areas, such as the health care sector, which have been traditionally considered the terrain of organisations of civil society. Indeed, J. Kendall ('The Third Sector and Social Care for Older People in England', Civil Society WP8, London School of Economics, 2000) goes so far as to argue that because of the well-known effects of reputation and the pressures applied by consumers' associations, which are increasingly informed and combative, the for-profit firm is induced to act in a non-opportunistic way, even though it would like to be opportunistic, and thus to turn the for profit firm into a non-profit one.

It is not difficult to grasp the practical implications of conclusions of this kind. Not only would forms of public support of a fiscal kind for non profit organisations not be more justified but forms of permanent subsidy for such organisations could not be accepted. The logic of competition, to put it another way, requires that the same contracts must be signed with subjects that work in the health care sector whether they are non-profit firms or for-profit firms.

How did we come to this u-turn? Because of two sets of circumstances, one of a theoretical character and the other of a practical kind. It is certainly true that in the area of health care services phenomena are present that involve both asymmetric information and social externalities. But these are not the only ones that are relevant nor are they the most important. In reality, health care services are, typically, services provided to a person, services that include a fundamental relational dimension that can certainly not be captured by the comparative advantage approach, which, indeed, is not equipped to deal with relational goods. As we are told by the most recent economic literature on relational goods, the instruments that must be employed to take the relational dimension into account, compared to those usually applied to efficiency, are of another kind. It is, therefore, evident that if in the calculation of comparative advantage between different forms of enterprises there is an a priori elimination from the attributes relevant to comparison of those that constitute so-called relational medicine, then the non-profit form, which is naturally led to exalt the relational dimension, is disadvantaged from the outset. But more should be said on this point. The quality standards in health care are a 'moving target', not something that can be defined at intervals of varying levels of regularity over time. It follows from this

that even the most enlightened and rational of the systems of regulation employed by the public controller can never ‘keep up with’ a reality that is in constant evolution, which, indeed, is what the health care sector is.

And yet the analytical technique on which the comparative advantage approach is based has a method that is essentially static in character, and this method is in itself unable to take into account the fact that illness is not a mere pathological accident but belongs to a pathway of existence marked by a plurality events. Once again, in a situation in which the biographical dimension of the patient is not seen as less important than the biological dimension alone, it is clear that a non-profit organisation, *coeteris paribus*, is damaged to the advantage of a for-profit organisation.

A very significant confirmation of what has just been said comes from the recent empirical survey carried out by B.A. Weisbrod, who has demonstrated that in the United States of America old people’s and disabled people’s homes managed by organisations of civil society which are the expressions of various Churches treat their guests ‘in a more human way’ than analogous for-profit forms. In particular, Weisbrod has shown that non-profit hospitals, once they have become transformed into for-profit structures, cease to provide services such as ‘community advice’ and no longer allocate resources to research into ‘orphan diseases’ – these are activities that are certainly not designed to achieve profits (cf. ‘Institutional Form and Organizational Behaviour’, in Powell W. and Clemens E. (eds.), *Private Action and the Public Good*, New Haven, Yale University Press, 1998).

The second set of circumstances to which I alluded to above is connected with the fact that for various reasons, which I cannot dwell on here, a large number of organisations of civil society working in the health care field have not been able to demonstrate their specific added value in the way they supply their services. To generalise for a moment, this happens whenever an organisation of civil society ‘chooses’ the strategy of isomorphism, that is to say chooses to become similar to a rival for-profit company by concentrating all its efforts on the objective of efficiency and by adopting internally those organisational and managerial systems that are typical of the for-profit firm. To put it another way, when an organisation of civil society ceases to demonstrate at the level of facts that it is able to translate a specific conception of social quality (able to take into account the process and the product) into practice, it happens that only those attributes of quality that can be assured by the for-profit firm as well are recognised as worthy of attention by a public agency and thus regulated by that agency. And it is thus obvious that interpreted reductively in this way social quality ceases to be a trait that characterises the action of an organisation of civil society, which, indeed, can no longer seek or claim for itself any special ‘exceptions’.

To put the point in more explicit terms, once social quality is reduced to the level of what is quantifiable by the familiar methods of statistical inquiry, it is clear that it is discovered that in relation to this notion of quality the organisations of civil society cannot ‘do better’ than a for-profit firm. With this, the complex set of issues and questions connected with the so-termed welfare mix in health care becomes reduced to the question, of the typology of contracts that public authorities should sign with the various subjects that provide supply, whatever their specific nature may be. In this way, the very important subject of pluralism in health care is reduced to the old and obsolete alternative between the state and the market, between more state and less market or the opposite. The propulsive and creative role of civil society organised as a subject that generates ‘social capital’ is thus emptied of meaning or at the most seen as a mere functional support for the market.

To conclude, the problem is not at all that (as some would have it believed) of eliminating the category of competition in a sector such as health care. Rather, the problem is that of enriching such a category so as to ensure that subjects of supply that are the bearers of specific abilities – such as those that are required to emphasize a full conception of social quality – can compete on equal terms with subjects of supply that are the bearers of other abilities, leaving the customer-citizens of health care services to decide what relevance it should have, that is to say how much economic space one or other type of subject of supply should have. In essential terms, those who believe in the tenets of freedom cannot

accept that the subjects called upon to compete in the health care sector are pre-selected on the basis of a criterion – that of economic efficiency – that cannot, by its very nature, take into account attributes such as those of social quality or the production of collective externalities. These are attributes, it should be observed, that citizens declare that they appreciate but which they are also disposed to strive to achieve. To go on not grasping the point would mean to fall into the trap of economicism.

## A FINAL NOTE

The argument outlined in this essay has an ultimate purpose – that of showing that the governance of such a complex system as the health care system cannot be carried out by remaining within the traditional contraposition of a statist vision and a neo-liberal vision of the political-economic world. According to this approach, state control and market mechanisms are seen as antithetical alternatives when it comes to the planning of a health care system. And yet, as is now well known, neither the institution of the state nor the institution of the market are able, on their own, to solve fundamental conflicts, and in particular to remove in an acceptable way those ‘tragic choices’ that are present in health care in a systematic and not occasional way.

In view of this I consider more promising the path of a co-operative relationship between the public dimension and the private dimension, according to which the state, for its part, adopts the function of being a stimulator of the evolution of organisational arrangements that are intended to eliminate the areas of inefficiency that are present in an endemic way in health care, and in addition becomes a regulator, that promotes civil society so as to avoid the risks of health care privatism. At the same time, the market, which must be organised into the different but complementary forms of private economy and civil economy,[16] has the dual task of providing resources, beyond those that are secured through the general fiscal processes, in order to make health care of a universalistic kind sustainable, and to counter the recurrent temptation of economic and political statism, demonstrating thereby, at the level of facts, that one can achieve socially optimal results in the field of health care.

What has been said above is connected with the notion of the ‘limited state’, as I like to call it. The limited state is in opposition both to the ‘minimal state’ (a notion held dear by liberal-individualistic thought according to which the state must guarantee only a few things: laws, public order, the currency, defence) and the ‘assistance state’, which must decide in a paternalistic way, and directly provide, what is good for citizens. The limited state, in different fashion, is a state that intervenes, perhaps in a strong way, in some fields and not in others, at the same time as recognising (but not itself authorising or granting) the greatest possible freedom for the free organisations of civil society. In his famous Voluntary Action, Lord Beveridge wrote: ‘The formation of a good society depends not on the state but on the citizens who act individually or in free associations... The happiness or unhappiness of the society in which we live depends on ourselves as citizens and not on that instrument of political power that we call the state. The state must encourage voluntary action of every kind to achieve social progress’. And this, in essential terms, is the idea underlying the principle of subsidiary according to which the state should promote and encourage all those forms of collective action that have public effects, as indeed happens in the health care field.

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[1] A. Giddens demonstrates at a detailed level how the move from the exogenous risk to the endogenous risk compels us to think in terms of a system of ‘positive welfare’, a system, that is to say, that is able to attack the problems of ‘the politics of life’ through a mobilisation of life decisions: cf. A. Giddens, *Oltre la destra e la sinistra* (Il Mulino, Bologna, 1997), chaps. 4 and 5.

[2] Cf. J. Buchanan, ‘La crisi nelle democrazie del welfare’, in M. Arcelli (ed.), *Globalizzazione dei mercati e orizzonti del capitalismo* (Laterza, Rome, 1997). This is an essay that condenses the theses advanced in the volume J. Buchanan and R.D. Congleton, *Politics by Principle not Interest: towards Non-discriminatory Democracy* (Cambridge, CUP, 2000).

[3] U. Jensen and G. Mooney, *Changing Values in Medical and Health Care Decision Making* (Wiley, London, 1990), distinguish between deontological autonomy (it is the patient who must in all cases and always decide) and relativistic autonomy, a notion that they themselves favour.

[4] For an accurate critical examination of the pros and cons of the three notions, in addition to the difficulties of a practical kind that are encountered at the level of their implementation, see G. Mooney (1994), *Key Issues in Health Economics* (Harvester, New York, 1994). See also the important work C. Donaldson and K. Gerard, *Economics of Health Care Financing* (MacMillan, London, 1993).

[5] J. Lenaghan, *Hard Choices in Health Care: Rights and Rationing in Europe* (BMJ Pu. Co., Bristol, 1997) provides an accurate presentation of the terms of the debate on the subject of priorities in Europe and North America.

[6] In the classification by DRGs, admissions are differentiated into 492 groups belonging to 25 principal categories of diagnosis on the basis of the same 10.0 grouper adopted in the United States of America by the Health Care Financing Administration within the framework of the Medicare programme. The calculation of the tariffs associated with each category of admissions is based on the average cost of resources used during hospitalisation. It is to be observed that since 2004 in the English NHS, as well, the method of DRGs has been adopted, although in this case the term used is 'Healthcare Resource Group' (HRG) and they are applied in an extensive way – not only to activities connected with hospital admissions but also to services involving clinical specialisations.

[7] But, as is well known, Descartes was the winner. Theorising that there can be no dialogue between philosophy that is concerned with the spirit on the one hand, and science that is concerned with material things on the other, the Cartesian paradigm ensured the predominance of the disjunction of tasks over their conjunction. On this subject of utility see E. Agazzi, *Il bene, il male e la scienza* (Rusconi, Milan, 1992).

[8] For a discussion of the problems associated with the second level of analysis with explicit reference to the Italian situation, I refer the reader to A. Stefanini, 'Criteri e soggetti delle scelte nell'allocazione delle risorse in sanità', in M. Geddes and G. Berlinguer (eds.), op. cit., 1998. For a useful comparative examination of the experiences now underway in various countries see F. Vanara, 'Esperienze internazionali nelle scelte di priorità', in M. Trabucchi and F. Vanara (eds.), op. cit., 1998. The criteria used by the Artificial Kidney Centre of Seattle, according to the account of Mary Douglas in *Come pensano le istituzioni*, were the following: 'Only those individuals who demonstrated qualities such as decorum and a sense of responsibility were thought to be worthy of having their lives saved through rare and expensive treatment, such as chronic dialysis. Imprisonment, any act of social deviance, for example, any clue to the effect that married life was not immaculate or absent from scandals were equally grave indications against selection'.

[9] On the techniques used to measure Qaly for various pathologies and on the methods employed to create a Qaly table see G. Mooney, op. cit., 1994.

[10] As early as 1987, in Oregon, the case of Jacoby Howard, an eleven-year-old boy who had died of leukaemia because his parents were not able to find the necessary \$100,000 in time to pay for the bone marrow transplant, caused great concern. If Jacoby had fallen ill a year before previously, the transplant would have been carried out at the expense of the State. The parliament of the State of Oregon, faced with the dilemma of whether with the resources available it was more advisable to extend primary treatment to 1,500 people (above all children) who did not have it, or to continue to finance the transplant of organs for about twenty people a year, decided in 1986 in favour of the first alternative, specifically applying the Qaly method.

[11] See J. Broome, 'Qalys', *Journal of Public Economics*, 50, 1993, pp. 149-167, who, overall, is in favour of the approach in question and argues that the method of time followed to assess quality of life is compatible with individual preferences only if the years of life are not taken for granted. For that matter, the probabilistic method is always compatible with individual preferences only if the subjects are neutral in relation to risks. But M. Johannesson, 'Qalys: a comment', in *Journal of Public Economics*, 56, 1995, pp. 327-8, demonstrates that under certain specific conditions such is not the case.

[12] For example, I. Kamm, *Morality and Mortality*, vol. I, Oxford University Press, Oxford, 1993, argues that need varies directly with age: we are worse off if we die at age n than if we die at age (n + 1). If the criterion is to help those who are worse off, the rationing that should be carried out is that carried out on the basis of age.

[13] One may observe that it is specifically the contemporaneous presence of all three of these characteristics that determine the existence in the field of health care of the very many trade-offs that are not to be found in any other sector. P. Diamond, 'Rationing Medical Care: an Economist's Perspective', *Economics and Philosophy*, 14, 1998, pp. 1-26, observes how the phenomena of the

temporal incoherence of the preferences of subjects can have especially catastrophic consequences in the case of health care. If I do not decide today to purchase a ticket for tomorrow's baseball match, when, indeed, my preferences could be different from those of today, is something that is of little importance. But if I do not decide today to take out insurance to have health care in the future, this could have rather grave damage both at the level of expenditure and because of insecurity in relation to conditions of life. And it is for this reason, as well, that health care coverage belongs to the category of great risks, in relation to which the insurance markets, as is only too well known, do not function well.

[14] According to the well-known definition of 1947 of the World Health Organisation, health is a 'state of complete physical, mental and social well being'. This is a definition which says at one and the same time too much (complete well-being is a complete utopia) and too little, because it neglects the responsibility of the individual to engage in forms of behaviour that are intended to prevent or repair damage to health.

[15] M. Gouveia, 'Majority Rule and the Public Provision of a Private Good', *Public Choice*, 93, 1997, pp. 221-44, provides perhaps the first theoretical model to demonstrate the existence, under majority rule, of a political balance for the supply of health care services in which private supply supplements public supply.

[16] I examine and explore the connection between civil society and the civil economy in the essay by L. Bruni and S. Zamagni, *Economia civile* (Il Mulino, Bologna, 2004).

# **MARKUS HENGSTSCHLÄGER**

## **THE PHARMACEUTICAL PRODUCT AS A MEDICINE, AS A COMMERCIAL PRODUCT AND AS A CONSUMER COMMODITY**

### **INTRODUCTION**

It is the major aim of researchers in medical sciences, medical doctors and nurses to heal sick individuals. One of the most effective approaches to reach this aim can be the usage of pharmaceutical products. Pharmaceutical drug products are of great importance to providing consumers with a myriad of treatments and cures. For millions of people they represent a chance to increase life expectancy and to enhance lives. The relevance of the pharmaceutical industry performing research and development cannot be stressed enough. On the other hand, the spectrum of these products is tremendously wide.

#### **Pharmaceutical products**

- prescription and non-prescription drugs, medications and therapeutics
- antibiotics
- anti-viral and anti-cancer drugs
- analgesics and anti-inflammatory drugs
- cardiovascular products
- immune system products and antihistamines
- advanced cellular research products for preventative and therapeutic medicines
- cosmetic products, such as e.g. skin and hair care products.

It includes a wide range of prescription and non-prescription drugs, medications and therapeutics, advanced antibiotics, anti-viral and anti-cancer drugs, analgesics and anti-inflammatory drugs, cardiovascular products, immune system products and antihistamines, advanced cellular research products for preventative and therapeutic medicines, but also cosmetic products, such as e.g. skin and hair care products. Where are the boundaries between pharmaceutical products exclusively useful for the beauty industry and such products really of importance for human medicine in terms of treating diseases? Who decides a condition to be a disease or just to be a, so called, non-disease?

To bring more light into this discussion the World Health Organization developed the term “essential medicines”. “Essential medicines are those that satisfy the priority health care needs of the population. They are selected with due regard to public health relevance, evidence on efficacy and safety, and comparative cost-effectiveness. Essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and community can afford. The implementation of the concept of essential medicines is intended to be flexible and adaptable to many different situations; exactly which medicines are regarded as essential remains a national responsibility.” (World Health Organization, 2002).

In addition, the definition of good manufacturing practice (GMP) in pharmaceutical production is of great importance. Poor quality medicines, e.g. containing toxic substances that have been unintentionally added, are not only health hazard, but waste of money for both governments and individual consumers. It is an important aim that all countries will only accept import and sale of pharmaceutical products that have been manufactured to internationally recognized good manufacturing practice (World Health Organization, 2002).

Here, the different views of how to use pharmaceutical products are compared and discussed with special focus on the interactions and contraries of exclusively medical indications for the usage of these products and the commercial interests of the pharmaceutical industry.

World Health Organization criteria for essential medicines

- satisfy priority health care needs
- public health relevance
- evidence on efficacy and safety
- comparative cost-effectiveness
- availability: all times, adequate amounts, appropriate dosages forms
- assured quality
- adequate information
- reasonable price

### The process of the discovery and development of a new drug

An objective discussion of the aspects described above must start with a description of the enormous efforts pharmaceutical companies must invest for the development of a new medicine. Well known research-based pharmaceutical companies invest up to US\$ 30 billion in research and development per year. It is estimated that it costs US\$ 500 million to develop a new drug from starting research to reaching the market. About 70% of the cost is accounted for by failures during pre-clinical research and development and the average time for such a development is 15 years (Robbins-Roth, 2000; Furness and Pollock, 2001; Rohmann et al., 2002).

First, basic research projects are performed in laboratories to identify novel drug targets that contribute to the pathology of specific diseases. It is the hope of investigators and patients alike that compounds that interact with those targets are able to modify the resulting pathology. Research projects of this kind take two to ten years and result in a drug candidate being progressed to clinical testing. In phase I, phase II and phase III clinical trials the question should and must be answered whether really a new medicine has been developed, which satisfies unmet medical needs with improved efficacy, reduced toxicity and less likelihood of adverse effects (see Figure 1, adapted from Furness and Pollock, 2001). But why investing such enormous efforts? The benefits for the pharmaceutical industry become clear looking at statistics showing that in the United States of America an average prescription drug generates about US\$ 1.5 million per day in revenue (Getz and De Bruin, 2000).

### The research on and with pharmaceutical products

A very important ethical aspect comes up looking at the information described above. What if the estimated prevalence of a disease is low? Obviously, the benefits for the pharmaceutical company that develops a medicine for the treatment of such a disease are much lower compared to a more common disease. In contrast, the efforts for the discovery and the development of such a drug are the same independent of the prevalence of the disease. In other words, the pharmaceutical industry invests in the development of drugs for common diseases and research on, so called, orphan diseases misses. An orphan disease is a condition which has not been adopted by the pharmaceutical industry because it provides little financial incentive for the private sector to make and market new medications to treat or prevent it. According to criteria of the United States of America, an orphan disease is one that affects fewer than 200000 people. There are more than 5000 such rare disorders. An orphan disease may also be a common disease that has been ignored (such as tuberculosis, cholera, malaria), because it is far more prevalent in developing countries than in the developed world. In the last twenty years the United States of America, Japan, Australia and the European Union adopted orphan medicinal products legislation. Marketing exclusivity and tax incentive on research and clinical trials on pharmaceutical

products developed for conditions that occur only rarely and including tropical diseases and other disorders prevalent only in the developing world are offered (Robbins-Roth, 2000). It cannot be stressed enough that it is a very important challenge for politicians, the society and the pharmaceutical research community to keep on walking into this direction.

Because of the high amount of money needed it is not surprising that a permanently increasing number of research projects and clinical trials at all stages in a pharmaceutical product's life cycle are funded by the pharmaceutical industry. This raises also a very important ethical issue. What is the influence of the interests of the pharmaceutical industry on the results obtained with those basic research projects and clinical trials? Here it is important to note that this influence can be more direct but also indirect, depending on whether the studies are either done in-house by the pharmaceutical companies or externally by researchers, medical doctors and consultants who are paid for by a company (Anis and Gagnon, 2000). Results that are unfavourable to the sponsoring industry can pose considerable financial risks to the company. It is clear that no company wants to "waste" money for showing that one of its drugs is less clinically effective or cost effective or less safe than other drugs used to treat the same condition. Pressure to show that the drug causes a favourable outcome may result in biases in design, outcome, and reporting of industry sponsored research (Bero and Rennie, 1996). Accordingly, it is of great importance to investigate whether funding of drug studies by the pharmaceutical industry is associated with outcomes that are favourable to the funder and whether the methods of trials funded by the pharmaceutical companies differ from the methods in trials with other sources of sponsors. A systematic review of the impact of financial conflicts on biomedical research found that studies financed by the pharmaceutical industry, although obviously as rigorous as other studies, always found outcomes favourable to the sponsoring company (Bekelman et al., 2003). A recent investigation of this issue demonstrated that the fact that research funded by drug companies is more likely to have outcomes that favour the sponsor's product than research funded by other sources cannot be explained by the reported quality of the methods in research sponsored by industry. The results are more likely due to inappropriate comparators or to publication bias (Lexchin et al., 2003).

It is a new policy of prominent medical research journals to ask the authors of manuscripts reporting basic research results and/or results from clinical trials dealing with a specific pharmaceutical compound to officially explain any connections with pharmaceutical companies or any support from the industry. Although this is clearly a step in the right direction, one doubts about its power to avoid the companies' influence.

### Patenting and generic products

For the pharmaceutical industry the discovered and developed new drug must also be seen as a commercial product. The development of new pharmaceutical products is of highest importance to providing consumers with new strategies to treat and cure the wide variety of "old and new" diseases. As described above, the process of the discovery and development of a new drug is very costly and risky. It is of interest for pharmaceutical companies and patients alike to maintain appropriate incentives for the development of new drugs. It seems reasonable, that maintaining appropriate incentives for the companies will contribute to the fast progress in understanding diseases and in generating new strategies for therapy also in future.

The patenting of new inventions provides a major aspect of the opportunity to maintain appropriate incentives for the pharmaceutical industry. Only patents provide the exclusive rights to use and exploit the new pharmaceutical invention for a specific time period. After having invested a lot of money and time in the process of discovery and development of a new drug the pharmaceutical company must be very interested in the commercialization of the new invention. Exclusive rights to use and exploit the invention prevent others from commercially using the patented invention, what leads to reduced

competition and the establishment of the developing company in the market. Patents allow the generation of a product that can be sold on the market. On the other hand, if the company chose not to exploit the patent itself, it may be sold or the rights to commercialize it may be licensed to another company. Nowadays, business partners, investors and shareholders interpret patent portfolios as a demonstration of the high level of expertise, specialization and technology capacity of a pharmaceutical company. Here it is important to note, that this holds also true for the situation of research laboratories on state universities. Patenting of new life science inventions plays a major role for the positive image of a research institution. Comparable to publication in international peer-reviewed journals, patenting is seen as an important representation of scientific success. Last but not least, it may also be of commercial interest for a university to hold patents (Robbins-Roth, 2000; Knoppers, 2001; Rohmann et al., 2002; Rohnke, 2002).

#### Reasons for patenting

- exclusive rights of usage
- commercialization – higher returns of investments
- reducing the competition leads to a strong market position
- commercialization of the invention to another company

From an ethical point of view it is more a question of what is patentable. In the context of biomedicine and the pharmaceutical industry it appears that the question is discussed whether life is patentable. It once has been defined that while processes devised to extract what is found in nature can be patented, objects discovered there cannot. They are not inventions, nor can they as a class be made anyone's exclusive property. The newest development in biomedical research raises a lot of questions in this context. Keeping with this statement neither a piece of DNA, a gene, nor stem cells from the human body and of course not entire human embryos at any stage of human embryonic development are patentable. Of course, in the latter a lot of other aspects specific for human beings (beside the fact of "natural occurring") clearly argue against it. Nevertheless, patents on genes and stem cells have already been accepted. Meanwhile, most of them have been retracted. But what is about artificially manipulated organic life? It is well known, that patents on transgenic mice carrying human genes have been approved. To justify such patents people have argued that these animals do not exist in nature and are an "artificial product". On the other hand, the approach to treat genetically altered living organisms as simply another class of human inventions patentable under the same rules and justifications as any other invention is clearly questionable. Especially, if one considers putative future developments of human gene therapy (Knoppers, 2001; Rohnke, 2002; Schneider, 2002; Mieth, 2002; Capurro, 2002)

#### What is patentable?

NO: objects discovered in nature

YES: processes to extract or analyse natural objects

As mentioned above, the World Health Organization criteria for essential medicines include that a pharmaceutical drug must be available at a price the individual and community can afford. From a commercial point of view the development of drugs that may benefit only a few is not of high interest. The same is true for the development of drugs that may benefit millions of people in developing countries too poor to pay for the new drug. For example, while AIDS, malaria, and tuberculosis affect countries that together contain ninety percent of the world's population, only about ten percent of the world's medical research funding is targeted at these diseases. This opened the discussion about a deal, which could allow poor countries facing humanitarian crises caused by diseases such as AIDS and malaria to import controversial generic versions of patented drugs.

A generic drug is safe, effective and equivalent to brand name medications. It usually costs considerably less than the brand name medication. Generic drugs must meet the same high standards of quality as brand name drugs and are formulated to have the same effect in the body as the brand name version. Generic drugs often become available when a brand name drug's patent expires. According to the Congressional Budget Office in the United States of America, generic drugs save consumers estimated US\$ 8 to 10 billion a year at retail pharmacies. Even more billions are saved when hospitals use generics.

The pharmaceutical firms that hold the patents have long argued against such generic imports, insisting that high profit margins are needed to fund the discovery and development process of a new pharmaceutical product. In addition, the pharmaceutical companies fear that these generic drugs will be inferior to the name brands and would enter the United States of America and European markets at low prices. A good example for this conflict is the discussion about AIDS drugs. Brazil has registered generic versions of several AIDS drugs, and manufactures them for itself and other developing countries. In response to worldwide pressure, drug companies have agreed to sell some AIDS drugs at deep discounts to developing countries. However, even with the discount, the price is much higher than the generic versions, limiting the number of AIDS victims who can be treated in poorer nations. Could a solution be considered including two different prices for the same pharmaceutical product - a higher price for the markets in the United States of America and in Europe to maintain appropriate incentives for the pharmaceutical industry, and a much lower price for developing countries? Such a development would have to be accompanied by the establishment of international laws strictly prohibiting the re-export of these lower price products from developing countries (US Food and Drug Administration, 2004).

### What is the aim of using a pharmaceutical product?

The discovery and development of new pharmaceutical drugs accompanied by the research on the molecular mechanisms of diseases offers new changes for therapy and prevention. However, a lot of drugs have the potential for abuse. These drugs can be abused by people for whom they are not a medication. For example, Ritalin (methylphenidate) is a medication for individuals (usually children) who have an abnormal high level of activity or attention-deficit hyperactivity disorder, which is characterized by agitated behaviour and an inability to focus on tasks. Ritalin also is occasionally prescribed for treating narcolepsy. Ritalin is a central nervous system stimulant with a notably calming effect on hyperactive children and a focusing effect on those with attention-deficit hyperactivity disorder. When taken as prescribed, Ritalin is a valuable medicine and people do not become addicted to it. Because of its stimulant properties Ritalin is abused by people for its side effects: appetite suppression, wakefulness, increased focus/attentiveness, and euphoria (National Institute on Drug Abuse, 2000; Hengstschläger, 2003; Spencer et al., 2004).

More recent studies have highlighted the increasing number of teenagers and adults abusing painkillers, such as the prescription drugs Vicodin and OxyContin. Both are opiates and are very powerful medications against pain, but they need to be taken under close supervision of a doctor. These same medications when taken inappropriately can cause addiction for they act on the same places in the brain as does heroin. The National Institute on Drug Abuse reported the finding of increased abuse of these painkillers for non-medical reasons (Volkow, 2004).

Another well known abuse of pharmaceutical products is doping in sport. The world anti-doping agency is an international collaboration of organizations and governments united in their efforts to achieve completely drug free sport. In 2004 the World Anti-Doping Code was implemented by sport organizations prior to the Olympic Games in Athens. This Code should ensure that, for the first time,

the rules and regulations governing anti-doping will be the same across all sports and all countries (World Anti-Doping Agency, 2004).

Abuse of prescription drugs can lead to serious adverse consequences, including death from overdose.

### The non-diseases

A lot of money can be made from healthy people who believe they are sick. Pharmaceutical companies sponsor diseases and promote them to prescribers and consumers (Moynihan et al., 2002). To expand markets for new pharmaceutical products and treatments informal alliances have emerged to widen the boundaries of treatable illness. The key strategy is to target the news media with stories designed to create fears about a condition or disease and attention to the latest drugs or treatment.

The medicalisation of baldness is a good example. Always around the time when new hair growth drugs are approved, it appears that this ordinary process of life turns into a medical phenomena. The results of new research projects are reported describing that losing hair can lead to panic and other emotional difficulties and even has an impact on job prospects and mental wellbeing. Very often, the news media do not report that this research has been supported by the pharmaceutical company selling a new hair growth drug.

Disease mongering, a form of medicalisation, can include turning ordinary ailments into medical problems, seeing mild symptoms as serious, treating personal problems as medical, seeing risks as diseases, and framing prevalence estimates to maximise potential markets of pharmaceutical products. To stop this process of disease mongering it is necessary to define what is not a disease, but could be interpreted as a disease depending on the specific aim. To underline this aspect the term “non-disease” has been established.

The British Medical Journal ran a vote to identify the top non-diseases with the aim to prompt a debate on what is and what is not a disease and to draw attention to the increasing tendency to classify people’s problems as diseases. A “non-disease” was defined as “a human process or problem that some have defined as a medical condition but where people may have better outcomes if the problem or process was not defined that way” (Smith, 2002).

1 Aging	11 Childbirth
2 Work	12 Allergy to the 21st century
3 Boredom	13 Jet lag
4 Bags under eyes	14 Unhappiness
5 Ignorance	15 Cellulite
6 Baldness	16 Hangover
7 Freckles	17 Anxiety about penis size/ penis envy
8 Big ears	18 Pregnancy
9 Grey hair	19 Road rage
10 Ugliness	20 Loneliness

Such an inappropriate medicalisation can induce unwarranted fears, can trigger economic waste, and probably creates costs that result when resources are diverted away from treating or preventing more serious diseases. To my opinion, Moynihan and colleagues (Moynihan et al., 2002) have summarized

in an optimal way what is needed: The public is entitled to know about the controversy surrounding disease definitions and about the self limiting and relatively benign natural course of many conditions. A publicly funded and independently run programme of “de-medicalisation”, based on respect for human dignity, rather than shareholder value or professional hubris, is overdue.

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## **WALTER. RICCIARDI**

### **HEALTH POLICIES AND QUALITY OF LIFE IN WESTERN DEMOCRACIES**

We are all taught the definition of health as given by the World Health Organisation, who for 50 years has guided health policies worldwide.

Perhaps less universally known is this more definition for "good health" which is "the state of physical and mental well-being necessary in order live a happy, productive and rich life", it is now an integral part of the functioning of modern western societies, a milestone in successful economies and a principle absolutely shared throughout all the democracies in the world.

The populations of western democracies today have the best health conditions in themans' living memory, this does not however mean that it is fairly distributed. A state of good health for all is the objective but in reality it is still a long way away.

Not only this, the difference between those who have good health and those whose health conditions are worsening is continuously increasing.

Today enjoying good health depends essentially on where you live, your behaviours and how much you earn.

The poor, excluded and the minority groups are particular groups of interest who suffer poor health.

If we examine the 25 countries in the European Union the differences remain important.

The life expectancy for men varies from 70 years in Latvia to 79 years in Sweden, the incidence of lung cancer varies by 500%, it ranges from 21 cases per 100,000 in Sweden to 102 cases per 100,000 in Hungary, for tuberculosis the difference is 1300% as it ranges from 6.4 cases per 100,000 in Italy to 86 per 100,000 in Lithuania. The mortality rates for ischaemic heart diseases in females varies from 29 cases per 100,000 in France to 226 in Slovakia, rates for suicide in males goes from 4.9 cases per 100,000 in Greece to 44 in Hungary.

As far as our country goes specifically, in the course of the last 40 years Italy has made remarkable progress with many positive outcomes: for example, the gain of life expectancy between 1960 and 1998, is equal to an increase of 11.5% for men and 12.4% for women, these results are higher than the corresponding increments of 10.7% and 11% respectively found across the 15 countries of the European Union.

Today both Italian men and women are in forth place in Europe with regards to life expectancy from birth, with women living 82 years and men 75 years.

Italy is also in a relatively favourable position in relation to its older population with the expectancy of life to 65 years being superior to that of the European average for men and for women.

But how much of this turns out to be attributable to health policy and to the performance of our health service? And why are the results for these indicators positive, even in comparison to countries whose health systems are traditionally recognised as being effective and efficient, for example those of the Scandinavian countries or, to be more general those of the northern European countries?

The WHO in its Report on the Health of the World in year 2000 (WHO, 2000) has published one classification of health systems world-wide.

In summary, the complete performance of the systems was evaluated according to a composite indicator that included the results of the distribution of the levels of health services, the ability of the health service to respond and their financial equity. The performance is aggregated and then the results are weighted in terms of the level of economic functioning and the social development of the country. While it delighted some countries like France, who were first, and Italy who were second, it infuriated others such as Brazil who were 125th and triggered an animated discussion on the principles and the methods of this type of evaluation.

In 2001 the British Medical Journal dedicated an entire edition to this topic from which came some interesting points for consideration:

\* The first point relates to the definition of a health system, in the World Health Report the WHO considers it to include "all the activities whose primary objective is to promote, to recover and to maintain health" (WHO, 2000). This approach is truly positive, since it emphasises the importance of interdisciplinary action in the promotion of health, unfortunately it also represents a notable practical problem since it is not possible to find a definition for "all of the activity" in the budgets expense section in any country of the world. Consequently the comparators are inputs (i.e. human resources, financial institutions, logistic and technologies) of the National Health Services, with the results coming from the activities and interactions between the entire productive and social system.

\* The second problem relates how we interpret the results for health function in relation to the various types of activities carried out not only within the National Health Services, but within a wider national context. By now there is growing evidence of how health gains cannot only be derived from other health interventions, but also from activities carried out in other areas, for example road safety or education. But there are still innumerable determinants of health. As an example, in industrialised countries the health of the population reflects their traditional eating habits, founded in the climate and type of agricultural production, therefore it stands to reason that many of "the healthier" countries are characterised by the eating of a Mediterranean diet.

\* A third problem is the availability of data: many governments have only a vague idea of how many people are alive in their own area, since censuses are carried out irregularly or not at all. Essentially, it is not possible to create data when it does not exist and therefore every step often requires an elaborated set of estimates and often heroic extrapolations, to ensure reckless statements are avoided in publications such as the World Health Report. Equally, there are substantial problems regarding the comparability of the data, also when correlations are made with other measures, for example the relative health expenses as compared to the socio-economic levels of the populations. The authors of the report have recognised this problem and are organising a well constructed set of procedures to address this, generating indicators for life expectancy - adjusted for disability, is also an extremely controversial measure, as evidenced by Ellen Nolte and Martin McKee in their splendid job on 19 of approximately 200 countries present in the WHO classification.

So it is possible to observe that using avoidable mortality as an indicator, based on the concept that some causes of death would be avoidable if health assistance is timely and effective (which is indicative of a well functioning health system) no country maintains the same position in both of the classifications.

It is not necessarily the case that the greatest decreases have taken place in countries that go through large crises in the functioning of their own health systems like Japan (from 1° to 13° place), Greece (from 7° to 12°), Great Britain (from 10° to 18°), while the greatest increases are in countries famous for the optimal functioning of their systems: Norway (from 11° to 2°), Canada (from 9° to 4°), Finland (from 13° to 8°), Germany (from 14° to 6°), Denmark (from 17° to 10°).

In general, how does this concern Europe: all the Nordic countries improved their positions, while all those in southern Europe came down in the classification (France from 3° to 5°, Italy from 6° to 9°, Spain from 5° to 7°).

All this goes to confirm that when one takes into consideration the indicators most congruent with the performance of health systems, the classification is modified and if it is true that the progresses in health attendance has contributed to the reduction of mortality, for example, cardiovascular diseases, it is equally clear that important differences in mortality are determined by factors, such as dietetics, behaviour and the environment, which are to a large extent outside of the health services.

Health policies once exclusively related to financing and the distribution of medical attendance. However, if general access to health services is clearly essential in order to increase survival and to improve the prognosis of important diseases, then more important to the health of the population is the economic and social conditions that made them ill and rendered them needy of medical attendance.

One of the countries in which during the last 10 years it has been possible to confirm this hypothesis has been in Eastern Europe and in particular Germany before and after its unification. Fifteen years ago, a little less than a year after the fall of the Berlin wall, the two Germanys had become a single state. In a decade during which Europe had been experiencing an immense social and political transition, the experience of the population of the former German Democratic Republic was that the institutions and the political system developed over 45 years of communist government had been swept away almost instantaneously.

Health was affected, as the transfer of the social insurance model of the Federal Republic of Germany was immediately extended to the East.

From the point of view of the indicators, the period immediately after the re-unification was characterised by an increase in mortality in the East, with a life expectancy that was reduced by almost a year for men and was essentially due to the increase in violent male deaths and traffic accidents due to the unexpected availability of fast western cars, but from 1991 onwards, life expectancy from birth has increased in the former Germany more than any other European country and by 1997, they had succeeded in cancelling out all the differences between the two Germanys.

What were the factors that influenced these incredible events? These studies indicate a rapid modification in diet as one of the primary factors along with a new availability of fresh fruit, vegetables and vegetable oils, previously impossible to find. The second determinant is the improvement in living conditions, particularly those of the elderly, whose conditions previously went unnoticed. The third is the substantial improvement in health services, for example, the dramatic decrease in testicular cancer mortality, which has been attributed to the improved access to modern pharmaceuticals and the substantial fall in neonatal mortality due to the improved treatment of low birth weight neonates. Another group of countries, in which it is possible to confirm the intersectorial correlation of health conditions and the effect of external factors in determining the health of a population, is the former Soviet Union. In fact during the last twenty years of the previous century the life expectancy steadily climbed in all ex-communist countries, while the life expectancy in the Soviet Republic declined considerably.

In 1990 the probability of death before the age of 65 in the Soviet Union was double that of the European average. The life expectancy for men is 64 years, nine years less than the European average and although in all industrialised countries women live longer than men, the difference in Russia is considerably higher, with a difference of 10 years. There are many factors which contribute to this, but the most important is the excessively high mortality for those between the ages of 35-44 due to accidents, violence and cardiovascular disease.

In 1997 mortality from all external causes, before the 65 years, was higher in the Ex-Soviet Republic by 500%. How does death from accidents and violence affect this? All of the reasons for mortality are alarmingly higher than those found in the West, with levels 350% higher for suicides and 1900% higher for homicides. However, the difference for road traffic accidents is relatively low, only 50% higher in comparison to Western Europe. Other common causes of death among women are drowning and burns.

Unfortunately in these countries, accidents and violence have received relatively little attention from the policy-makers, where even in the home and workplace they are without the normal basic security and prevention measures, which have been in place for a long time in the west. This goes along with a lack of timeliness and quality in the health services, which are health system indicators directly comparable to those in the west.

A crucial contributing factor to the high levels of accidents and homicides in the Ex-Soviet Union is the large consumption of alcohol. In Russia, the number of deaths attributable to external causes reflects the number of deaths from alcohol poisoning both geographically and chronologically. For example, in many of the male suicides alcoholic poisoning was shown to be a contributing factor.

How does the epidemiological patterns of mortality for cardiovascular diseases, in the former Soviet Union, compare to those found in Western Europe and the other Countries former-Communists.

Mortality for cardiovascular disease is particularly high in the young, with death often being unexpected and in many cases there is little evidence of coronary lesions.

The traditional important Western risk factors of smoking, elevated lipid levels and physical activity have a limited predictive value in Russia, as lipid metabolism in Russians has been shown to differ greatly from that found in the west.

There is evidence of other contributing factors regarding diet, it is not only the high consumption of animal fats and limited amounts of fresh fruit and vegetables (which results in low antioxidant levels), but it is also the way that they consume alcohol, in particular "spirits" especially Vodka, which contrasts greatly to the more diverse yet stable drinking habits found in the west. Finally, although not proven scientifically is the contributing factor of physico-social stress.

Another example of this shattering effect is given by comparing countries in a similar political-economic transition, but who have different non-essential habits.

There are also other studies that have been carried out in Ex-communist block countries which seem to show that their health conditions are heavily influenced by socio-economic factors which are closely bound together with their health services.

It is evident, for example, that not all of the citizens' conditions were equal between the communist system and those that had undergone successive democratic transition.

The worse consequences are identified in countries in which the economic transition has been more brutal, often measured in terms of loss of employment opportunities and the mechanisms of social protection.

Men with low educational attainment are most vulnerable, especially if they are not married and are without family support, not being in a position to react to wide-scale rapid changes. Poor diet, elevated tobacco taxes and the easy access to alcohol all lead to premature female deaths, especially in societies that lack the mechanisms to provide protection in both the work and home environments.

We find ourselves today, in western countries, in the particular situation of living in two or more social-economic contexts and therefore epidemiology's.

The modifications that our societies are facing today are equal to those faced 150 years ago in the golden age of public health, consequently we need a new conceptual map for Public Health action that incorporates scientific developments and technology and socio-economic actions and policies at both national and international levels, directed globally.

If we study the teachings of Professor Geoffrey Roses, of the London School of Hygiene and Tropical Medicine, he said: "the determinants of disease are essentially economic and social: therefore the solutions must be economic and social".

In western democracies you find contemporary countries characterised by:

- an elevated life expectancy and a strong aging population
  - an extensive and costly health system
  - health as a dominant topic in both social and political arguments
  - good health as a main personal objective in the life of its citizens,
- and countries characterized by:
- a stable or a decrease in life expectancy
  - difficulty or the lack of access to often essential health services
  - health as a secondary topic in respect to, for example, economic development
  - the personal objective of health is often mere survival.

The myths of Hygea and Asclepius symbolize the infinite oscillation between two different points of view on medicine and, therefore, of health policy. For the supporters, like us, of Hygea, health is the natural order of the things, a positive attribute of which is our own ability to govern our own lives.

According to them, the most important function of medicine is to discover and teach natural laws that

agree with a person having a sound body and mind. Others who believe in the goodness of human actions, might follow the view of Asclepius that the task of the medicine is to heal diseases and to correct health imperfections caused by accidents of birth or life.

The contrast here is healing, the key for the next revolution in public health policies of western democracies: to face contemporary problems bound to the continuously improvement in the understanding of the structure and operation of the human body and in preparing health services to be in a position so that when there are problems it can respond both appropriately and timely, and also to be totally aware that health is not only guaranteed by the interventions performed, but also by the improvement of environmental conditions in which it operates.

Therefore, points to consider in order to improve the health of our populations:

\* to favour a good start for all: because a birth in good health reduces the risk of diseases in adulthood;

\* to favour healthy foods because it helps in living more and better;

\* to constantly reduce the social gradient between the different population layers

\* to reduce social exclusion

\* to improve working conditions

\* to improve social support networks

\* to favour the best outcomes for all

\* to provide effective, efficient, appropriate and equitable health services developing a new partnership between citizens and health professionals.

In conclusion of my roundup on the conditions of health and quality of life in the western democracies, I have perhaps generated more questions than supplied answers, but our work, that of Public Health, very rarely provides magical, fast or obvious solutions, and we need to have what Adrienne Rich called "wild patience", with the ingenuity of bringing together scientific evidence, common sense, passion, a sense of urgency and above all justice.

The World Health Organization hopes that after years of dominant economic imperatives, the reforms to the health systems can be inspired by ethical concerns.

The state of a health system depends in fact on the ability of the decision makers to logically bring together the structure of the health institutions with the value system of the population.

Nevertheless current health policies seem to go in the opposite direction and in doing so they will harm the health of the world populations and will loose some of the most important issues concerning economic efficiency and social justice that contemporary societies will be urged to face in the future.

**MANFRED LÜTZ**

**THE "RELIGION OF HEALTH" AND  
THE NEW VIEW OF THE HUMAN BEEING**

Whoever thought that Christianity, even though it had been steeled from the devastating battles of the 20th century, would have a unique chance to spread the gospel of universal redemption to the people with no relevant resistance after the fall of the Berlin Wall in 1989 and the marking of the effective end of "real existing socialism", found himself disappointed. Certainly, earlier world views that had been hostile to Christianity, evidenced in the form of texts, structures and individuals, may well have disappeared like a bad dream, but they left behind a chaotic morass with a murky blend of resignation, scepticism, nihilism, atheism, and agnosticism – which is much more difficult to confront, because it is so difficult to grasp. It is no longer a case of one or several world views which can be countered with arguments, faith or planning, but of an atmosphere which is gaining ground well into Christian churches and individual Christians, and which appears, and is increasingly experienced, as being foreign to the Christian faith. When, "beyond good and evil"(Nietzsche), economic success, according to a totally secularised Calvinism[1] becomes the unparalleled value criterion, then any set of ethics based on the concept that one can, out of a sense of moral duty, make choices to one's own disadvantage, is stripped of its foundation. Economic success is, however, in the final analysis, irrational. Stock market reports have fewer claims to validity than weather reports. They are not ruled by logic, but, at best, by a kind of psycho-logic. And the instruments of this psycho-logic are the powerful media, blown up to gigantic dimensions. Certainly, on the one hand, they develop their own peculiar dynamics and create atmospheres. Simultaneously, on the other hand, they are dependent on these atmospheres in a way that cannot be logically represented.

In the face of this chaotic, confusing public atmosphere, which is characterised by many irrationalities, Christians run the risk of withdrawing into an equally irrational group atmosphere which simply sets a more feeling-oriented, rather than a thought-oriented counter-world against the "world out there". This is the path to cults.

Pope John Paul II shows us a different path, a Catholic path. When he, in his first encyclical letter, "Redemptor hominis", at a time still very much influenced by debates on world views, throws light on the human beeing as God's path through history and promotes his preaching from such a standpoint of Christian anthropology, his message anticipates a development that is plain to see today: the time of debates concerning worldviews is over and the time of debates concerning "the view of the human being" has begun. From now on, one will be able to especially recognise Christians by asking whether people see the human beeing as a collection of potentials, as do Peter Singer[2] and many others, whose dignity depends on the immediate presence of these abilities, or whether one, together with the entire Christian tradition, may also ascribe complete dignity to the human beeing, when it is in the very state of extreme need. In fact, there is hardly a greater, more conceivable contradiction than that between the already atmospherically dominant mentality of denying the very weakest and most needy – the embryos at the beginning of life and the severely brain-damaged at the end of life – human rights and human dignity, and the Christian view that Christ himself is particularly present in the most weak and needy. Thus in preaching the "Good News" today, the good news of man's salvation must be brought into the very foreground of discussion. This is not an abstract salvation. It is very concretely a deliverance from images of man that are unseemly and lead to degrading consequences. In this way, the Church secures human progress, because a progress that would "stomp" both man and his dignity to death might well be a continuation of evolution, but it would no longer be human progress. For this reason, the encyclical letter "Evangelium vitae" is part of the core preaching of Pope John Paul II. and this presents our academy with a central task in evangelising and re-evangelising the world. We are obliged "to account for the hope that lives in us" (1Pet 3:15), with the light of reason that God gave to

man; this means that above all, we must enter into a rational discourse with a world today that seems to be forgetting who man is and on what his dignity rests. We must reveal changes in consciousness of values soberly and bring Christian convictions to bear in concrete bioethical questions, using scientific competence. This has been happening for years, while receiving increasing international attention. The question now arises, however, as to whether, behind all of the questionable images of man that are so prevalent today, a uniform tendency, a "view of the human being" accessible for rational ethical discourse, can be recognized. I believe that such a "view of the human being" does in fact exist, and that it is becoming internationally increasingly dominant across the world today; it is what one might call the "religion of health"[3]. Not God, but health, individual health, stands undisputed as one's "greatest good". People no longer await salvation and redemption in an afterlife, but in the here and now. Whereas the collective immanent eschatologies such as Marxism- Leninism are no longer considered to be relevant, it are now the individual immanent eschatologies which offer themselves to people. And they do so with incomparably greater success than the old world views. People expect eternal life quantitatively from medicine – in the case of non-fulfilment, of course, one may sue – and qualitatively, one expects eternal bliss from psychotherapy.

Imperceptibly but with great determination, all religious conventionalities have now arrived in the health system. Not only do we have doctors as demigods, but we have places of pilgrimage, heresies, "ascetic" diet movements, rites, state-supported missionary campaigns for healthy living. In a quasi-Pelagian sense, health, salvation, like almost everything in our society, is seen as a product which can be manufactured – one must do something for one's health, since nothing comes of nothing; it's one's own fault if one dies. A sense of guilt is unscrupulously produced and the word "sin" is no longer heard in churches but instead, only in connection with "nutritional sins", for example, eating cream cakes. Above all, however, the religion of health not only apes the "taboo of blasphemy" in western societies, but it has been completely transferred, so to speak, from Christianity to the religion of health. This means that in the meantime, it is perfectly alright to make any silly joke at all about Jesus Christ, but jokes about health are considered to be no laughing matter.

If, however, health is to be seen as the holy, untouchable, highest goal of all mankind, every reasonable health policy is stripped of its foundation. Politics is the art of weighing up different aspects. One cannot weigh the "greatest good"; one must do everything for it. And for this reason, health care policy has no longer really been taking place in the western world for years. One changes the systems, attributes deficits to various sections of the population, explaining with the politically correct but meaningless statement that "all that is medically necessary" should, of course, be financed for every citizen, that there must be no "two-class medical system", etc. But everyone knows that this already exists all around the world. Rich people could always live longer than the poor and that is still the case today – although now to a lesser extent, thank God – and is unlikely to be fundamentally changed. What should have been achieved politically is to secure a reasonable measure of solidarity. But this is only possible if the state order presupposes health as albeit a great good, but not the greatest of all goods. Yet any politician who were to call for cuts in the area of health would run the risk of never being elected again. For this reason, there is hardly any field of politics in which politicians act with less reason and wisdom and instead with more populism and demagogery – although without really solving problems, especially financial problems.

In the meantime, the religion of health's egotism is now also taking effect on society. Whereas Christianity, Judaism and Islam always also have a social impetus, the religion of health is entirely egocentric. The "believers in health" are only interested in their test results, their blood pressure, their prognoses. The solidarity so frequently cited in health policy debates has to take its justification from another source. The religion of health itself is completely indifferent in the social sense.

However, the ethical consequences of this new trans-national, quasi-religious movement are even graver. If health is viewed as the greatest good, then healthy man will, as a consequence, be the only "real man". If someone is not healthy, or if above all, he cannot become healthy again, then it is

implied that he is a second or third class person. And this brings us to the key problem of the bioethical debates of the past years. The dominant religion of health may well have led to an enormous increase in public interest for treatment and therapy. However, the indirect message of this avid interest in medical treatment is that the no longer treatable, the chronically ill, the disabled stand in the shadow of public interest. A place is reserved for them at the margins of society. Little is reported and, in general, the view is subtly spread that one would "not want to live that way" and that, for that reason, one must therefore have "the right to a good death", in greek translation "eu-thanasia". At the beginning of life, it is now no longer a question of preventing disabilities, but of preventing the existence of the disabled. In Germany, for example, banal disabilities such as a cleft lip suffice for a lethal potassium injection to the heart – right up to just prior to birth, even in the birth canal itself – as a broadly defined "medical grounds for abortion". Such a killing is neither illegal nor punishable by law in Germany, but a regular service covered by health insurance companies.

Such monstrosities can only be practised in a society once the adequate atmosphere has been created. It is the religion of health that sets the tone of this atmosphere. The significance of the religion of health, for society's value judgements, becomes particularly clear in the case of what is called the "ethics of healing". This term was coined in Germany in the context of the debate on the use of embryonic stem cells. It was admitted that killing embryos presented a problem, but one absolved oneself through the expression "ethics of healing": – these embryos were simply being killed for a "highly noble cause", namely to heal others. There were certainly ethical reservations about killing embryos, but there was also the "ethics of healing", which required society to help sick people, purportedly justifying the sacrifice of embryos. Such a use of the word ethics must have appeared suspect from the perspective of philosophical ethics. Certainly, there is always an ethics of healing, since healing itself has to take place according to ethical principles. But that which calls itself the "ethics of healing" here was designed to end rational ethical debate on the matter, through the use of an extremely effective demagogical manner, or better yet, to prevent it entirely. It was stated at the time that research with embryonic stem cells would one day be able to cure Parkinson's disease. From a neurological point of view, this is rather unlikely, and experience to date does not exactly encourage scientific optimism. Yet, the public debate takes a different course than the scientific debate. Over-simplistic arguments are what works here. The Germans have an old saying attributed to Paracelsus, "He who heals is right". This good old medical principle has been ethically abused in the public debate, and turned into a cynical knockout argument. The "ethics of healing" forms the fundamentalism of the religion of health; it no longer responds to rational argument.

This is exactly the reason why, however, ecclesiastical documents regarding bioethical issues, even while giving convincing arguments, are often paid so little attention. The arguments are almost powerless against the dominant irrational atmosphere. For this reason, I believe that it is necessary to make the revolutionary transformation of the image of man a fundamental topic in connection with the idolisation of health, particularly in western societies. The effort must be demanded from Christians that is necessary to articulate an appropriate Christian understanding of health.

While doing this, the danger has to be avoided of falling into the other extreme, namely into a neo-Platonic contempt for health that rejects the body. Christianity has believed in the incarnation of God from the very beginning, to the horror of neo-Platonic philosophers. Therefore, from the beginning, we must hold the body, as a "temple to the Holy Spirit" (1 Cor 6:19), in high esteem. Pope John Paul II expressed important aspects on this subject and other ethical implications in his "Theology of the Body"[4]. This means, however, that the health of the body is, if not the greatest good, still of an indisputably high value. Jesus' healings are a sign of this; the healings accomplished by the disciples are a sign for the truly holistic body and soul redeeming dynamic of the Good News. The early Fathers of the Church referred to Christ as the physician; "There is only one physician ..." [5] says Ignatius of Antioch. Ephraim the Syrian writes: "Blessed He Whose tender mercies made Him descend to visit our infirmities! (...) Blessed be the Physician Who came down and amputated without pain, and healed

wounds with a medicine that was not harsh."<sup>[6]</sup> Christians have always placed their hopes in truly holistic healing, even to the places of pilgrimage, such as Lourdes, where people seek healing for body and soul. After all, the doctrine of the resurrection of the flesh makes the body and its state a central Christian category, with final clarity. Never, however, in the entire Christian tradition, has something like health been considered to be the greatest good. Health is a great good, nothing more and nothing less.

There is always a risk that healthy Catholic doctrine, however, may become obscure in daily practice, in the life of the individual Christian, in the life of the parish, in homilies, in ceremonious speeches, and even in devotional writings. It does seem, in fact, that the religion of health has even infiltrated Church practice. "Fasting for health" takes place during Lent in our parishes. But fasting, in order to die "as far distant in the future" and as healthy as possible is something entirely different from Christian fasting: "Through fasting of the body you hold sin down, you elevate your spirit ..." <sup>[7]</sup>. The remark thoughtlessly made, "the main thing is one's health ..." is now even common among German Christians, even when congratulating someone for the birth of a child. Church educational centres offer an enormous range of health-related courses, as opposed to the modest number of religious seminars. Ceremonious speeches in Catholic hospitals are at times fiery apotheoses of holistic health, calling on a few quotations from the bible to back them up. Even some ecclesiastical texts demonstrate a lack of necessary composure towards the subject of health. None of this happens with malicious intent, but is rather unreflected, in a naive attempt "to obtain contact with the people of today". Of course, Christians' efforts towards health should never be subject to rebuke. My only intention is to warn against excesses, including in the formulation of statements.

In our times, psychology has become particularly established worldwide as an attractive discipline for "holistic" medicinal approaches, even in Church circles. Psychology is a serious science, which has to be concerned with the scientific examination of measurable and comprehensible aspects of human psychical life. The focus of attention in the science of psychology is not man's freedom but instead, patterns, principles and predictabilities of behaviour. The science of psychology forms the basis of psychotherapy, with which it is by no means identical and which is highly valued generally and in the Church. Psychotherapy is a goal-oriented, temporally restricted, methodical and thus an artificial relationship in exchange for money. It is characterised by an asymmetry of the relationship between the suffering person seeking help and the method-utilizing expert. Psychotherapy, using whatever method, is – in the positive sense of the word – always manipulative, as it is always intended to "remove" the symptoms from which a person is suffering in the shortest time possible. It is thus not an existential relationship such as love or the experience of the meaning of life. Love and the meaning of life cannot be bought for money. In this sense, then, good psychotherapy is thus never "holistic" in the actual sense of the word, as it does not show the way to salvation. A holistic relationship is never restricted, never manipulative, never asymmetrical. Pastoral care, in its true sense, for example, as a deep relationship of belief, is holistic, dialogic in Martin Buber's sense<sup>[8]</sup>, or sacramental.

A blend of psychotherapy and pastoral care, as is often propagated, is therefore very unhealthy. For with such a blend, the pastoral relationship becomes manipulative, asymmetrical, and simultaneously unrestricted; guru situations arise with problematic dependencies, and it is no longer Jesus Christ, but the figure of such a "holistic" therapist who becomes the focus. Such blends thus ruin both psychotherapy and pastoral care. Certainly, mental disturbances can prevent a person from obtaining a deeper relationship to God. They must then be treated. But this treatment cannot create the relationship to God. It can only open up jammed doors. Where the patient then goes is entirely up to him.

Techniques of health must thus never be misunderstood as leading to salvation. And, in any event, salvation is not found primarily in so-called healthy states, according to Christian conviction – but rather at least a dawning sense of it may be found in extreme situations of human existence, which are disregarded by the religion of health as deficits to be avoided or removed. It is particularly in disability, sickness, pain, suffering, old age, dying, and death that one may often experience the most meaningful

aspects of life much more closely and clearly than in "uneventful times", in which one is not "restricted" in any way. Since such extreme situations of human life distinguish themselves by the fact that they are unavoidable, the Christian message can show people of today, who are in search of salvation, a powerful way to fulfilling their lives via a positive view of these unavoidable apparent deficits. "Salvifici doloris", "On the Christian Meaning of Human Suffering", is the title of a highly impressive document from our Holy Father at the beginning of his pontificate. The fact that the Holy Father now lives out what he then wrote incarnates this message in the most conceivable, intensive manner. This is the lived alternative to the dominant excessive concern about health, as it directs one's attention to beyond oneself.

The religion of health revolves around the ancient subject of religion, coping with the experience of contingency and uncertainties, and, above all, coping with the experience of death. Yet it seduces people into losing themselves in the struggle against death. There are people who only live preventatively, so to speak, so that they can then die healthy. One could say that to avoid death, people might take their own lives, namely, lifetimes that can never be repeated. And when afterward, they lie on their deathbeds, and the unavoidable does happen – that which they have always wanted to avoid by all possible efforts in regard to their health – then they may well ask themselves whether they shouldn't have spent a little more time with their wives, with their children, with friends, instead of at the gym. They may well ask themselves whether they shouldn't have done more for other people.

The Christian message gains its deepest power and character when it is preached in the face of death. "Evangelium vitae" gets light from there. For, whoever suppresses death misses out on life. It is life that Christ preaches when he says: "I am the way, the truth and the life" (John 14:6). It is not an easy life, but "suffered ..., crucified, died and buried, ... rose again from the dead"[9]. That is "the hope that lives in us".

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[1] Cf. WEBER M., Die protestantische Ethik und der Geist des Kapitalismus, Tübingen: Verlag J.C.B. Mohr, 1920.

[2] Cf. SINGER P., Practical Ethics, Cambridge: Cambridge University Press, 1979.

[3] Cf. LÜTZ M., Lebenslust – Wider die Diätsadisten, den Gesundheitswahn und den Fitness-Kult, München: Pattloch Verlag, 2002.

[4] JOHN PAUL II., The Wednesday-Catechesis from September 5, 1979 to November 28, 1984.

[5] IGNATIUS OF ANTIOCH, Ad Ephesos, Chapter 7.

[6] EPHRAIM THE SYRIAN; cit. in: BEINERT W., Hilft Glaube heilen?, Düsseldorf: Patmos Verlag, 1985, p.69.

[7] PREFACE OF THE LENT.

[8] BUBER M., Das dialogische Prinzip, Heidelberg: Verlag Lambert Schneider, 1962.

[9] APOSTOLIC SYMBOLUM.

**THE FIGURE OF THE MEDICAL DOCTOR AND THE EXPECTATIONS OF CITIZENS:  
CONTINUITY AND FORMS OF CONDITIONING**

The figure of the medical doctor as projected in the image of it that is held by citizens is very difficult to outline if we do not limit our field to contemporary Western scientific medicine, where, indeed, various profiles can be identified. At a historical level, the gap which for millennia marked the ‘empirical medicines’ that developed in the various continents of the world, although they were very different, was less great than the deep gap that exists today: at the present time the distance between modern scientific medicine and the so-called traditional or alternative forms of medicine that survive in various areas of the world, and are in expansion even in the regions of Western medicine, is sidereal. The continuity of the figure of the Western medical doctor can be identified, under certain conditions, with the lines of development that began with Hippocratic medicine, which continues to be influential and to conserve its basic features, even today, despite the arrival over the last three centuries of scientific medicine which, if we study the question well, is not only based on Hippocratic deontology but strengthens its central principles, which, indeed, are concentrated in the Hippocratic oath.

This trajectory, it is generally argued, began with the era of Hippocrates (460-377 BC) and followed on from the previous era which attributed priestly qualities to medical doctors. But if we look closely, this was not so distant from the forms of medicine of Babylon and of ancient Egypt, both of which bore the heavy risk of sentences for failures. In ancient Egypt these sentences included the death penalty for medical doctors whose patient had not been treated in line with protocols tried and tested by experience or who had died because of a presumed causal nexus with a violation of professional rules of conduct. Hippocratic medicine, which we can know about through the Hippocratic corpus, bore the marks of the Greek interest – developed during the second half of the fifth century – in scientific techniques and methods. It sought to free medicine from all magical ideas and to turn it into a science based upon a safe and rational method of diagnosis and treatment. Its central points were the observation of the patient, the interview with him or her, subsequent dialogue that was updated during the course of the illness, and a set of essential deontological rules.

At the centre of these rules were the interests alone of the patient, but at the same time a self-imposed ban on going beyond the limits that the Hippocratic school had specifically established which envisaged the autonomous rejection by the medical doctor of requests from patients which were adjudged to be outside the goals of medicine. A refusal to practice abortion and euthanasia were the most evident and emblematic examples of this Hippocratic position. Another essential aspect was the affirmation of the need to respect the limits to one’s own expertise and to leave to ‘specialists’ the task of dealing with cases that required specific experience.

The other precepts of the Hippocratic decalogue, made up of respect for the teachers of the medical art, professional secrecy, the prohibition on the abuse of freedom of access to the family and the home of the patient, and lastly innocence and lifestyle, are certainly not marginal. Indeed, it was specifically from this set of rules, summarised in an albeit brief oath, that there emerged the figure of the medical doctor that was handed down for millennia and still in part exists today, as can be deduced from texts, testimonies, pictorial images, books, films and television series that almost always depict medical doctors who are active and involved, ready at any moment of the day or night to sacrifice themselves, weighed down by responsibilities with a strong emotional content, and exposed to the suffering of failure and ingratitude but also gratified by positive results that are very often achieved and by the gratitude that they receive from the patients who have benefited and their families.

These artistic contributions have the same objective when they present the opposite figures of medical doctors who betray their mission and are held up to public reprobation. There can be no doubt, indeed, as is the case with all the other professions – but with very different consequences in relation to public

opinion which has always privileged an ideal image of the medical doctor and medicine – that since ancient times there has also been the figure of the medical doctor who violates the precepts of his or her own discipline: both because of culpable or non-culpable incapacity and because of negligence and greed (the cause of real and authentic criminal behaviour) and, lastly, because of ideological leanings. Such leanings now have their own special role. Indeed, whereas deplorable professional behaviour, or professional behaviour held to be such, is subject to the sentences inflicted by penal and civil courts (in a way similar to what occurred in ancient Egypt because of what was envisaged by the Hammurabi Code and other sanctions envisaged and carried out in other cultures), and to the condemnations of a person's image by the media, by the injured patients and by their friends and relatives, and by society as a whole when it is informed, ideological differences divide the category of doctors in a more radical way into differentiated alignments, each of which in general enjoys the approval of its own ideological 'side' and suffers from the reprobation of the opposing side.

This division, which I will consider in particular in this paper because it seriously and injuriously damages the 'continuity' of the image of the Western medical doctor, has become increasingly emphasised over the last century, and above all over the last fifty years, because of so-called 'modernity', that is to say the great advances in scientific culture and technical means which allow professional services to be possible whose licit or illicit character of an ethical and deontological nature are increasingly subject to differentiated assessments, and often in radical way, through the filter of political and philosophical ideology.

In democratic countries, which are a minority on the world scene but constitute the advanced front of scientific medicine (both as regards its production and its application on an increasing scale), and in line with the majority that prevails at a democratic level, permissive or restrictive laws and directives are fostered and in relation to which real and authentic alignments of groups of medical doctors are formed. Courts, through variegated sentences in relation to cases that bear strongly on the medical profession, also produce divisions in law that often consolidate the ideological forms of radicalisation in society as a whole and which are reflected onto medical doctors who in their turn are conditioned, divided, and loyal to positions that are of dubious conformity with the Hippocratic approach. This is only one aspect, which we could term 'passive', of the forms of conditioning that are experienced by medical doctors because of the impact of influential sectors of public opinion (intellectuals, the press, the television, and political scientists), by laws and directives, and by directions taken by law. But equally important as a factor of division is the 'active' aspect, made up of the autonomous production of proposals that are not of a Hippocratic character and are strongly ideological in character but not always motivated at an intimate level by ideology but rather by a plurality of interests.

These various trends follow a large number of lines and in this brief summary only a few of the most emblematic examples may be given.

The huge and dynamic area of the incessant development of scientific medicine has uncertain boundaries in which the ethically and deontologically licit frequently clashes – but often in a way that is not always grasped by public opinion except on individual cases – with dangerousness recklessness, which has a large number of victims, namely the dead or those rendered infirm.

The impulse to innovation and improvement (which is motivated by scientific interest but also by ambition, the drive for gain, and the very nature of man who has been marked by, and whose history has been marked by, that very nature) produces an enormous quantity of damaging collateral effects that sacrifice the well-being of individuals (who are in general unaware of this). General and specialist surgery, anaesthetics, obstetrics and gynaecology, but also the disciplines of internal medicine, follow to varying extents this path, which rejects the ethical principle of limits and spreads within society an unjustified 'triumphalism' that fosters the acceptance, usually unknowingly, of taking part in decisions which bear very high risks that have consequent forms of damage.

The principle of doing good is often marginalised in these circumstances and the development of hospital ethical committees – which in the main are not called to pronounce on individual cases – is not

always sufficient to hinder this phenomenon, which, indeed, is often manifested a posteriori and very often unexpectedly. However, these ethical committees are a sign of an awareness of the risks of uncontrolled experimentation and the ‘invasiveness’ of many forms of contemporary medical treatment. Here it is advisable to refer to the fact that the usual attribution to the term medical ‘invasiveness’ of the meaning of a blood-spilling intervention (even of minimal importance such as in the case of a banal injection) is by now held to be superseded if one considers the risk connected with a very relevant number of pharmacological therapies which, as for that matter we are told by the illustrative enclosures that accompany specialist drugs and medicines, can give rise to iatrogenic side effects, which at times can be very serious and on occasions also fatal.

In truth, in this sector real divisions at the level of principle do not exist within the medical classes. Instead there are divisions at a practical level between individual medical doctors, namely between those who by experience, culture and character favour prudent approaches and are not easily conditioned by new proposals which are often not corroborated at the level of practical application, and those who (not always on the solid basis of scientifically founded beliefs and preliminary experience) venture into activity with unjustified risks which are at times crowned by success but at others are a failure both from the point of view of a lack of success and uselessness, and from the more serious point of view of iatrogenic pathologies, which, indeed, are often fatal or create permanent infirmity. Public opinion itself often aligns with the boldest medical doctors because public opinion is conditioned by the mass media and the fascination of research, the myth of on-going progress, and the hope for a better life.

This sector, which is the core of modern scientific medicine, in truth does not produce relevant divisions at the level of principle. The divisions – which often reverberate around the mass media and throw shadows over the ‘entire medical class’ – take place in relation to individual cases and have given rise to a progressive and alarming increase in penal and civil legal actions against medical doctors and in civil legal actions against public and private health-care structures.

The sectors that are characterised by deeper and opposing divisions are well known and belong to other fields: abortion, contraception, assisted fertilisation, euthanasia, sterilisation and psychiatric care. The problem of informed consent, which is connected with the principle of autonomy, is also a source of by no means few divisions at the level of principle and practice.

One cannot deny that in ancient times abortion and euthanasia, and professional practices that were not only culpably but also often deliberately incongruous in character, were engaged in by medical doctors. It is no accident that their image has often been denigrated and vilified (here one need only recall the harsh works of Molière), without, however, tarnishing at a deep level the relationship of the medical doctor with his or her patients and their families, something that has been very much supported by a prevalent obedience on the part of medical doctors to the deontological models shaped through historical developments.

Today, forms of conditioning have a profound effect on public opinion and also bear upon medical doctors, who, for that matter, are often their originators. The proposals of advanced medicine, which are lacerating bioethics, are real and authentic temptations which for a multiplicity of reasons both stimulate and divide society. The profoundly negative successes of these forms of conditioning are undeniable, and the battle is becoming increasingly harsh, forcing back the defenders of traditional bioethics – bioethics authentic from the outset – and the defenders of a deontologically rigorous medical profession, behind fences where their voices grow weak at the same time as a reckless and imprudent utilitarianism untiringly pushes on towards new transgressions.

In this situation it is difficult to test in a certain way the thought of the whole of public opinion, but it must be recognised that the ways in which a triumphant scientific medicine – which is occupying increasingly greater space beyond the boundaries of treatment (for example in cosmetic surgery) – presents itself, are provoking an imbalance whose final outcome cannot be predicted but which at the present time induces a realistic pessimism. It is certainly the case that the requests made by a large part

of public opinion are increasingly centred round the objective of meeting any desire that medicine can satisfy and it is obvious in this context that the first desire is health at any price, the elimination of pain, and a life span without limits.

From these unrealistic expectations arises, in a not limited number of cases, the juridical reaction to failures. These reactions increasingly take place in relation to forms of treatment applied to people of an advanced age whose health is very compromised, and from which miracles are expected of medical doctors. Or, in contrary fashion, we encounter the elimination of the useless and very ill, which now extends to neonatal and paediatric euthanasia, side by side with the elimination of embryos and foetuses. This is a very distressing and devastating picture that taints the profile of many medical doctors and also reflects negatively on the image of the very many – probably the majority – who engage in activity that is meritorious and efficacious

The spread of so-called alternative non-scientific forms of medicine may appear singular and paradoxical in this context. The contradictions that run through society, including so-called ‘advanced’ societies, are in themselves a simple explanation. But on closer examination one realises that this wrong direction is the composite outcome of a fear of suffering, including that fear that is inevitably induced by scientific medicine, and a fear of medical errors. This wrong direction is at the same time propelled forward by consumerist action which has many accomplices (who are increasingly aggressive) amongst medical doctors, is principally motivated by commercial and professional interests, and is promoted with the complicity of the mass media in search of sensations and curiosities and able to influence public opinion unscrupulously and often irresponsibly beyond any reasonable limit, with accompanying risks and forms of damage.

One may state that Western scientific medicine is today exposed to a series of conditioning factors that are able to alter – at least in part – its ancient Hippocratic image, inducing in it temptations that are for that matter largely born within it and breaking down the barriers that authentic bioethics (the bioethics born to defend humanity) has sought to establish, being undermined as this last is by ‘promotional’ bioethics which betrays the purpose of that medicine. Fortunately, many medical doctors, probably the majority of them, keep alive the flame of the deontological tradition and safeguard the traditional image of medical doctors in the industrious silence of their difficult daily activity.

These brief reflections on a subject of great difficulty can be ended with an attempt to capture the principal points.

The figure of the medical doctor and the image of medicine today have a polymorphism that is rich in contradictions that run through not only the least developed countries – some of which are at a stage of rapid evolution, such as China and India – but also the West and the advanced East. Medicine based upon scientific evidence, and a great variety of alternative practices that in an objective sense are without scientific bases even though at times they are able to produce beneficial effects in relation to lesser pathologies (most of the time through mechanisms involving suggestion), co-exist, and this co-existence does not appear to be transitory.

Scientific medicine is the medicine to which patients turn in the case of most illnesses, whether general or local in nature, and which are susceptible to real forms of treatment and can often be eliminated. In nearly all citizens there is an awareness that it is this form of medicine, which is modern and dynamic, that has assured profound changes in the health of societies which is enjoyed to the full, as can be seen when we consider the progressive increase in average life spans that has taken place in these societies, which in truth has been brought about by better conditions of life, especially as regards diet, which the more prosperous inhabitants of such societies enjoy. The most keenly felt hopes for cures and a longer life are placed in scientific medicine by the majority of the population. And they can take advantage of scientific medicine in the most suitable and dynamically updated way. It is because of these hopes that the most economically advanced countries accept the allocation of increasingly sizeable economic resources to biomedical research and to the public and private management of scientific medicine, whose needs and requirements become more onerous every year both from the point of view of

technological updating and in terms of expenditure in forms of treatment and the complex organisation of health care.

One should, however, distinguish between the positive assessment expressed by a sizeable part of citizens in relation to medical science and the frequently critical and pessimistic assessment of the medical doctors who practice it. In general, there is a lack of an adequate awareness of the intrinsic risks of medicine brought about by the parallel reality of the capacity to cause damage of illnesses and the possible capacity to cause damage of diagnostic and above all therapeutic, surgical and medical forms of treatment. In the same way, there is a lack of an adequate awareness of the great limits that characterise advanced medicine as well. The genesis of many illnesses is still not clear, and in the case of others, of varying kinds, the therapies that are available bear upon symptoms and do not ensure a cure but often only a longer life span and the possibility of being able to bear the chronic character of the illness with less suffering.

Inevitably, failures or even damaging iatrogenic consequences which in general are not attributed to medicine as such but to individual medical doctors or groups of medical doctors or to deficiencies in certain health-care structures, derive from these risks and the limits of scientific medicine. Such attributions are very often justified but on other occasions they are the outcome of inadequate information received by individual patients and their relatives or society as a whole.

From this confused situation springs the real risk, which often comes true, of a fracture in that therapeutic alliance which is the inescapable basis of Hippocratic medicine. Only an initiative of courageous and honest information can obviate, to a certain extent, such a deterioration, so as to achieve a really informed social consensus directed towards re-establishing balance in the relationships between society and the medical classes. Such information must, without being dramatic, make citizens understand the real price that everyone, albeit in varying ways, must pay in order to be able to benefit from modern medicine, with its very positive aspects but also its by no means few negative ones.

The road that many medical doctors and patients follow through recourse to ‘sweet’ alternative medicines can have some validity in reducing tension and conflicts. But this alternative road, in addition to being in most cases a deception – because it employs arguments and means that are not of proven efficacy – has its economic costs and its disappointments and can also help to introduce elements of doubt into society by creating dismay and ambiguity that darken both the image of medicine and the image of medical doctors.

However, the division that has opened up within the medical classes because of contrasting ideologies as regards the essential subjects of life and death should be seen as being even more serious.

The black connecting line that down the millennia threads through projects and initiatives designed to guide society on the basis of utilitarian or at any rate ideological principle has seen, and continues to see, medical doctors join with sociologists, philosophers and politicians in accepting principles that are in radical opposition to Hippocratic medicine, which for its part is directed towards the benefit alone of the patient and opposed to taking part in any project of death. This sequence of projects, and the ways in which they are implemented, became accentuated during the twentieth century both because of the dominion for many years of absolutist political movements which paid no attention to life and because of the advances of scientific medicine which placed medical doctors and society face to face with sensitive and worrying problems. The legalisation of abortion, permissive laws in relation to euthanasia (and also ‘peridiatics’), the production of embryos which are then abandoned or used for experimentation, the selection and destruction of embryos through pre-implantation diagnosis during assisted fertilisation and prenatal diagnosis during pregnancy, and sterilisation, are all examples of a profound threat to Hippocratic medicine and unfortunately find many medical doctors aligned on the side opposed to that of the total defence of life. ‘If the body is touched, everything is lost’, the great French biologist Jean Rostand accurately observed, and this warning, directed towards those who overturn medicine, must lead to a multiplication of efforts to bring back medicine within the sphere of life, to which it has belonged following a tradition that goes back millennia.

## VICENTE BELLVER CAPELLA

### THE RIGHT TO LIFE AND THE RIGHT TO HEALTH CARE: CONTENTS AND LIMITS

It has been said that the discipline of Bioethics dates back to the early 1970s when, almost simultaneously, Van Renssaeler Potter at the University of Michigan and André Hellegers at the University of Georgetown coined the term. I am not absolutely convinced Bioethics is a recent discipline but, if it is to be viewed as such, then there is good reason to argue that it really began in the aftermath of World War II. This was when we saw the emergence of the technology in the field of biomedicine that was to give rise to so many new problems. It was also the period that saw the adoption of the Universal Declaration of Human Rights (1948) and the Nuremberg Code (1946). In the Declaration, for the first time ever, recognition was given to the two rights that to a large extent underpin contemporary Bioethics discourse: the right to life (art. 3) and the right to health and to medical care (art. 25). For its part, the Nuremberg Code laid down the conditions to be met by experimentation on human beings in order for it to be considered lawful.

The question of the content and limits of the rights to life and health can be addressed from at least three different perspectives. One approach is to focus on the texts (laws and court rulings) that establish the scope of the rights in domestic law. A comparison of the regulations in each country highlights the major differences that exist between some nations and others. This would be the Constitutional Law and Comparative Law perspective. Secondly, one might adopt the International Law perspective and review international law texts setting out the various features of the aforementioned rights. Such texts are generally worded in sufficiently broad terms to give States flexibility when specifying the exact content of the rights. Lastly, one might adopt a philosophical approach and ask what the content of the right to life and the right to health should be, over and above the provisions put in place by States and by international bodies.

Although it might be considered an approach excessively focused on positive law, I will begin my paper by reviewing the main international law texts in which the rights to life and health are addressed. Although some mention will be made of national provisions, I prefer to concentrate on international texts because these give us some idea of the content which is conferred on the two rights in the world's major regions. Secondly, I will discuss the difficulties that arise when seeking to define the content, object and the holders of the rights. Before moving on to these two areas, a classification of international legal texts that refer to the human rights to life and health is appropriate.

### INTERNATIONAL HUMAN RIGHTS LAW

Legal texts containing references to human rights can be classified according to their scope, that is, whether they are national or international texts. Although international human rights norms did not exist prior to the 20th century, they have grown exponentially since the Universal Declaration of Human Rights of 1948. Such norms may be either universal or regional in scope. In the former case, the texts are generally adopted by the United Nations or by one of its specialised bodies (UNESCO, FAO, WHO). The latter are generally drawn up by international bodies devoted exclusively or partly to the protection of human rights in a particular region of the world. Generally speaking, there are four main regions with bodies of this type: Europe (Council of Europe, European Union), Africa (African Union), the Americas (Organisation of American States) and the Arab Countries (League of Arab States, Organization of Islamic Conference).

Depending on their coercive force, international law texts can be classified as declarations or conventions. Declarations are texts that set out an agreement of wills among the signatory States, but

have no power to act against said countries in case of non-compliance. Conventions (also called Covenants, Treaties, Protocols etc) do have coercive mechanisms to force the States Party to comply with their obligations. In the area of human rights, States often begin by adopting a Declaration, which -as the name suggests- is a mere expression of goodwill. On the basis of the Declaration, consensus is often then sought for a binding text (Convention).

Human rights fall into two main categories: civil and political rights, and economic, social and cultural rights. The first category covers highly personal rights, such as the right to life, physical integrity, privacy, religious freedom, etc, or the right to participate in politics (passive and active suffrage, but also the right of assembly, association, demonstration, etc). The second seeks to enable all people to have their basic needs met and to participate on equal terms in the social, cultural and economic life of the country. The first group of rights are relatively simple to guarantee: it suffices for a State to refrain from interfering in these realms of personal life and to put in place the necessary mechanisms (police, judicial and punitive) to punish anyone who does. The rights contained in the second group are more difficult to guarantee since the State is required to participate actively by putting in place the provisions required to give its citizens access to aspects that are vital for their development (health, education, culture, social security, etc). The availability of these rights is heavily conditioned by the State's economic capacity and their content is therefore considerably more limited in poorer nations. Given this situation, some doubt whether they can truly be considered rights: if human rights are universal, how can we speak of rights when the content - and even the very existence - of such rights is conditioned by economic capacity?

I will not enter here a discussion of the legality of social rights. I will assume they do, in fact, exist and are not merely guidelines to be taken into account when establishing public policies and drawing up legislation. Consequently, the right to health and health care would fall within the second category of human rights, whereas the right to life forms part of civil and political rights, that is, rights whose guarantee does not depend to such an extent on the State's economic capacity.

## THE RIGHT TO LIFE AND THE RIGHT TO HEALTH IN INTERNATIONAL NORMS

### Universal texts

Despite having only minor normative value, on account of its status as a mere Declaration signed in its day by barely fifty countries, there is no doubt that the most influential human rights text anywhere in the world is the Universal Declaration of Human Rights of 1948. The Declaration refers to the right to life (art. 3) in the following terms: Everyone has the right to life, liberty and security of person. One of the most controversial aspects in regard to this right concerns determining who its subjects are. As we shall see later, considerable discussion has arisen as to the interpretation of the word everyone. No specific mention is made in the Declaration of capital punishment, although article 5 states that No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Regarding the right to health, article 25 states as follows: (1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection. The reference to the right to health is an exacting one, since express mention is made of the right to medical assistance and to the fact that the right is held by individuals and families, and protects childhood and motherhood in particular.

In 1966 the General Assembly of the United Nations adopted two International Covenants which gave coercive force in law to the Universal Declaration of 1948. At the time, the world was divided into two blocks that could not agree on the terms of an International Convention on Human Rights. The stalemate led to the adoption of two Covenants: one on civil and political rights and a second one establishing economic, social and cultural rights. The former recognises the right to life and the latter the right to health.

The right to life is recognised in the International Covenant on Civil and Political Rights. It does not specify whether those not yet born hold this right, although in contrast to the 1948 Declaration which used the term everyone, here every human being is used. It does not prohibit the death penalty, but does lay down certain conditions in order for it to be considered lawful and also makes clear that States should aspire to abolish it[1]. This provision was later supplemented by an additional Protocol for the abolition of capital punishment, adopted in 1989[2]. Article 7 of the Covenant prohibits torture or cruel, inhuman or degrading treatment or punishment and stipulates that experimentation on human beings shall take place only with the free consent of the persons concerned[3].

In the International Covenant on Economic, Social and Cultural Rights the right to health is mentioned in ambitious terms[4], in line with the doctrine laid down by the World Health Organisation in its Constitution. As in the Universal Declaration, reference is made also to the protection merited by childhood and motherhood[5]. Interestingly, although the right is spoken of in terms of the highest standard of health, the measures included to give it effect are realistic ones and focus mainly on environmental conditions and public health measures. In contrast to the medicalisation of society and the development of a form of medicine centred on treating critical problems, preventive action and environmental protection are advocated here, since they are more viable and effective in the medium term.

The special protection merited by childhood, and particularly children's health conditions, had already featured in a previous United Nations text: the International Declaration on the Rights of the Child, adopted in 1959[6]. Thirty years later, this Declaration was followed by the Convention on the Rights of the Child (1989). Whereas the former contained just ten principles and filled barely two pages, the Convention comprises 54 articles running to 15 pages. The Declaration underlined the principle of the protection of children, whereas the Convention places the emphasis on the principle of autonomy.

These differences serve to highlight important, and not necessarily positive, changes in the world of human rights norms: the aim of rights is not to protect a person's fundamental goods (in this case a child's) but to underline the prevalence of individual will over the will of others. Moreover, rights are not protected by adopting principles but rather through rules endowed with very specific content.

However, the prevalence of autonomy ahead of protection is not apparent in the articles concerning children's health; here the Convention limits itself to developing further the principles already set out in the Declaration of 1959 and the International Covenant of 1966. Article 24 retains the reference to the highest attainable standard of health but the measures referred to centre on the consideration of environmental conditions, food, accident prevention, education and primary attention. In short, essentially preventive measures[7]. In a somewhat controversial reference, the article also prohibits traditional practices which are prejudicial to the health of children. On the one hand, it is not simply stipulated that health should prevail over respect for cultures. Secondly, even if it is accepted that health should take preference over cultural practices that are detrimental to it, since the notion of health is conditioned by culture it is not always easy to determine when such conflict situations arise. Article 25 refers to children placed by the authorities on health grounds, while article 32 establishes that one of the conditions under which children may work is that the work should not be harmful to their health.

The definition of child given in article 1 of the Convention does not make clear whether the nasciturus should or should not be considered as being a child[8]. To avoid ambiguity Argentina issued a declaration when ratifying the Convention that article 1 should be interpreted as meaning that child denotes all human beings, from the moment of conception until the age of 18.

A significant difference is seen between the Declaration and the Convention as regards prenatal and postnatal care. The former states that care shall be directed towards both mother and child, whereas the latter refers to mothers only. Principle 4 would imply, therefore, that the nasciturus has the right to protection of health and to health care, a possibility ruled out by the terms employed in article 24 of the Convention.

A crucial event in relation to the right to health was the creation in 1948 of the World Health Organisation (WHO), a specialised UN body whose purpose, according to its Constitution, is the attainment by all peoples of the highest possible level of health (art. 1). The Preamble to the Constitution sets out in very broad terms a concept of health and the characteristics of the right to health, as we will see below[9].

The Preamble refers to the guiding principles of public health policy - justice among countries, the need for public participation, harmonious relations between humans and their environment etc - on which there is near universal agreement, notwithstanding the varying degrees to which States take them into consideration and the interpretation given to them. The concept of health and the right to health established in the Preamble have proven highly controversial. Both are so wide-ranging that they actually undermine the guarantee of the health of individuals and populations. When health is all-encompassing and everyone is entitled to everything, in reality nobody is entitled to anything.

## REGIONAL TEXTS

Major world regions to have adopted normative texts on human rights are the Americas, Europe, Africa and the Arab countries.

### The Americas

The ceremony marking the formal adoption of the Charter of the Organisation of American States (Bogotá, 1948) to promote mutual assistance among members also saw the adoption of the American Declaration of the Rights and Duties of Man, just a few months before the signing of the Universal Declaration. Article I establishes the right to life as follows: Every human being has the right to life, liberty and the security of his person. Protection of motherhood and childhood is recognised in article VII: All women, during pregnancy and the nursing period, and all children have the right to special protection, care and aid. The right to health is set out in the following terms: Every person has the right to the preservation of his health through sanitary and social measures relating to food, clothing, housing and medical care, to the extent permitted by public and community resources (article XI).

This Declaration subsequently gave rise to a binding text, the American Convention on Human Rights (San José, 1969). Here, article 4 sets out the right to life[10] in very new terms. It recognises that protection of life commences with conception and, although not prohibiting capital punishment generally, it does stipulate that States who have abolished it may not restore it.

In turn the American Convention has been supplemented by the Protocol of San Salvador (1989), on economic, social and cultural rights. Article 10 of the Protocol expressly regulates the right to health, stating that health is a public good and that the authorities must not only ensure public health but also that all citizens receive the required medical care[11].

In setting out the right to protection of the elderly, the Protocol includes, among other State commitments, the provision of suitable facilities, as well as food and specialized medical care, for elderly individuals who lack them and are unable to provide them for themselves (art. 17.a). Regarding the right to protection of the handicapped, it states that Everyone affected by a diminution of his physical or mental capacities is entitled to receive special attention designed to help him achieve the greatest possible development of his personality (art. 18).

## Europe

In Europe, two organisations - the Council of Europe, and, of late, the European Union - have adopted texts addressing the recognition and protection of human rights.

The Council of Europe was created in 1949 with the twin aim of defending democracy and the rule of law and protecting human rights, and thus avoid a repeat of experiences such as the recently-ended World War II. In Rome in 1950 members adopted the European Convention on Human Rights, whose major contribution was to put in place, at a level above members' national jurisdictions, a judicial system of protection for the rights set out in the Convention. Thus, when a person had exhausted all domestic remedies for breaches of his human rights, he could seek redress from the European Court of Human Rights. The Convention concerns itself solely with civil and political rights.

The adoption of the Convention marked a veritable revolution in legislative policy. For the first time since the advent of the modern State, a group of States ceded a piece of their sovereignty to a supranational body which was given the powers to judge and, if appropriate, condemn their conduct. This curtailment of sovereign powers demonstrated that, for States, guaranteeing citizens' rights was more important than their own power. Since its adoption, the Convention has been supplemented by 11 additional Protocols extending the scope of the rights and enhancing the mechanisms established for their protection.

Article 2 recognises the right to life[12] while article 3 prohibits torture[13]. Although capital punishment was not initially prohibited, the Additional Protocol to the European Convention on Human Rights concerning the Abolition of the Death Penalty, signed in Strasbourg in 1983, introduced the ban, except in times of war.

The Council of Europe also adopted (Turin, 1961) the European Social Charter on economic, social and cultural rights[14]. Although a Convention, this does not have the guarantee mechanisms needed for effective exercise of the rights set out in the Rome Convention. The Charter refers to the right to health, drawing a distinct difference between the right to protection of health[15] and the right to social and medical assistance[16]. The content of these rights is supplemented further by references elsewhere in the Charter to safe and healthy working conditions (art. 3), special health protection for young persons in employment (art. 7) and protection of motherhood (art. 9).

In addition to the aforementioned - the most general of its Conventions -, the Council of Europe has adopted many other Conventions aimed at protecting certain human rights against new threats. One of the most important, directly addressing the rights to life and health, is the European Convention on Human Rights and Biomedicine of 1997, also known as the Oviedo Convention, which aims to protect human rights against the threats posed by biomedical technologies. It provides for the adoption of additional Protocols to regulate aspects not covered by it or to regulate in greater detail those already included[17].

The Oviedo Convention refers to the right to health and - in referring to the protection merited by embryos - the right to life also. This reference to health is very general and is limited to the requirement that States distribute health care equitably. Article 3 reads as follows: Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

The Convention recognises that human embryos must be treated with respect but, at the same time, states that this respect may be compatible with their use for research purposes. It sets a minimum threshold for protection, namely, the prohibition of the creation of embryos for research[18].

On this issue doubts have arisen on the level of interpretation: does the Convention permit the creation of embryos for purely therapeutic ends? A literal and restrictive interpretation of the prohibition would lead to an affirmative answer, although it would also lead to the conclusion that the Convention allows embryos to be created for industrial or other purposes, but not research. From the teleological perspective, however, it appears odd that the Convention should allow the creation of embryos for

therapeutic use when it expressly prohibits their creation for experiments that might lead to therapies using embryo cells.

This argument, in turn, can be challenged, to the extent that the Convention does allow research on embryos which have not been used, or are not going to be used, in assisted reproduction programmes. From this perspective, the Convention establishes degrees of protection, prohibiting the creation of embryos for research ends (the investigation may only be conducted on ‘surplus’ embryos) but not when cells from the embryo might be used directly in therapeutic treatments.

The fact that the Convention itself acknowledges that human life commences with conception and as of that moment merits protection[19], would appear to rule out the creation and destruction of embryos, even for a directly therapeutic purpose, since this would represent an instrumentalisation of human embryos and a denial of the protection required by article 18 of the Convention.

Although what we know today as the European Union was created as a supranational organisation primarily for economic and commercial reasons, today it aspires to political union also. In 2000 in Nice the Member States adopted the European Declaration of Fundamental Rights which subsequently came to form the second part of the Treaty of the European Constitution, signed in Rome on 4 November 2004 and entitled The Charter of Fundamental Rights of the Union. This contains references to the right to life[20] and to health[21], with special attention paid to health in the workplace (art. 31), protection of minors in employment (art. 32) and motherhood (art. 33). Also set out are a series of biotechnology-related prohibitions, such as eugenic practices, human reproductive cloning and the use of human body parts for financial gain[22]. The prohibition of cloning is open to two contradictory interpretations. If the embryo is acknowledged as being a human being, then embryo cloning is prohibited, regardless of the intended purpose. If it is accepted that the moment of birth marks the beginning of a human being, only cloning that aims to give birth a human being is prohibited.

## Africa

The Organisation of African Unity[23], created in 1963 to promote unity and solidarity among African countries, has put in place extensive legislation governing human rights. The most important text is the African Charter on Human and Peoples' Rights, also known as the Banjul Charter (1981), which expressly recognises the right to life[24] and the right to health[25]. A new feature was the incorporation of the duty of the State to protect families' physical and moral health[26].

The African Charter on the Rights and Welfare of the Child (1990), which was also adopted by the African Union, establishes in article 14 on health and health services[27] a series of criteria very similar to those included in article 24 of the Convention on the Rights of the Child. In contrast to this degree of continuity with other international human rights texts, it is striking to note that the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa sets out for the first time in an international law text the right of a woman to undergo abortion in certain circumstances[28].

## Arab countries

In the Arab world we find two human rights texts. The first of these is the Cairo Declaration on Human Rights in Islam - adopted by the Islamic Conference in 1990 - which refers to the rights to life[29] and health[30]. Regarding the former, euthanasia is explicitly prohibited, in view of the obligation to preserve human life during the time determined by God.

In 1994 the League of Arab States adopted the Arab Charter on Human Rights which recognises the right to life, although not prohibiting capital punishment, and requires freely-given consent for experimentation on human beings[31].

## CONCLUSIONS

In the light of the foregoing review of universal and regional conventions and declarations on human rights, a number of conclusions can be drawn:

1. Human rights texts address both the right to life and the right to health.
2. The right to life raises two controversial aspects: capital punishment and respect for the life of human embryos and foetuses. While agreement has been reached in Europe on the abolition of capital punishment, in other regions and at universal level regulation is left to individual States.
3. Regarding protection of unborn human life, only the San José Convention specifically acknowledges the existence of the right to life from the moment of conception. Generally speaking, the countries of Latin America afford greater legal protection to the ‘nasciturus’. Nonetheless, in many such countries abortion is lawful in several circumstances and assisted reproduction techniques are permitted without special limits for the protection of the life of embryos[32]. Other texts leave the interpretation of the scope of the right to life of the unborn up to the States.
4. Abortion is decriminalised to a greater or lesser degree in most countries in the world. This does not mean that women have a right to abortion, but rather that abortion is not punishable. Only the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa establishes the right of women to abort.
5. Since the creation of the WHO, the concepts of health and the right to health used are extremely broad, thus making it difficult to determine the obligations of States to guarantee said rights. Although various international human rights texts mention both health protection and medical assistance when referring to the right to health, only the European Social Charter expressly distinguishes between the two.
6. The right to life benefits from a number of judicial protection mechanisms at supranational level in Europe and in the Americas. However, the right to health does not have such means to ensure it is effectively guaranteed. This is understandable given that, to guarantee the right to life, it suffices in principle for the State to refrain from intervention. Conversely, the right to health cannot be satisfied if the State does not make available the necessary economic resources. In the former case, the right is guaranteed by the State's abstention, whereas in the latter it necessarily has to intervene in order to provide the required assets and services. Moreover, the proposed concept of the right to health is so wide-ranging that it would be naïve to put forward guarantees to give effect to it.

## OBJECT, CONTENT AND SUBJECT OF THE RIGHT TO LIFE

No specific problems arise in regard to the object of the right to life: it is the life of every human being. There are problems, however, when seeking to determine the content of the right: does it include the right to dispose of one's own life? Does the duty to respect the life of human beings include prohibition of capital punishment?

The answer to the first question, yes or no, depends on which theory of rights we defend. If rights are understood as embodying the preferential wishes of the subject over the wishes of all others on a particular issue, then the right to life would include the right to dispose of one's life. Conversely, if they are deemed to be the means of protecting goods considered so vital to human beings that nobody can be deprived of said goods, the right to life would include also the duty to respect one's own life. This was Kant's understanding when he stated that suicide was not a manifestation of the right to life but a violation thereof, because in disposing of one's life the subject is not considered an end but a mere means.

The issue is whether the right to life is, or is not, inalienable. Among the fundamental characteristics of human rights - universality, inviolability, inalienability and indivisibility - inalienability has been the most heavily contested by theorists of Law. Inalienability means that human rights must be respected by their holder, who may not destroy or alienate them. Consequently, a person does not have the right to stop being free, nor to renounce his privacy for ever or dispose of his life. Declarations of rights usually proclaim their inalienable nature, yet this nature tends to be negated by many philosophical standpoints.

Turning to the question of whether the duty to respect the life of human beings also includes the prohibition of capital punishment, with the exception of Europe this requirement does not figure in international texts, although they tend to manifest the wish for capital punishment to be abolished eventually in broader recognition of the right to life. This is clearly evident in the San José Convention, which prohibits the restoration of capital punishment in States where it has already been abolished (art. 4.3).

Three kinds of arguments are used to justify the compatibility of capital punishment and the right to life. In the English-speaking world, the view commonly held is that the perpetrators of certain actions lose their dignity as persons and hence no longer merit protection of their human rights, particularly the right to life. At least two objections can be raised to this view. Firstly, human dignity is not conditional on a person's moral conduct. The rights of a person do not exist or cease to exist depending on his moral qualities, but rather they are inherent to the human condition. Secondly, the judgment in Law that results in a death sentence is not a legal judgment- which determines whether the person's action corresponds to a given criminal offence and, if so, merits the appropriate punishment - but an ethical one: a death sentence is an assertion that a human being no longer deserves to live. It is thus a negative judgment on the existence of a person, transcending considerably the kind of judgments the Law is competent to deal with.

A second argument used to justify the legitimacy of capital punishment relates to the defence of society. Under this approach, it is lawful to end the life of those who represent a threat to society, provided that the threat cannot be neutralised by other means. This view may be acceptable in general terms but at this moment it is inconceivable to think that the death penalty is warranted by the need to safeguard the common good.

A third line of argument is that cultural differences represent an insurmountable barrier. Some cultures see the death penalty as part of the range of punishments a State must be able to avail itself of to castigate the perpetrators of certain crimes. If the cultures themselves cannot be scrutinised or, where appropriate, criticised, then we have to accept the continued existence of capital punishment in some States. However, if we acknowledge that human rights are universal, we would also have to agree that they constitute the obligatory basis for the development of a society's cultural manifestations. Rights are not merely the product of a given culture, they are the condition required to enable people's lives and cultures to thrive.

Therefore, and notwithstanding a drastic change in future circumstances that might render recourse to capital punishment legitimate in very exceptional cases, it would be desirable for States and international bodies to aim for total worldwide abolition of the death sentence.

The main controversy today surrounding the right to life centres on who the subjects of the right are. Here too we can illustrate the problems through three questions: are nascituri and preimplantation human embryos subjects of the right to life? Are animals, or at least some animals? Are humans who are in a permanent vegetative state? Of the three, I will discuss only the first in detail, and will mention the other two only briefly.

The legal status of embryos and foetuses has received considerable attention in discussions of the ethical valuation of three highly controversial activities: abortion, the freezing of embryos and the creation of embryos in laboratories for research use.

Abortion. International human rights texts avoid establishing a universal criterion governing abortion, preferring to leave regulation to States. Not even the European Court of Human Rights has ruled on whether the nasciturus has the right to life[33]. This line is a reflection of the diverse responses adopted by States in addressing the problem. At least four approaches can be identified:

a.- The nasciturus is the subject of the right to life and hence its life may not be harmed. Only in the event of a tragic conflict between rights – the life of the mother vs. the right of the child - or where the law cannot oblige a woman to behave ‘heroically’ (i.e. force a rape victim to continue with the resulting pregnancy) would abortion not be punishable. This is the position taken by several Latin American countries and Ireland.

b.- The nasciturus is the subject of the right to life but this right may yield to the preferential right of the woman, as occurs in Germany where, although the nasciturus is acknowledged as being a person and the holder of the right to life[34], abortion is readily available[35].

c.- It is not recognised, or at least there are doubts, that the nasciturus is a person and therefore possesses the right to life. However, life is acknowledged as being a legally protected interest and human life must be protected from the moment of conception, although in certain circumstances this protection may be waived in favour of other interests deemed preferential. This is the position taken by Spain’s Constitutional Court in 1985 when it ruled on the constitutional challenge filed against a law decriminalising abortion. The position has been adhered to in several rulings on constitutional challenges to two 1988 laws, one on assisted reproduction techniques and the other one on the donation and use of human embryos and foetuses or their cells, tissues and organs.

d.- The State does not make any pronouncement on the value of the life of the nasciturus but does maintain that one of the fundamental rights of the person is privacy, which is harmed if the State seeks to impose its will on a woman during the course of pregnancy. This criterion was established by the famous Roe vs. Wade ruling handed down by the US Supreme Court in 1973.

Freezing of embryos. The first test tube baby was born in 1978. To reach that stage many embryos had to be created and research was necessary on these embryos. All this research was possible thanks to a legal void which some countries only began to remedy as of the mid-1980s.

Legislation on assisted reproduction techniques addressed two important issues in relation to the protection of the human embryo: firstly, whether it should be permissible to create more embryos than would actually be transferred to the woman and to freeze any not used; secondly, whether it should be permissible to create embryos for research to help improve reproduction techniques. Regarding the first question, the mainstream position has been to allow fertilisation of more eggs than are needed for transfer in a first cycle and freeze any not used[36].

The advent of embryo freezing has led to the creation of large numbers of frozen embryos which are subsequently ‘abandoned’ by their biological parents, thus creating the problem of what should be done with them. It has been said frequently that it is better to freeze them than to allow them to die.

However, the reason for freezing was not to benefit the embryo, otherwise the decision would have been taken to create only the number required for transfer in each cycle. The sole reason for creating more embryos was to reduce the inconvenience caused to women by ovary stimulation and follicle extraction. On the subject of embryo freezing we must ask ourselves firstly whether or not it is contrary to the right to life. Some argue that it is a way of ensuring the embryos do not die and hence freezing is not contrary to the right to life. Others argue that freezing amounts to an attack on the dignity of embryos because it prevents their natural development.

Over and above the issue of whether freezing human embryos is licit, a very serious problem has arisen with regard to the destiny of such embryos. A range of alternatives or complementary responses have been put forward: donation to other couples willing to receive them; indefinite freezing until their development can be guaranteed; thawing; research use.

Of all the options advocated, thawing is the only licit and realistic one, in my opinion. None of the others meets this twin condition. Transferring frozen embryos to other willing couples is a legitimate and very laudable practice but it fails to fully resolve the problem.

Creation and use of embryos for reproductive purposes. Since 1998, when embryo stem cells were first obtained in the laboratory, considerable pressure has been brought to bear to allow frozen embryos to be used in experiments to obtain stem cell lines. Frozen embryos suddenly ceased to be a problem and became a resource for stem cell research. But some people went further, proposing that human embryos should be created through in vitro fertilisation and even cloning in order to use them for research of this type. In favour of embryo cloning for research it was argued that embryos obtained in this way should not be called embryos, nor be treated the same as those resulting from the fusion of gametes.

In my opinion, this form of cloning, commonly but mistakenly called ‘therapeutic’, is even more serious than cloning that leads to the birth of a child because it entails creating human life to destroy it. And yet public opinion appears more negative with respect to the latter type of cloning than the former. The United Nations is currently preparing a Convention aimed at securing the universal prohibition of human cloning. The process leading to the adoption of a text supported by a majority of countries is not proving easy because one block of countries favours prohibiting human cloning under any circumstances, whereas others would like to see only cloning that leads to the birth of a human punished.

Thus far very few national laws have permitted the creation of human embryos for research. The pressure to do so is becoming intense, however. Some countries (Singapore, Israel, South Korea, etc) have amended laws in recent years to enable embryos to be created for use in research.

Animals and the right to life. One of the most renowned moral philosophers of our day, Peter Singer, is also one of the staunchest advocates of animal rights[37]. In his view, recognising rights solely to the members of the human species amounts to ‘speciesism’, i.e. discrimination on grounds of belonging to a species. He argues that moral value should not be associated with membership of a species but with the capacity to experience pleasure and pain. Thus, the circle of moral subjects would be modified substantially and would include adult specimens of the most advanced animal species but would exclude members of the human species who lack even a minimum capacity for feeling.

Singer’s position has been challenged by the most radical ecologists and also by personalist sectors. According to the former, using the capacity to feel pleasure and pain as the criterion for dignity is itself discriminatory (they call it ‘sentientism’), in that it denies moral value to life forms that do not feel. Conversely, personalists affirm that only subjects capable of assuming duties can possess rights and, since human beings alone have this capacity, only humans are the holders of rights. They also argue that denying rights to animals in no way means that we do not have serious obligations towards animals.

The right to life of persons in a permanent vegetative state. Some authors take the view that when brain stem activity ceases we are no longer dealing with a human being and therefore it would be quite licit, and even obligatory, to put an end to his physical life. The battle to approve euthanasia is essentially grounded on two appeals, namely, that people should be allowed to decide when to end their lives and, secondly, that it should be possible to end the lives of those who will never recover their specifically human brain functions.

If we accept that human beings do not cease to be persons just because they are in a permanent vegetative state, then they cannot be denied the right to life and their life cannot be ended. A separate issue is deciding which measures should be provided to maintain their life and health.

## OBJECT, CONTENT AND SUBJECT OF THE RIGHT TO HEALTH

There are two fundamental aspects of the right to health: the right to the maintenance of health conditions and the right to medical assistance. In both cases the object of the right is the health of individuals and society. The problem arises due to the lack of agreement on what is to be understood by the word ‘health’. The best-known concept is that established by the WHO in its Constitution: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. This extremely broad definition generates great expectations in people and makes it difficult to define the content of these rights in precise terms.

This concept of health embraces virtually all aspects of human life. However, health also becomes a subjective category, an aspiration which is defined entirely by the individual. The pursuit of happiness mentioned in the United States Declaration of Independence as one of the inalienable rights, along with freedom and equality, is today replaced by the pursuit of health. The current concept of health leads us to the notion of salvation, with which it is etymologically associated. This salvation is not eschatological - it is not attained in another life - but rather is inherent to existence. Health-salvation as an existential goal is attained to the extent that a feeling of well-being is enjoyed.

Until recent times health had been a teleological category interpreted by doctors, who decided who was healthy and who needed their professional care. Doctors’ work involved curing the ill rather than satisfying demands or wishes expressed by individuals. Doctors worked with the patient’s nature to restore his health or they repaired the damage caused to human nature when this could not cure itself. The outcome of medical activity was never wholly predictable and hence it was meaningless to establish contracts to guarantee a given result. Doctors could undertake to carry out certain activities but not to attain results that did not lie entirely in their hands[38].

In contrast, the new concept of health is defined by the individuals themselves. The work of a doctor is no longer to cure what he understands as illness but to satisfy individuals’ health care demands. Gone is the notion of cooperating with nature to cure the patient. Today, the art of medicine not only restores but transforms also. Doctor-patient relations acquire the status of a contract, in which certain services (and even results) are exchanged.

In this new concept of health autonomy is the essential ethical principle governing doctor-patient relations. The patient has an idea of health he would like to see fulfilled and the doctor is there to satisfy that idea. The enormous progress made lately in aesthetic medicine, artificial reproduction and the use of psychodrugs for reasons other than to treat pathologies are all evidence of the transformation seen in medicine, whereby health is now confused with desire.

Germ-line genetic interventions are not performed at present in human beings and are banned in many national and international norms (including the European Convention on Human Rights and Biomedicine and the Universal Declaration of Human Rights and the Human Genome). In the not too distant future, however, the question will arise whether such interventions should be prohibited, whether they should be allowed solely to eradicate very serious genetic conditions or whether they might be used to modify the genetic characteristics of our offspring. Clearly, the concept of health prevailing at the time will determine the answer to these questions.

The subjectivist concept of health has three important consequences. It hinders the establishment of a shared concept of public health, it causes health care to be diverted to the private sector and also tends to overlook issues of global justice in the field of health.

1.- If health is a concept built by individuals, as opposed to a ‘natural norm’ governing people’s lives, agreement on the interpretation of public health will, in principle, be reached at the level of the lowest common denominator and the measures taken will be few and far between. This already occurs in many cases, with dramatic repercussions on the health of entire populations. Until relatively recently, for example, advocating sexual abstinence or the need to restrict sexual relations to habitual partners as the most effective way of combating Aids was a taboo subject. Similarly, the scant attention paid to

tackling air pollution in many cities is resulting in serious health problems for children. This lack of attention to certain aspects of public health is accompanied by the development of public health policies in other areas on the basis of the financial and social costs incurred by certain activities or life styles: compulsory seat belts and helmets, restrictions on purchases of alcohol, breast cancer screening as of a certain age, etc.

2.- The concept of health conditions the content of the right to medical assistance. If health is considered a natural norm - a teleological principle governing the lives of all human beings -, the right to health will normally include a duty on the part of the public authorities to guarantee health care to all citizens to enable them to develop their personal and social life. Conversely, if health is identified with individual desire, the content of the right to health will be limited considerably. It will guarantee people's freedom to procure their preferred health care and the State will merely be answerable for the qualifications of those providing such services and for the safety and efficacy of diagnostic tests and treatments.

3.- Lastly, the concept of health also conditions health policy at the international level. If a subjective health concept is defended, it is acceptable for the criteria for experimenting on human beings to vary from country to country. The emphasis will not be on ensuring basic health cover throughout the world. The gap between rich and poor will widen because resources that ought to be used to combat the most serious health problems in poor countries will instead be used to develop luxury medicine in richer ones. Thus, economic differences will be accompanied by increasingly wider differences in health care levels. These massive differences could well pale into insignificance with the prospect of differences between 'genetically enhanced' and 'genetically natural' humans if genetic interventions are used to improve the human species[39].

Over and above these doubts concerning the concept of health, doubts also arise with regard to the very existence of the right to health. Various arguments are used in support of this view:

1.- Social rights- and, consequently, the right to health - do not exist. Rights guarantee negative freedoms only, i.e. spaces in which those possessing the rights can act without interference from anyone else. The role of the State is to refrain from restricting individuals and to provide the necessary mechanisms to ensure that justice can be sought in the event that a right is violated. This approach is adopted only by the most extremely liberal positions.

2.- The only social rights that exist are those that have the appropriate legal guarantees giving them effect. Since the right to health does not have these guarantees, it cannot properly be considered a right. In many Constitutions the right to education - a social right - enjoys the same constitutional mechanisms of protection as civil and political rights. This is the only social right to benefit from such status, and it has occurred in but a small number of countries. Other social rights, among them health, merely receive the protection derived from laws enacted to implement the content of the rights. In sum, the inclusion of such rights in constitutions, and even more so in international legal texts, is designed solely to establish a guiding principle for States' economic and social policies.

3.-Human rights are universal but, since social rights are not, they cannot be considered human rights. There is no disputing that the content of the right to health is heavily conditioned by a State's economic capacity and its public policies. Neither the measures taken to preserve health nor health care provision are, or can be, the same or even similar in a rich country as in a poor one, in a more socially-oriented country as in a more liberal one.

Defining the subject of the right to health can also prove problematic. If we are referring to the conditions for preserving the health of individuals and populations, we might consider that the subject is society, rather than the individual. This raises the controversial question of whether rights are purely individual or can also be considered collective. In my opinion, in order to assert the existence of the right to conditions of health, one need not necessarily call into question the notion that rights are always individual.

It is argued that the individual right to health (the freedom to dispose of one's own health) clashes with the collective right and that, in such cases, tragic decisions are often necessary. Individual freedom to smoke or to refuse to be vaccinated would therefore clash with society's right to breathe clean air in enclosed public spaces or to be free from the risk of infection. In my opinion, the basic premise on which such conflicts are based is incorrect because the content of individual freedom concerning one's own health does not include the power to place at risk the health of others.

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[1] Article 6:

1. Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.

2. In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgement rendered by a competent court.

3. When deprivation of life constitutes the crime of genocide, it is understood that nothing in this article shall authorize any State Party to the present Covenant to derogate in any way from any obligation assumed under the provisions of the Convention on the Prevention and Punishment of the Crime of Genocide.

4. Anyone sentenced to death shall have the right to seek pardon or commutation of the sentence. Amnesty, pardon or commutation of the sentence of death may be granted in all cases.

5. Sentence of death shall not be imposed for crimes committed by persons below eighteen years of age and shall not be carried out on pregnant women.

6. Nothing in this article shall be invoked to delay or to prevent the abolition of capital punishment by any State Party to the present Covenant.

[2] Additional protocols to the Covenants may or may not be ratified by the States Parties. If ratified, they have the same binding force as the Covenants. Second Optional Protocol to the International Covenant on Civil and Political Rights, aiming at the abolition of the death penalty, adopted on 15 December 1989 by Resolution 44/128.

[3] Article 7: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

[4] Article 12:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

(b) The improvement of all aspects of environmental and industrial hygiene;

(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

[5] Article 10: The States Parties to the present Covenant recognize that:

1. The widest possible protection and assistance should be accorded to the family, which is the natural and fundamental group unit of society, particularly for its establishment and while it is responsible for the care and education of dependent children. Marriage must be entered into with the free consent of the intending spouses.

2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.

3. Special measures of protection and assistance should be taken on behalf of all children and young persons without any discrimination for reasons of parentage or other conditions. Children and young persons should be protected from economic and social exploitation. Their employment in work harmful to their morals or health or dangerous to life or likely to hamper their normal development should be punishable by law. States should also set age limits below which the paid employment of child labour should be prohibited and punishable by law.

[6] Principle 4: The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided both to him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services.

Principle 5: The child who is physically, mentally or socially handicapped shall be given the special treatment, education and care required by his particular condition.

[7] Article 24:

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:

(a) To diminish infant and child mortality;

(b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

(c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

(d) To ensure appropriate pre-natal and post-natal health care for mothers;

(e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

(f) To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

[8] Article 1: For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

[9] The States parties to this Constitution declare, in conformity with the Charter of the United Nations, that the following principles are basic to the happiness, harmonious relations and security of all peoples:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest cooperation of individuals and States.

The achievement of any State in the promotion and protection of health is of value to all.

Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.

Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.

The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.

Informed opinion and active cooperation on the part of the public are of the utmost importance in the improvement of the health of the people.

Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

[10] Article 4:

1. Every person has the right to have his life respected. This right shall be protected by law and, in general, from the moment of conception. No one shall be arbitrarily deprived of his life.

2. In countries that have not abolished the death penalty, it may be imposed only for the most serious crimes and pursuant to a final judgment rendered by a competent court and in accordance with a law establishing such punishment, enacted prior to the commission of the crime. The application of such punishment shall not be extended to crimes to which it does not presently apply.

3. The death penalty shall not be reestablished in states that have abolished it.

4. In no case shall capital punishment be inflicted for political offences or related common crimes.

5. Capital punishment shall not be imposed upon persons who, at the time the crime was committed, were under 18 years of age or over 70 years of age; nor shall it be applied to pregnant women.

6. Every person condemned to death shall have the right to apply for amnesty, pardon, or commutation of sentence, which may be granted in all cases. Capital punishment shall not be imposed while such a petition is pending decision by the competent authority.

[11] Article 10:

1. Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and social well-being.

2. In order to ensure the exercise of the right to health, the States Parties agree to recognize health as a public good and, particularly, to adopt the following measures to ensure that right:

a. Primary health care, that is, essential health care made available to all individuals and families in the community;

b. Extension of the benefits of health services to all individuals subject to the State's jurisdiction;

c. Universal immunization against the principal infectious diseases;

d. Prevention and treatment of endemic, occupational and other diseases;

e. Education of the population on the prevention and treatment of health problems, and

f. Satisfaction of the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable.

[12] Article 2:

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:

a. in defence of any person from unlawful violence;

b. in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;

c. in action lawfully taken for the purpose of quelling a riot or insurrection.

[13] Article 3: No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

[14] The Charter was entirely revised in 1996 and reopened for signature and ratification by Member States of the Council of Europe. It entered force in 1999.

[15] Article 11 – The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia:

\* to remove as far as possible the causes of ill-health;

\* to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;

\* to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

[16] Article 13 – The right to social and medical assistance

With a view to ensuring the effective exercise of the right to social and medical assistance, the Parties undertake:

\* to ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition;

\* to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights;

\* to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want;

\* to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11 December 1953.

[17] Three additional Protocols have been adopted to date: on human cloning (1998), on transplants of human tissues and organs (2002), on biomedical research (2004).

[18] Article 18 – Research on embryos in vitro

1. Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo.

2. The creation of human embryos for research purposes is prohibited.

[19] The explanatory report to the Convention states, with respect to article 1: The Convention also uses the expression "human being" to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began (n. 19).

[20] Article II-2: Right to life.

1. Everyone has the right to life.

2. No one shall be condemned to the death penalty, or executed.

[21] Article IV-35: Health care.

Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

[22] Article I-3: Right to the integrity of the person

1. Everyone has the right to respect for his or her physical and mental integrity.

2. In the fields of medicine and biology, the following must be respected in particular:

(a) the free and informed consent of the person concerned, according to the procedures laid down by law,

- (b) the prohibition of eugenic practices, in particular those aiming at the selection of persons,
- (c) the prohibition on making the human body and its parts as such a source of financial gain,
- (d) the prohibition of the reproductive cloning of human beings.

[23] In 2002 this Organisation was dissolved and replaced by the African Union, created along similar lines to the European Union.

[24] Article 4: Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.

[25] Article 16: 1. Every individual shall have the right to enjoy the best attainable state of physical and mental health. 2. States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

[26] Article 18: 1. The family shall be the natural unit and basis of society. It shall be protected by the State which shall take care of its physical health and moral.

[27] Article 14:

1. Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.

2. States Parties to the present Charter shall undertake to pursue the full implementation of this right and in particular shall take measures:

- (a) to reduce infant and child mortality rate;
- (b) to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
- (c) to ensure the provision of adequate nutrition and safe drinking water;
- (d) to combat disease and malnutrition within the framework of primary health care through the application of appropriate technology;
- (e) to ensure appropriate health care for expectant and nursing mothers;
- (f) to develop preventive health care and family life education and provision of service;
- (g) to integrate basic health service programmes in national development plans;
- (h) to ensure that all sectors of the society, in particular, parents, children, community leaders and community workers are informed and supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of domestic and other accidents;
- (i) to ensure the meaningful participation of non-governmental organizations, local communities and the beneficiary population in the planning and management of a basic service programme for children;
- (j) to support through technical and financial means, the mobilization of local community resources in the development of primary health care for children.

[28] Article 14: Health and Reproductive Rights

1. States Parties shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted. This includes:

- a) the right to control their fertility;
- b) the right to decide whether to have children, the number of children and the spacing of children;
- c) the right to choose any method of contraception;
- d) the right to self protection and to be protected against sexually transmitted infections, including HIV/AIDS;
- e) the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognised standards and best practices;
- f) the right to have family planning education.

2. States Parties shall take all appropriate measures to:

a) provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas;

b) establish and strengthen existing pre-natal, delivery and post-natal health and nutritional services for women during pregnancy and while they are breast-feeding;

c) protect the reproductive rights of women by authorising medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or the foetus.

[29] Article 2:

(a) Life is a God-given gift and the right to life is guaranteed to every human being. It is the duty of individuals, societies and states to protect this right from any violation, and it is prohibited to take away life except for a Shari'ah-prescribed reason.

(b) It is forbidden to resort to such means as may result in the genocidal annihilation of mankind.

(c) The preservation of human life throughout the term of time willed by God is a duty prescribed by Shari'ah.

(d) Safety from bodily harm is a guaranteed right. It is the duty of the state to safeguard it, and it is prohibited to breach it without a Shari'ah-prescribed reason.

[30] Article 17:

(a) Everyone shall have the right to live in a clean environment, away from vice and moral corruption, an environment that would foster his self-development; and it is incumbent upon the State and society in general to afford that right.

(b) Everyone shall have the right to medical and social care, and to all public amenities provided by society and the State within the limits of their available resources.

(c) The State shall ensure the right of the individual to a decent living which will enable him to meet all his requirements and those of his dependents, including food, clothing, housing, education, medical care and all other basic needs.

[31] Article 5: Every individual has the right to life, liberty and security of person. These rights shall be protected by law.

Article 10: The death penalty may be imposed only for the most serious crimes and anyone sentenced to death shall have the right to seek pardon or commutation of the sentence.

Article 11: The death penalty shall under no circumstances be imposed for a political offence.

Article 12: The death penalty shall not be inflicted on a person under 18 years of age, on a pregnant woman prior to her delivery or on a nursing mother within two years from the date on which she gave birth.

Article 13: (b) No medical or scientific experimentation shall be carried out on any person without his free consent.

[32] The only country to have declared legislation regulating assisted reproduction techniques as being unconstitutional was Costa Rica, which took the view that the risk posed to the life of embryos by such techniques was disproportionate.

[33] In 1991 Mrs Vo, who was six months pregnant, was mistakenly operated on and, in the process, the amniotic bag of the foetus was pierced, making a therapeutic abortion necessary. She instituted criminal proceedings in the courts and France's Court of Cassation eventually cleared the doctor of criminal liability. Mrs Vo appealed this verdict to the European Court of Human Rights. In its judgement of 8 July 2004, the Court ruled that it was up to each State to decide whether article 2 of the European Convention on Human Rights was applicable to the nasciturus.

[34] Precisely because the foetus does have rights, Germany requires that any woman seeking an abortion must first receive information in an approved centre as to the implications of abortion and available alternatives. The Catholic Church runs such information centres for women but for some years now has not issued the certificates women are required to produce in order to undergo abortion.

[35] Germany's Constitutional Court has ruled on the subject of abortion on two occasions: in 1975, when it resolved a constitutional appeal against the law decriminalising abortion, and in 1993, when the new regulation of abortion following reunification was challenged. cf. Rhonheimer, M., Derecho a la vida y Estado moderno, Rialp, Madrid, 1998, pp. 40 ff.

[36] Germany's embryo protection law does not allow more embryos to be created than are to be transferred nor does it permit freezing. However, it does allow freezing of an egg which has been penetrated by the sperm but fusion of the two nuclei has not taken place. This leads to the question of when does an embryo actually come into being.

[37] Singer, P., Animal Liberation, Pimlico, London, 1995.

[38] Cf. Kass, L. R. Towards a more natural science, The Free Press, New York, 1985, pp.

[39] Cf. Silver, L., Remaking Eden. Cloning and beyond in a new brave world, Weidenfeld and Nicolson, London, 1998.

**ALEJANDRO SERANI-MERLO,  
PEDORO PAULO MARÍN LARRAÍN,  
BEATRIZ ZEGERS PRADO**

## **QUALITY OF LIFE IN GERIATRICS**

### **SUMMARY**

Longevity in modern societies is creating a unique demographic revolution. Geriatrics can approach this phenomenon from a medical anthropology and from a clinical point of view. Division of human life in stages can be useful but implies a proportion of arbitrariness, the actual picture of most people over 65 years old has dramatically changed. Declining of powers and capacities is only a part of the process of aging. A great proportion of senior people experience an expansion of their conscious self and a progress in personal autonomy which is not incompatible with physical dependence and medical ailments.

From a clinical point of view we propose that quality of life can be understood in three different ways. 1) Essential; 1) Accidental or Objective and 3) Personal or Subjective. This differentiated approach of quality of life permits to recognize the complexity of the quality of life discourse, to acknowledge the truth of each perspective and to articulate them in a unitary and hierarchical order.

### **INTRODUCTION**

People nowadays live longer than in ancient times; this seems to be an undisputed fact. However, the in-depth understanding of this, with all its details and implications for society and medicine, is a quite less obvious issue.

The information starts to make sense if one considers that in most modern countries today, each person who reaches age 65 in a relatively healthy condition has on average a life expectation of around twenty supplemental years. If we consider that the proportion of the whole population actually reaching 65 years age in relatively good health is much greater than what humanity has seen in the past, then one would have the necessary elements to conclude that modern societies are being confronted by a social demographic phenomenon unique in the history of mankind[1]. We are just starting to face the challenges that this new demographic situation is bringing to our cultures in various dimensions: medical, psychological, social, economical and political.

#### **Geriatrics and the phenomenon of human aging**

Contemporary geriatrics can approach this problem from two different and complementary perspectives: a medical anthropology point of view, and a clinical perspective. We will first elaborate a range of medical anthropology views and then we will complement them with clinical reflections.

#### **A medical anthropology point of view**

The first issue concerns the rationality of dividing human life into stages. Human life is fundamentally a continuum. If we accept this position, the distinction of defined stages, even if not completely devoid of foundation, lies on a substantial amount of arbitrariness. In the Rome of Saint Augustine people were considered young until they reach the 50's. and mature life extended from 50 to 70 years of age. In our times people are considered sufficiently mature to vote at 18, but too young to be a legislator, for instance. A healthy man at 60 can perform physical activities that an ill man of 20 could not do, and so

on. All these considerations and many others show with sufficient evidence that there are not defined absolute natural limits between human life stages. In this sense one could say that old age is more a cultural prejudice than a natural category. This does not deny that there are natural facts that justify the recognition of changes through life and that its acknowledgment matters for the individuals and for society.

One of the most general and visible natural facts is that becoming old implies losing something[2]. Capacities that were acquired during development are no longer operative or begin to decline. This biological and psychological reality is perhaps the most important source of personal suffering and of social stigmatization, and the most important challenge that individuals and society must face in order to cope with the phenomenon of aging.

In contrast with this manifest decrease in physical and psychological capabilities old people experience the permanence and even the expansion of the conscious self[3]. This crucial aspect of reality is however, not easily apparent to external inspection by others. In consequence, the inability of another persons to grasp and appreciate the richness of this internal life is probably the main contributing factor to a projection of negative feelings and of the general ominous prejudice that our society as a whole has against the elderly and that very often they have against themselves.

Medical anthropology must not only examine the universal manifestations of aging in personal life but it must study also the main variants of the human experience in the process of coping with aging; in this matter anthropology, sociology and psychology, complement and illuminate each other. In fact psychology and sociology can illustrate for us the cultural phenomenon of the denial of aging, its reality and its meaning[4].

Some metaphors applied to the understanding of human life are usually utilized for the comprehension of aging. Life can be compared to a journey, to a river, to a mission, to a project. Each of these metaphors captures some real aspect of life and is more or less pertinent to understand the particular moment that seniors live. Together they give us a comprehensive approach to ourselves.

From a narrow medical or clinical perspective, and based on the above mentioned facts, one may propose the dichotomy that geriatrics is and is not a separate branch of medicine. In a sense geriatrics is no more than the application of general adult medical principles to some particular patients. In another sense geriatrics can be seen as a specialty of its own, given that its specialist has a particular concern, qualification and experience with the specific anthropological aspect of this group of patients and in the most frequent manifestations of disease, its response to treatment and rehabilitation. One could even say that from a strictly clinical point of view the medical attention of the elderly is often a most complex, interesting and demanding challenge for skilled clinicians.

### THREE DIFFERENT MEANINGS FOR A WORD AND THREE DIFFERENT APPROACHES TO THE SAME PATIENT

#### Essential quality of life

What about quality of life and the geriatric patient? Here a philosophical (aristotelean) distinction is highly pertinent. From an ontological point of view, quality has two fundamental, indeed related, but separate meanings, substantial and accidental. In first place, the substantial qualification of every natural being is related to its essence. In that sense quality is, an all or nothing phenomenon. Natural entities are qualified as what they are in an absolute way or they are not qualified at all. Substantial qualification of a thing admits no increase or decrease, no change[5]. In this main and fundamental way elders do not differ at all in any sense from when they were young or from other people. They possess equal dignity and equal rights. This simple classical philosophical distinction is an extremely important point that a medical education impregnated with a materialistic philosophy can easily ignore. Human

life in this fundamental and primary sense cannot be considered as having more or less quality. Each human life is valuable by itself in an absolute unqualified sense.

### Accidental (objective) quality of life

In a second meaning quality refers to the accidental qualification of the substance and in that sense it can be more or less intensely qualified. Any substantial entity can be then judged as having a greater or a lesser degree of some quality[6]. In this sense we can speak of persons having a richer or a poorer material, social, cultural, artistic or spiritual life in comparison to another, and we can speculate for any of these particular aspects of human existence about the relative intensity of its ‘quality’. It appears already obvious from this perspective that quality of life becomes a multidimensional parameter, and that one could in principle consider as many different qualities of life as aspects could be discerned. If the number of significant aspects for most persons can be reduced in the whole to six or four broad categories, as proposed by the collaborative international group of the World Health Organization (WHO), nothing opposes it in principle[7].

The process by which the WHO group arrived at these four final categories or dimensions of quality of life is not devoid of interest. They started with the agreement in a conceptual definition. Quality of life was defined then as: “Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” In a second step and through work in 15 different countries they arrived at the recognition of what they called ‘facets’ of life. 24 facets were retained. In a third final step they clustered all these facets in six broad domains that were ultimately reduced to four: 1) physical health; 2) psychological; 3) social relationships; 4) environment. (WHOQOL-BREF Field Trial Version)

It is worth considering that in the proposed multidimensional definition there is a final global unitary evaluation performed by every person. The question then is: if quality of life, in this accidental sense, is highly diversified, how can it be judged in a final global unitary evaluation?

### Personal (subjective) quality of life

From a philosophical perspective one could affirm that even if highly diversified, accidental qualities of life can be hierarchically ordered, there must be one dimension of human life that is objectively the most important one for each person. This most important dimension has to do with what each person considers to be its global accomplishment as a free subject and must be the main criteria in every subjective final global unitary evaluation.

This global accomplishment that, in principle, every person seeks, even if it could share some objective common traits, is in fact, in its concrete incarnation subjectively different for everyone.

To sum up, let's assume that one of the difficulties that can be found in the discussions of quality of life is the usual confusion of these three aforementioned aspects: substantial quality of life, accidental quality of life, subjective evaluation of global achievement.

## QUALITY OF LIFE: HUMAN RIGHT OR HUMAN TASK?

A final aspect to consider, and that is quite neglected in modern analysis, is the view of global accomplishment in life as more of an ideal to pursue than a real actual concrete possibility. Not addressing this consideration is reflected in the vindictory tone that discourses on quality of life usually assume in the elderly, as if perfect quality of life could eventually be provided by society. In view of this consideration on the final accomplishment or fulfilment of life, one can understand why discussions of quality of life seem to acquire a particular actuality or urgency when considering the

well being of old people, more than when discussing it in any other age group. In fact, discussions on final achievement or accomplishment in life become much more pertinent when facing the final stages of life, and, more concretely, at the possibility of approaching the proximity of death.

How do all these considerations apply to our approach to geriatric patients? By considering quality of life in its primary and substantial meaning, it is clear that elderly people, as any patients, must be treated as a people with equal dignity and equal rights. Being intelligent, loving and free subjects, they must be treated as such. We must treat them first as intelligent people, transforming them in an active, comprehensive agent of their own process of health. Secondly, they must be loved as any other person wishes to be loved, and this love for others must always be the main reason for treating patients of any age. Lastly they must be treated as free agents by respecting their autonomy, promoting it and aiding in effectively maintaining this autonomy[8].

In considering quality of life in its accidental secondary meaning, the medical approach to old people must be faced seriously as an interesting and demanding professional challenge. This medical approach must consider not only the so called biomedical dimensions of health care but a more integrative interdisciplinary approach guided and ordered by a realistic medical anthropology and comprehensive bioethics.

Finally when considering the subjective evaluation of accomplishment and fulfillment, we think that geriatric medicine cannot reduce itself in its social discourse to a kind of human rights activism but that it must open its discourse to integrate wider and more intimate dimensions of human accomplishment. If a change of focus in the discourse could be achieved, then aging people in our societies could be seen by others and by themselves not as a burden for society but as the bearers of wisdom and the witnesses a better life.

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[1] CELADE (Centro Latinoamericano y Caribeño de Demografía), Los Adultos Mayores en América Latina y el Caribe: Datos e Indicadores Boletín Informativo con ocasión de la II Asamblea Mundial de Naciones Unidas sobre el Envejecimiento, Madrid, 2002

[2] LOLAS F., Escritos sobre vejez, envejecimiento y muerte, Iquique, Ediciones Campus/Universidad Arturo Prat, 2002. I owe some general interesting anthropological observations to this book.

[3] Some authors have emphasized that decline is not the sole perspective by which aging must be envisaged. Others are: Change, Development, Maturing. Cf. VAILLANT GE MUKAMAL K, Successful Aging, Am J Psychiatry 2001, 158: 839-849.

[4] ZEGERS B, Psicología del envejecimiento, Santiago de Chile: Documento Docente 36 Universidad de los Andes, 2002.

[5] MILLÁN PUELLES A., Léxico Filosófico, Madrid: Rialp, 2002. pp.195-204.

[6] Ib.

[7] WORLD HEALTH ORGANIZATION, WHOQOL-100 and WHOQOL-BREF instruments, <http://www.who.int/evidence/assessment-instruments/qol/>

[8] This general consideration must be adapted for cases in which dependence or autonomy is affected.

## **PATRICIO VENTURA-JUNCÁ**

### **QUALITY OF LIFE IN NEWBORN MEDICINE**

#### **QUALITY OF LIFE: AN IMPORTANT AND COMPLEX TOPIC IN NEONATAL MEDICINE**

##### **The concept of quality of life**

This topic has already been addressed by previous speakers. I am going to approach it from the perspective of a neonatologist engaged with its philosophical dimension and, specifically, in the context of its ethical clinical implications for my field of specialty. For the purpose of this paper, it is necessary at the outset to establish the fact that the simple identification of quality of life with an ontological evaluation of the value of a person is not acceptable. The intrinsic value of a human being does not depend on his qualities or capacity to express himself. This first anthropological distinction is indispensable for a correct approach to the problem and has major importance for clinical ethical decisions in neonatology. On the one hand, quality of life should be understood primarily as the individual's overall appraisal of their situation and subjective sense of well being. On the other hand, there are many objective conditions that will influence this subjective appreciation. One of these is health. The definition of health by the World Health Organization (WHO)[1] is quiet similar to some definitions of quality of life. But although health is undoubtedly a very important factor, there are nonmedical aspects of life, like family, work, housing, education and environmental factors that play a role in the subjective sense of well being, hence on quality of life. On the basis of these facts, we think it is more appropriate to talk about Health Related Quality of Life (HRQL) understood as the impact of disease and its consequences (impairments and disabilities) on quality of life.[2]

##### **The importance of the neonatal period for quality of life**

The neonatal period is the most vulnerable period of human life with respect to the risk of dying and the occurrence of developmental impairments of different types and degree which affect the rest of the person's life. That is why neonatal medicine has as its main objective not only survival, but intact survival. What characterizes the neonatal period is the transition from intra-uterine to extra-uterine life.[3] This is a major physiological event in which practically all systems and organs undergo a significant change in order to adapt themselves to the new requirements of extra-uterine life. In some systems this adaptation must be accomplished within a few minutes to guarantee the survival and indemnity of the newborn babies. The most dramatic example is cardiopulmonary adaptation. Simply stated, placental respiration ceases at the moment of birth, and pulmonary respiration must immediately begin functioning in its stead. This presupposes a drastic change in circulation and heart function which must take place in a very brief span of time. This crucial physiological adaptation can be altered by different causes and result in death or hypoxic injury in the newborn baby. Something similar occurs with other organs and systems, but without the same urgency and priority that are essential for cardiopulmonary adaptation. Major causes that affect the physiology of adaptation are: prematurity, perinatal hypoxia, congenital malformation and perinatal infections. Many of these pathologies can be prevented or anticipated with good prenatal care. Hence, a comprehensive medical approach to the prevention of factors that can affect quality of life begins with good prenatal care. This must be considered a medical and ethical priority in perinatal medicine. Neonatal medicine then follows up and tries to anticipate and supervise the correct process of this adaptation, making the opportune and necessary interventions.

## Quality of life: a complex topic in neonatal medicine

Newborn babies by nature are incapable of evaluating their quality of life and hence of expressing their preferences, except some responses to their immediate physical or psychological environment, like screaming and moving. But a rational subjective evaluation of their real or potential future quality of life basically cannot be made. What can be evaluated by them directly through follow up studies over a period of several years is the risk of neurodevelopmental and other impairments which condition the HRQL. Studies that try to evaluate, above and beyond this, HRQL in later life, however, have not been validated, especially when the aim is to use this parameter to evaluate the quality of neonatal medicine as such. Dr. M Hack, a well known researcher in this area, recognizes that: "Disabled persons might rate their quality of life as good or acceptable: however, their impairment and its resulting disability is a poor outcome for neonatal intensive care." [4].

A second aspect that complicates the evaluation of a future quality of life is the great plasticity of infants and their capacity to recuperate from injuries which occur during the newborn period.

A third factor to take into consideration is the fact that the evaluation of the quality of development of a determined group of infants years after their neonatal hospitalization is related to the care they received at the time they were born, but not to the care that neonates are receiving today. This complicates the prudential judgments made in evaluating the proportionality of certain treatments in complex situations.

## Quality of life and the parents

The birth of a child is a major event and probably one of the more profound experiences in human life. The child is awaited with great hope and joy, but also with a certain degree of uncertainty. Is the child normal? Does it have any problem? The mother has a special sensibility for bonding with her child during the first hours and days after the child is born. [5] The high sensitivity of the mother during this period must be taken into consideration by the health team when she is to be involved in any deliberation concerning problems of her child. Parents are profoundly affected by any problem of their newborn baby. They are very concerned not only with their child's survival, but also with possible impairments that can affect the future life of their child. Prolonged stays of the infant in a neonatal intensive care unit very frequently cause extreme stress for the parents. The involvement of the parents in making weighty decisions with respect to the course of treatment is emotionally and psychologically very challenging and many times agonizing due to the complexity of some treatments and their risks and the difficulty of understanding all the factors at stake.

## Quality of life and health/ethical issues in newborn medicine

The ethical problems related to quality of life are similar everywhere in some aspects but differ in others depending on the development and resources of a country and on its prevailing health situation and priorities. The causes and the rate of neonatal mortality and the factors conditioning developmental impairments are significantly different in developed and wealthy countries than those we find in poor and lesser developed countries. Subsequently, the health and ethical challenges are distinct. For this reason it is compelling to address this topic separately in each of the two cases. We will turn our attention first to the former.

## NEONATAL HEALTH AND QUALITY OF LIFE IN DEVELOPED COUNTRIES

### The impact of intensive care

Impressive changes in neonatal care began taking place in the decades of the sixties and seventies.[6] The traditional care of the newborn and premature infant, which consisted mainly in temperature control, prevention of infections and careful oral feeding, gave place to a complex and aggressive form of intervention which included a permanent monitoring of vital signs, the frequent correction of vital parameters and complex treatment that can replace the function of vital systems, by a very specialized health team of nurses, respiratory therapists, and doctors. Many of the immature functions of the premature infants could temporarily be replaced by artificial ventilation, nutrition and fluid administration. All of the progress which the technical advances of the space era brought in terms of monitoring the vital signs of the astronauts[7] was introduced into the ordinary care of premature infants. Astronauts are subjected to a different atmosphere in outer space for which they are physiologically not prepared. In an analogous way, the premature infants enter the extra-uterine world without the physiological maturation of many of their vital functions and hence are not prepared for the transition they have to make.

The result of the implementation of intensive care was an impressive improvement in neonatal survival and in the prevention of known causes of sensory and neurodevelopment impairments.[8],[9] In Chile, a country of a medium level of development, at the Catholic University Hospital in Santiago, the advances made over decades in developed countries were implemented in the years 1977-78.[10] The results in terms of lowering neonatal mortality show the great progress that was made in this area of medicine (Table 1). Resuscitation at birth and the adequate control of oxygenation and ventilation diminished the incidence of hypoxic ischaemic encephalopathy and the resulting neurodevelopmental impairments, as well as the incidence of retrolental fibroplasia (blindness that resulted from high oxygen tension in arterial blood) and cerebral palsy. This progress was first reflected in full term babies and low birth weight infants (1500-2500g) and very low birth weight infants (VLBW) ranging from 1000-1500g (Table 2). During these decades, however the results of treating extremely low birth weight infants (ELBW <1000g) were not so impressive and there were doubts about the real benefit of intensive care in these infants. In fact, in our unit as well as in others, the decision was made during the first years not to implement mechanical ventilation in the treatment of these babies. The decision was made in consideration of the scarcity of resources and of the judgment of proportionality of the treatments.

In the following decades major progress was made in the treatment of ELBW infants in terms of survival and long-term prognosis. Encouraged by these results, major efforts were then undertaken to treat infants of < 1000g and < 750g. In these cases, the result obtained in bigger babies could not be matched. This was especially true in the instance of infants of < 750g (3). Today, about 65% of intensive care beds are occupied by infants of < 1000g. Their stay is long and unstable with many complications of different types. The cost of treating these infants increases significantly (Table 4).

### Clinical ethical problems in neonatal intensive care

The major ethical problem in NICU, which has existed since its very beginning, is the prudential judgment deciding whether or not to withhold or withdraw treatment. The ethical justification for these difficult and complex decisions has been expressed in an overly simplistic manner: aligning, on the one side, those who invoke the principle of the sanctity of life in order to continue treatments under all costs and circumstances, and, on the other side, those who give prioritization to the principle of the “quality of life” and intend to decide lightly not only when and whether continuing extraordinary means of life support and treatment are obligatory, but also when, according to their view, even ordinary

means of life support (such as feeding) should be stopped[11][12] Somewhere in between these two positions is a third one that prioritizes the preference of the parents, arguing that they are most suited to choose a treatment plan that best protects the child's interest.

A third approach or aspect of the problem is who should make these complex decisions: hospital administrator, doctors, nurses, or parents. There is a widely noticeable shift from laying all burden for these decisions to the medical staff towards a position that prioritizes the preference of the parents, arguing that they are most suited to chose the treatment plan that best protects the child's interest. As soon as this position is interpreted not as the consequence of a trust in a superior sensitivity of parents to make the correct ethical decisions in the best interest of their children or of their special right over them, but as a liberty of deciding even against the perennial human goods and for intrinsically wrong acts, the inordinate weight given to parental decisions is an outgrowth of an ethical theory that absolutizes the principle of autonomy as the sufficient justification for moral decisions.[13]

Not only the legitimate role of parental decisions, however, but also the unchangeable morally relevant goods must be respected in all situations and the ethical imperatives that result from them and are valid under all circumstances are sometimes understood in different ways. For example, some pediatricians have understood the "principle of the sanctity of life" to be equivalent to an obligation to save or prolong life at all costs and under all circumstances.[14] Others pit against the "principle of the sanctity of life" that of quality of life, maintaining that major handicaps and impairments result in a quality of life that is meaningless and thus devoid of any value for the child. Direct killing, would then be justified by a quality of life judgment.[15] This position was defended in the Baby Doe cases. A third position that tends to absolutize the preference of parents as if they would have the right in certain cases to either request the limitation of proportionate therapies or the implementation of disproportionate and even futile life sustaining treatments.

The prudential judgments of proportionality of treatment are sometimes understood in light of the ethics of proportionalism which argues that there are no absolute moral values, which basically means that under certain circumstances a proportional judgment could end in a decision that could justify the direct killing of an infant or the withholding of such basic care as nutrition and hydration. This ethical position is very clearly dealt with and rejected in *Veritatis Splendor*: "Consequently, without in the least denying the influence on morality exercised by circumstances and especially by intentions, the Church teaches that "there exist acts which per se and in themselves, independently of circumstances, are always seriously wrong by reason of their object." [16]

A major issue at stake here is the correct understanding of the difference between "killing and letting die." Utilitarianism considers only the consequence of the action and hence makes no distinction between the two as Beauchamp and Childress, for instance, affirm "To assert (as we do) that killing is not morally different than allowing to die is simply to say that correct labeling of an act as 'killing' or as 'letting die' does nothing to determine if one form of action is better or worse, or more or less justified, than the other" [17]

The traditional and wise teaching of the Church Magisterium, if correctly understood, can enlighten the three positions mentioned above by distinguishing between ordinary and extraordinary and proportional and disproportional means and by recognizing the dignity of human persons and their endowment with basic inalienable rights. This sheds light on a correct interpretation of the concept of sanctity of life and its role in clinical ethical decisions, and on the place that HRQL has in them.

[18],[19],[20],[21],[22]. HRQL is important, but quality of life can never justified any action or omission intended for direct killing. Pope John Paul II states at this respect: "to admit that decisions regarding man's life can be based on the external acknowledgment of its quality, is the same as acknowledging that increasing and decreasing levels of quality of life, and therefore of human dignity, can be attributed from an external perspective to any subject, thus introducing into social relations a discriminatory and eugenic principle." [23]

A further contribution to the clarification of these complex ethical issues is the brilliant analysis that St Tomas Aquinas makes of the morality of human acts, distinguishing between intention, object and ends.[24] In his analysis, he also considers the ethical importance of the consequences of the act, when these are predictable.[25] This is what we are continually trying to investigate in medicine with follow up studies and statistics. It is interesting to look at Table 3 which suggests “that increasingly aggressive approach to extremely low birth weight infants, those less than 750g, resulted in both a prolongation of the dying process and an increase in the incidence of moderate to severe handicaps.”[26]

How small too small, how much is too much

This expression indicates the great concern of the neonatal community with regard to where the limit of viability is, and where treatments begin to be extraordinary or disproportionate and in some cases futile.[27],[28],[29],[30]. Based on the results of follow up studies and on the mortality of premature babies,[31],[32],[33] it is possible to develop a basic approach related to the weight and gestational age of the infant for the ethical justification in limiting treatment: Newborns > 1000g in general show a good outcome in terms of lower rates mortality and neurodevelopmental impairments. Newborns between 500 and 1000g frequently call for complex decisions regarding withholding or withdrawing treatments. Newborns of < 23 weeks of gestational age and < 500g have a risk of nearly 100% of mortality or major handicaps.

But statistical information only provides a baseline criteria for the outcome based on weight and gestational age. This must be complemented with an individualized prognostic strategy considering other clinical data. In all cases there is a variable uncertainty of prognosis and also there can be more than one ethically justified possible choice.

What was said above about the aspects in which parental ethical judgment about their newborn children may be wiser and about the ways in which it is more vulnerable in no case prevents the need and obligation that, whenever the availability of parents and their mental and psychical state and other factors make it possible, neonatologists and other health care team members must discuss this information with the family. Experience demonstrates how difficult it is for parents in some cases to understand the uncertainty of the prognosis and to make a decision by themselves. But in general, parents, whether of term or extremely premature children, are more in favor of intervening to save the infant irrespective of its weight or condition at birth than are health care professionals. The opinion and the values of the doctor in charge will have a great influence on the parents. “It therefore is imperative that there be a joint decision making, combining the knowledge of the physician with the wishes of the parents”.[34]

## NEONATAL HEALTH AND QUALITY OF LIFE IN DEVELOPING COUNTRIES

Priorities in health care in developing countries

The situation in developing countries puts the relation of quality of life and neonatal medicine in a global perspective. Neonatal intensive care is a very sophisticated and expensive form of medical care. The average cost of medical care during the first year of life for premature babies < 1500g ranges from US 58.000 to US 272.900 (Table 4). These type of care is unaffordable for poor countries. There is a well known relation between per capita income and health indicators, especially of infant mortality (Table 5). Countries with low income per capita have other priorities in infant health care. “Vast number of infants and newborn babies die each year from malnutrition, infection and other preventable tragedies.”[35],[36] Also neurodevelopmental impairment may result from these conditions. In addition, as stated earlier in this paper, quality of life is also influenced by many other factors such as family,

education, housing, nutrition, and employment of parents, which are critical in developing countries. In recent decades “millions of infants were saved by nutritional and oral rehydration efforts in eastern Africa.” At the same time, there are still millions of children worldwide not immunized against measles, which is a major cause of death and morbidity in infants.[37]

World inequalities between countries (Table 5)[38] and in different sectors in any given country pose relevant ethical problems of solidarity, on the background of which the imperative of a reorientation of global economics, ranging from military defense to education, housing and food production, becomes clear. The complex ethical clinical decisions of modern neonatal intensive care related to limitation of treatments are irrelevant in these countries and practically speaking do not arise.

### When to begin neonatal intensive care in a developing country

There are many other factors in these countries that condition quality of life which are much more cost efficient in terms of improving health. These factors necessarily should be dealt with first. As is stated by the World Health Organization: “A substantial proportion of fetal and neonatal morbidity and mortality in developing countries could be prevented through wider implementation of proven, affordable intervention during pregnancy, delivery and early postpartum and neonatal periods.”[39] Then, only after these measures have been implemented, one can consider the implementation of more complex medical care. Neonatal intensive care is a very expensive kind of medical service. Hence, the question regarding the ethical justification and the rationality of introducing this kind of medical service in a given area is extremely important to evaluate, especially in the context of developing countries. Investments made in NICU may prevent the possibility of investing in other highly cost-efficient areas of health care, such as primary care, good prenatal care, vaccination programs, nutrition etc. At this respect the Pontifical Council Cor Unum states: “Is it legitimate to use resources of refined medical technique for the benefit of only one patient, while others are still not receiving the most elementary treatment? If certain persons believe that such a question is «going against progress». Christians at least, should bear it in mind in their evaluation”. [40] Experience demonstrates that much can be done to improve neonatal health with the general measures previously delineated. Postneonatal mortality (28 days to 1 year) is much more dependent on sanitary conditions and primary care, whereas neonatal mortality is more directly connected with biological factors as is recognized by the World Health Organization: “It is commonly accepted that neonatal deaths are more related with biological factors and perinatal care, postneonatal mortality is predominantly dependent with socioeconomic factors and of the aggressiveness of the environment.”[41] In general, when infant mortality has been lowered to a rate of 25 to 300/00, it is necessary to consider the rationality of introducing neonatal intensive care.

### The just distribution and the rational use of neonatal health resources

A comprehensive approach to good neonatal care, and hence its influence on quality of life, must consider the just distribution of resources and a rational use of them. Although ‘distribution’ and ‘rational use’ of resources are two concepts that are closely connected to each other, they cannot be identified with each other.[42] As a matter of fact, health care indicators are related to the per capita income of a country, but this correlation is not a linear one. For example, the countries with a higher income do not necessarily have the lowest infant mortality, as is visualized in Table 5. This fact can be explained by an uneven distribution of medical resources among the different socioeconomic levels of a given population, by an incorrect estimation of the priority of the health care problems within this population, or by an inefficient organization of these resources. Thus, neither the amount of money assigned for health care, nor other health care resources, such as the number of physicians in a country, have always a linear correlation with the health care indicators. In this context, the importance of the

regionalization of perinatal care, as a basic aspect of the rational utilization of resources, must be emphasized. Regionalization consists in the organization of a national network of progressive health care in a given geographical area with different levels of increasingly complex medical attention (levels I-II-III). All these levels need to be efficiently interconnected so that the newborn can receive expedient care according to his risk status. The NICU resources have to be concentrated in the more complex facility, level III, to secure the space, personnel, and equipment required to treat all the critically ill babies of this particular region of the country.

The regional health care organization has proven to be highly cost-efficient, not only from an economical point of view but also in terms of the quality of the services offered.[43][44] By securing a sufficient number of patients, the health personnel have the possibility of remaining active in their fields, which allows them to maintain their expertise and skills, and to accumulate important clinical experience that will benefit future patients. This experience obtained from developed countries is indispensable to be taken into account in poorer countries. This kind of impact of regionalization is illustrated in Table 6, which show a clear difference in the survival rates of premature babies according to their birth weight and level of treatment (level I, II, III).[45] One must assume, furthermore, that the regionalization of NICU will have an important impact in HRQL of neonates.

## THE FAMILY: AN INTEGRATING AXIS FOR QUALITY OF LIFE

It is recognized, as we stated at the beginning, that there are objective and subjective components of the quality of life. Newborns and children are dependent persons. The most relevant challenge is how to best help them so that they can develop in accordance with what constitutes authentic human growth. This is true not only for the normal child, but particularly for those children with some type of impairment. In this context, the family plays a central and integrative role, especially in giving children an experience of the more fundamental aspects that contribute to a life with meaning and fulfillment. A comprehensive approach to the prevailing concern of quality of life in today's world must recognize the central role of the family and hence not shun any efforts to support the structure and conditions that permits the family to accomplish its indispensable task in society and specifically in the development of any child. This is valid for all social settings independent of economic and other factors. I would like to conclude this text with a quotation from Pope John Paul II: "The first and fundamental structure for "human ecology" is the family, in which man receives his first formative ideas about truth and goodness, and learns what it means to love and to be loved, and thus what it actually means to be a person. Here we mean the family founded on marriage, in which the mutual gift of self by husband and wife creates an environment in which children can be born and develop their potentialities, become aware of their dignity and prepare to face their unique and individual destiny"[46]

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## **WANDA POLTAWSKA**

### **MENTAL HANDICAP AND THE QUALITY OF LIFE**

#### **1. Divine Genealogy**

The quality of life is determined by its origin, and its value may be estimated differently according to one's view of the source of life. The basic question about human life is, then: Where do we come from? Who are we? And this is not as much a problem of knowledge, as an object of faith. This question has been answered by our faith in the existence of God the Creator.

The truth about the divine provenance of human persons discloses at once the value of men and women as created in the divine image. This truth applies to all people, to all times and to all races. There are no other people on earth than those created by God, people who always remain in a particular relation to their Creator.

#### **2. The Sanctity of Human Life**

A human being as created by God in His image is destined for immortality and for eternal participation in the divine life, for eternal happiness, for heaven.

This is the decisive factor which determines the sanctity – inviolability – of human life. God bestows upon man life and existence. He calls him or her to life and existence – He calls him through this earthly existence to eternal life.

#### **3. Life as Task**

The gift of life becomes a task for the person bestowed with it – the sanctity of life should be complemented by the sanctity of the living person.

There exists an easily understood temptation to value a human life by the observable sanctity of the person or by the lack of this sanctity. The basis of this valuation is not the divine provenience of human life but an estimation of human actions and their consequences.

Human actions, because of the great gift of freedom, of free will, which is bestowed upon the human being, may become “inhuman”, as we may easily perceive in the history of mankind.

#### **4. The Sanctity of the Human Person as the Goal of Life**

Created for heaven, a man or woman does not automatically pass into the eternal dimension of felicity on the strength of his or her very provenance, but they accede to it by realizing the gifts which they have received. A person should “fulfill” herself or himself in life, to fulfill his or her vocation.

Maturation for sanctity – for plenitude

To perceive the objective value of human life as a gift from God one just needs to realize one's own identity. But we acquire this knowledge gradually while developing, in the course of our life and in dependence upon the circumstances of this life, upon our capacity of understanding. Here lies the responsibility of all educators. People who have succeeded to fully develop themselves are responsible for this realization of their own identity by people whom they may influence. Full maturity – this is just an attained sanctity.

## 5. Mental Illness – an Obstacle to Development

Secondary psycho-biological factors may be – and often are – an obstacle to a correct development of a person –but, nevertheless, those factors do not annul the basic gift of the divine provenance nor the goal of creation – immortality. A human being is always human irrespective of the stage of his or her physical or mental development; he may be ill or handicapped, but his humanity – his similarity to God never ceases to exist. But a human person who willfully rejects God's plan for his life and destroys the values bestowed upon him denies his own humanity.

### 5.1 Mental Diseases

Some mental diseases advance slowly and the nearest environment may not be aware of their existence. Sometimes the family accuses the diseased person of ill will or bad character. Some psychoses cause excessive incitement and aggression which may become dangerous to the environment. Typical for mental diseases is the unawareness of the disease, lack of criticism.

The behaviour of the diseased person often causes tension in the family who, instead of seeking help of a physician, demands from him or her to behave better; and, even when the family realizes that the person is mentally ill and, therefore, irresponsible, there arise difficulties in therapy brought about by his or her resistance against any treatment while he regards himself as totally sane.

A number of mental diseases demands hospitalization of the patient, hospitalization which may be very difficult to secure because of the constitutionally guaranteed personal freedom. In Poland, e.g. the legislation does not allow to put a patient in a closed establishment without his consent, and the patient very often does not want to give this consent. To lock a patient up is only allowed when he or she is dangerous to himself or herself or to the environment.

Families burdened with a mentally diseased person are in internal conflict and, in spite of the best will of their members, they often do not succeed in keeping concord in the family. Such diseases bring about disintegration of marriages — because to endure the presence of a mentally diseased wife or husband may surpass the endurance of the spouse. In particular, when the diseased party is the woman. It comes mostly to divorce because, in general, men tolerate diseased wives with greater difficulty than wives their ill husbands.

Mental disease does not abolish the validity of the sacrament if it arises after the contraction of the marriage, and therefore it is well-advised to be careful when contracting marriage; but mental illness cancels the ability to contract a valid marriage and also to holy orders.

Mental disorders may arise in any age and the statistical data show that they grow in number. The care of the patients demands much patience and generosity, in particular as those diseases are, in general, chronic and often incurable and may demand isolation of the patient for many months or years.

The situation in which a member of the family becomes mentally ill demands from other members of this family, in the first place, a deep understanding of the sense of suffering. Moreover, chronic diseases demand big financial means — the mental patients take for months or years medicines which may exceed the financial means of the family. In better organized countries they get assistance from the State or from social organizations.

### 5.2 Mental Deficiency

Somewhat different is the fate of persons who, in consequence of the influence of different noxious agents, have been hindered in their personal development. Public opinion often discriminates those persons, in particular when their deficiency is deep and it is impossible to establish a proper contact with them. The life of the most handicapped persons is usually short, but a lesser inhibition does not endanger the life of the patient, who, nevertheless, is not self-reliant and needs care all his life long. The appearance of such a child in the family is always a trial for the parents and a test of the standard

of the society. But the necessity to care for infirm persons releases best human qualities — readiness to take care of other people, compassion, goodwill.

We may take as an example the life of professor Jerome Lejeune who, after having discovered one of the factors which cause mental handicap, did not limit himself to scientific work but initiated an organization which cares for those patients. Accurate care, goodwill often brings about positive change and development. An underdeveloped, neglected child under solicitous care often develops various talents. More and more medical reports give us hope for the healing of at least part of those troubles.

### 5.3 The Old Age

Medicine did not manage to discover the mystery of growing old. Although many diseases of the old age have been described, we cannot forecast the course of a person's old age. The family is sometimes surprised by the extent of change which occurs in a member who grows old — the change which may go as far as losing the awareness of one's identity.

There may be a physiological and a pathological growing old. The pathology of the old age has brought about the development of gerontology, but this does not solve the problem — a most accurate description of changes in the organism does not eliminate their causes. Old age cannot be cured, although we can cure an old person. But old age inevitably tends to death.

The care of old people became nowadays a social, and even a political problem. Here arises the problem of financial means — and people ask the fundamental question whether it is not out of place to give medical attendance to the aged. Such attitude leads to the more and more widespread acceptance of euthanasia. The aged person does not promise recovery, cannot be healed, is not going to be productive — and becomes a burden to the society. The awareness of this situation sometimes leads to suicides of old people who, badly treated, have the feeling of being useless.

## 6. Family and Society in Front of the Handicapped

A person who is irresponsible because of an illness is — or, at least, may be — innocent, even though his or her actions are objectionable by the normal standards. Thus there arises a difficult problem of protecting his or her family and the society from the consequences of those actions. It is a situation in which the action should be condemned while its doer should be protected. To secure this protection is the task of laws and social institutions. Isolated homes for those patients are organized.

The value of a human being is determined by his or her actions and responsibility for those actions. A person who for reasons beyond his control is unable to correctly appreciate his actions and his omissions is not responsible for them; nevertheless he or she is called to life by God himself and should live as long as the Creator wants him or her to live. (John Paul II said during a funeral of his friend: "A human person dies always at the moment which is best for him, because God is good"). The life of a human being, its beginning and its end are in the hands of the Creator — when we try to manipulate human conception or human death we transgress our authority, we rebel against the Creator.

However handicapped, a human being bestowed with life has a right — and even is, in a way, obliged — to live; and his presence influences his milieu. The helplessness of children and of ill persons compel the society to help them.

During the first debate in the French Parliament on the legalization of abortion, the first group which protested against such legalization was the World Organization of Parents of Handicapped Children; they argued that a handicapped child inflicts less pain than well-developed children who fall short of the hopes which were pinned on them; and, secondly, they stressed that the presence of such persons in the society keeps the mankind in the attitude of humanity, because it compels it to altruism, those persons not being able to pay for their care. The ill persons demand unselfish actions and without them the mankind might become cruel in its egoism.

Christ defines the Christian attitude towards ill persons by identifying himself with them: “as often as you did it for one of my least brothers, you did it for me” (Mt 26,40).

The existence of people in need appeals for help and this help is accomplished as well by single persons as by different Church communities. Obviously, the care for ill persons implies material expenses and this easily brings about tendencies towards elimination of those persons, tendencies which now prevail in the world (tendency to legalize euthanasia which was realized in large in Hitler’s program of the elimination of patients of psychiatric hospitals). There reigns a tendency to an egoistic and ruthless utilitarianism which appreciates a human being exclusively according to his or her ability to produce material goods; the unproductive persons are being relegated to the margin of society.

## 7. Moral Appreciation

No illness is sin, although some illnesses are consequences of a transgression. Each sin may be pardoned owing to the merciful God’s love, but its consequences such as a biologically conditioned illness are not subject to this sacramental annihilation and belong to the fate of the person involved – a fate which demands, which compels not only the very ill person but also people from his environment to bear hardships.

When an illness brings hardships, and this is particularly difficult in the case of mentally ill persons because the symptoms of this sort of disease may provoke painful consequences for the environment, e.g. the loss of contact with a loved person, aggression etc. This brings a particularly difficult situation about, a situation in which the immediate environment of the patient needs help. Thus, the real humanity of a society is in a way put to the test by the necessity of organizing the care of diseased persons in such a way that their and their families’ fate could be bearable.

Not being sin, lower intellectual capacity and mental illness are no obstacles for a person to confess or to go to communion, provided that she or he is able to understand the nature of sacraments.

## 8. Concluding Remarks

Objectively, the life of every human being has the same value, the sanctity of human life does not depend on the state of his or her body. But, in everyday life, it may be difficult to perceive this dimension of reality because there exists a tendency to hastily assess an illness as guilt and sin. The patients are often accused of the symptoms which are not dependent on them, which are not their guilt, but their difficult fate. Then we may ask: why? Why me? John Paul II said once: “The suffering of the innocent is the greatest mystery of God, one cannot understand it, one has just to accept it”.

All those persons, irrespective of the type of handicap, are a challenge to the society, in particular to the Christian society — for it is precisely with them that Christ identifies himself, their presence releases genuine human behaviour. The value of a man can be assessed after their attitude towards the diseased, the old, the disabled.

John Paul II wrote:

...the suffering person... in the spiritual dimension of the work of Redemption... is serving , like Christ, the salvation of his brothers and sisters. Therefore, he is carrying out an irreplaceable service... And so the Church sees in all Christ’s suffering brothers and sisters as it were a multiple subject of His supernatural power... the springs of divine power gush forth precisely in the midst of human weakness. Those who share in the sufferings of Christ preserve in their own sufferings a very special particle of the infinite treasure of the world’s Redemption, and can share this treasure with others.[1]

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[1] Salvifici doloris, Nr 27.

## **JOANNES. LELKENS**

### **QUALITY OF LIFE IN CANCER PATIENTS WITH UNFAVOURABLE PROGNOSIS**

#### **INTRODUCTION**

The expression 'quality of life' can already be found in the socio-political literature of the 1950s. It was president Lyndon Johnson of the U.S.A. who in a speech in 1964, stated that the goals he was pursuing could not be evaluated in terms of money but had to be assessed in terms of "quality of life"[1]. From that time onwards the notion 'quality of life' was found in innumerable writings and programs.

The term 'quality of life' lends itself to more than one interpretation and when used, this term is not always meaning the same since it depends on the context in which the quality of life consideration takes place.

Sometimes all kinds of these considerations are rejected as being morally inadmissible, irrespective of their content.

Speaking about quality of life hasn't been specific for medicine. As already mentioned, in the 1950s it was chiefly a notion of cultural and social criticism: quality of life versus a materialistic human existence. The term 'quality of life' was used to cover the notion quality of existence or well-being and even the quality of being a human person. All the definitions of quality of life mentioned are present in contemporary medicine.

After this introduction my lecture will successively deal with:

1. The meaning of 'quality of life'
2. The measurement of quality of life
3. Quality of life in cancer patients
4. The usefulness of measuring quality of life
5. Discussion and conclusions

#### **1. The meaning of quality of life**

It is still impossible to produce an adequate definition of life and thus this is also the case with regard to the definition of quality of life. As it is basically impossible to pronounce a value judgement on the quality of life itself as an intrinsic value of the human person, people have chosen to determine the quality of an expression of life and in particular the quality of somebody's state of health or well-being. 'Health' in contrast with 'life' can be defined. From a purely biological point of view we can say that a healthy person is a coordinated and integrated entity with an intact blood circulation, respiratory system and central nervous system. But this is not man in his totality.

Health as defined by the World Health Organization (WHO) is a state of physical, mental and social well-being and not merely the absence of disease or infirmity.

But even this definition is still incomplete and vague because 'well-being' is a rather subjective factor and hence it is impossible to define this state exactly.

Nevertheless, nowadays quality of life is being defined and measured as the functioning of persons in the physical, psychological and social field (or dimension), and its subjective evaluation[2].

Although the notion 'measurement of quality of life' is maintained, only the quality of expressions of life are measured and not of life itself. It would, therefore, be preferable to speak about measurement of Health Related Quality of Life (HRQoL).

What consequences the results of these measurements may have for life itself, is quite a different matter especially if the quality found is very low.

Thus, health related quality of life consists of objective as well as subjective aspects. Objective aspects deal with the fact that someone has certain limitations as a consequence of his health. Subjective aspects tell something about the judgement of the person regarding his health and his limitations: it isn't, for instance, only about whether somebody cannot climb the stairs, but also what he thinks about it.

## 2. The measurement of quality of life

Quality of life is multidimensional and contains a certain number of dimensions or fields. There are three main dimensions: a physical, a psychological and a social one. Dimensions can be subdivided into items such as, for instance, an item of the physical dimension which is called physical functioning and, among other things, contains questions about the possibilities of daily activities, like climbing stairs, shopping etc..

The psychological or emotional dimension has relations with psychic complaints such as feelings of fear or depression.

The social dimension can be characterized as the degree in which an illness reduces the possibility to play social roles, such as functioning in the family, work, circle of friends or time off.

Aspects not directly related to illness and health care are left aside.

A consequence of the increasing importance of the scientific research in healthcare, was the development of a large range of instruments-also being called constructs -to measure notions such as quality of life.

We'll mention only one of the oldest score lists and two frequently used nowadays.

### The Karnofsky Index

One of the first was the Karnofsky Index (see table 1.) developed by David Karnofsky and Joseph Burchenal in 1947.

It is an 'activity' index as an attempt to measure the outcome of cancer treatment: the patient's physical state, performance and prognosis after a therapeutic procedure. This index is also appropriate for determining a patient's suitability for therapy.

Like all the present instruments the Karnofsky Index consists of a number of questions to be answered by the patient. Dependent on the answers, the quality of life will be expressed as a percentage of a normal (100%) state of health.

Today's information about quality of life is based on studies in which generic measuring instruments are used, that is to say: instruments which contain questions related to physical, psychological and social functioning and are not confined to a specific disease.

The most widely used generic instruments of this kind are: The Medical Outcomes Study and the EuroQol.

### The Medical Outcomes Study

The Medical Outcomes Study (see table 2.) is a 36-Item Short Form Health Survey (abbreviated SF-36) and may serve as an example of the way quality of life can be determined today.

SF-36 has been developed in the U.S.A. and is a multidimensional instrument consisting of 8 dimensions: physical functioning, role limitations by physical problems, physical pain, experience of health, vitality, social functioning, role limitations by psychological (emotional) problems, and mental health.

Each dimension contains one or more items which are related to and covered by that dimension. One (extra) item is asking about changes of health. In all there are 36 items and hence the name SF-36.

Questions to be answered by the patient are related to these items. For instance, the dimension 'mental health' contains questions about feelings of depression and nervousness.

The SF-36 is significantly superior to a large number of other instruments as it covers the whole field of health and is not directed at specific illnesses or handicaps. The scores on the items are summarized by dimension and transformed to a scale from 0 to 100. The higher the score, the better the state of health and thus the quality of life.

The dimension 'physical functioning' has 10 items and to each item a list of questions, related to that item, has been attached. One of these items is called 'daily activities'.

For example, a list of questions related to the item 'daily activities' of the important dimension 'physical functioning' (see table 3.).

### The EuroQol-5D

The EuroQol-5D, abbreviated EQ-5D was developed In 1989 by the EuroQol-group[3] and is a generic questionnaire (see table 4.). The list of questions may be answered by anybody, irrespective of age, healthy or ill, at home or in hospital. Thus it is a non-disease specific instrument for describing and valuing health related quality of life. In contrast with SF-36, EQ-5D contains only 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Related to each dimension three simple questions of three different levels are asked: level one is no problem, level two is some or moderate problems and three is unable or extreme problems. Patients are asked to assess their own health by way of these descriptive statements and no doctor is needed to assist them.

The scores are not added together, but act as a description of a health state, e.g. state 22213 (see table 5.) indicates some problems with mobility, selfcare and usual activities, no pain or discomfort but extremely anxious or depressed.

In most clinical uses patients are also asked to assess their health state on a visual analogue scale (EQVAS, see fig. 1.).

The respondent has to draw a line from the box marked "your own health state today" to the appropriate point on the "thermometer".

Answering the questions is relatively undemanding and takes only a few minutes. Moreover the questionnaire can be disseminated as mail for completion at home. A lot of patients prefer to fill in a questionnaire to speaking about their complaints, afraid of being considered querulous.

### 3. Quality of life of cancer patient with an unfavourable prognosis

In this context an unfavourable diagnosis and prognosis, confirmed by x-rays, scans, examination of excised tumour tissue, may have two meanings: the tumour is malignant or the malignant tumour is also metastasized.

Although there are now a lot more medical possibilities to heal also patients of the second group than, for instance, decades ago, the communication of this unfavourable diagnosis may result in feelings of anxiety and depression.

In the first group the paradox of cancer treatment remains, namely: the majority of patients will have to undergo negative consequences of a treatment for the sake of an uncertain positive effect. That is why the context in which decisions have to be made regarding a cancer treatment, is often complex:[4]

1. doing nothing means the death of the patient;
2. the treatment will cause serious complaints;
3. it is difficult to predict in which patients a treatment will succeed and in which it will not.

This means that in cancer treatment almost always a choice has to be made between the chance of profit in terms of survival and of loss in terms of quality of life.

It is therefore not surprising that in oncology the research into the quality of life has received a lot of attention.

How is this quality of life of cancer patients influenced?

Three factors influencing quality of life may be distinguished:

- a. the medical treatment;
- b. the illness itself;
- c. the personal characteristics of the patient.

#### a. Medical treatment and quality of life

The most important factors which determine the quality of life of cancer patients appear to be the experience of somatic and psychological complaints. These complaints may be the consequences of the treatment. Surgery often brings along mutilation and radiology a range of common and specific complaints, while chemotherapy causes the most complaints.

By definition cancer treatment takes place at daggers drawn: one always tries to administer such a high dose treatment that the malignant cells are hit optimally and that on the other hand the toxicity is acceptable for the healthy cells.

#### b. Illness and quality of life

Apart from the medical treatment one must not forget that the illness itself also causes complaints. It appeared, for instance, that in patients who underwent the same chemotherapy, those who already had metastases had more complaints than patients without metastases.

This also has consequences for the care of these patients.

To what extent somatic and psychologic problems occur at various moments, depends, among other things, on the phase and the kind of the cancer.

Several decades ago the attention was aimed particularly at the possibility of treatment.

Nowadays it is recognised that for the quality of life it is at least of just as great importance to start from the complaints of the patient and to see if something can be done about them.

Research has shown that treatment will be better tolerated if the prognosis is favourable. If, on the other hand, it has been decided to stop treatment aimed at the prolongation of life, this often leads to relief: more attention can be paid to well-being and palliative care i.e. treatment of symptoms, in other words: the best possible quality of life.

#### c. Personal characteristics and quality of life

A strong relationship can be found in cancer patients between personal characteristics such as age and civil status and the experience of complaints. For instance, the experience of complaints is often stronger in singles than in married people. People with a great sense of self-esteem are less troubled by complaints than neurotics who need extra care.

### 4. The usefulness of measuring quality of life

Confining ourselves to the EQ-5D, this score list delivers a description of the quality of life of a cancer patient at a certain moment. Consecutive measurements mark the course of the illness and the results of the treatment, at any rate if one has chosen for a specific cancer measuring instrument. Nowadays there are questionnaires for almost every illness and every kind of cancer.

The easiest way for specialists in this field is to add to a generic or common EQ-5D questionnaire a

number of specific items related to possible problems in a specific type of cancer, for instance, cancer of the bladder and the accompanying problems with urination.

For the physician processing these results from the questionnaires in a database, this means that on the basis of the success of the treatment of earlier, similar patients, the best treatment for the present patient can be chosen. Moreover, the database also shows what side effects of the treatment are to be expected and in what percentage of the cases.

The care provider too can adjust his activities to results of the quality of life measurements and maybe be better prepared.

Another value obtained by using a quality of life measuring instrument such as EQ-5D is the assessment of cost-effectiveness of a certain therapy. In healthcare economics people with whatever illness or handicap are asked to value their state of health with a number between 0 and 1, in which complete health = 1. This number is multiplied with the number of years to be spent in such a condition.

For instance, 50 years living with a handicap to which a number or a so-called weight has been assigned, for instance 0.5, results in 25 'quality adjusted life-years', abbreviated QALY's. Thus a QALY is a measure of the life expectancy of a person (in years) adjusted for the quality of his life. The life expectancy depends on the mean age a person in that country can reach.

The cost-effectiveness (CE) of a treatment is the ratio between the costs (in money) and the number of the life prolonging years adjusted for quality.

Thus: CE = costs/number of QALY's.

## 5. Discussion and conclusions

From the above it appears that in daily practice by the notion 'quality of life' (QoL) is meant the 'health related quality of life' (HRQoL). In this sense measurement of quality of life has proved to be a useful instrument in health care, in medical and pharmaceutical research and in making decisions in the political and social fields.

But by no means everybody realizes that the term 'quality of life', only says something about a person's momentary state of health. It is in fact nothing more than a subjective awarding of a value to one's feeling of well-being based on an equally subjective judgement of one's own somatic and psychological condition.

The outcome of a measurement of quality of life by whatever instrument, is a value, but still a subjective value. It is nevertheless-also in science-accepted as such since the patient is the only one able to judge his own quality of life.

As long as one confines oneself to determining the quality of someone's life as his or her state of health or well-being, nobody can have reasons for objections, nor can the RC Church, as long as this practice remains in accordance with her doctrine.

The danger exists, however, that this value will be regarded as the quality of a human person and will be used as a criterion not only to judge a person's right to receive certain medical treatment but even his or her right to go on living.

It is not only the RC Church[5] that wishes the sanctity of life to remain unaffected but also secular organizations such as, for instance, the World Medical Association(W.M.A.)[6] say that it is the duty of the physician to protect the dignity of the human subject.

I think the most important objection against the use of the notion "quality of life" is the following: labelling a state of health as a quality of life offers the opportunity for the misuse that when the intrinsic value of the life of the human person is denied, the notion "quality of life" may be conceived as a judgement of the reasons for the further existence of a concrete person or a category of persons[7].

The same applies to the use of the QALY, for a QALY is not a neutral, value-free criterion[8]. Especially for cancer patients with an unfavourable diagnosis and older people, the QALY carries negative aspects with it.

Firstly, in the QALY-concept the profit is expressed in numbers of years of prolongation of life and generally speaking cancer patients and elderly have fewer years of life ahead of them than health and young people.

Secondly, the same effect is enhanced once again because in the QALY-concept prolongation of life is the principal goal and preservation or improvement of normal functioning regarded as a correction factor. For most cancer patients with an unfavourable prognosis and elderly people it is more important to live as long as possible with as few annoying symptoms and handicaps as possible.

Finally I would like to say that in a certain sense I am the wrong person to speak to you about the quality of life of a cancer patient. As we have seen quality of life is a subjective assessment by the cancer patient himself of his state of health and his well-being. Therefore in my place a cancer patient should have been the one to inform you about the feelings of fear and sometimes of anger, of hope and sometimes despair of someone who has received the horrific diagnosis of a tumour with an unfavourable prognosis.

No doubt, he would have given you a lifelike story of how it feels to know that you will have to leave your loved ones and die in a not too distant future. I am sure it would not be a dry summary of answers from a score list of a quality of life measuring instrument.

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[1] E. Sgreccia, Rispetto per la vita e ricerca della qualità di vita in medicina: aspetti etici. Dolentium Hominum 28 (1995), pp. 154-160.

[2] M. Tijhuis et al., Wat is kwaliteit van leven en hoe wordt het gemeten ? (What is quality of life and how is it measured), Nationaal Kompas Volksgezondheid (2004), 19th of May, Bilthoven, Olanda.

[3] R. Rabin e F. De Charro EQ-5D: a measure of health status from the EuroQol Group, The Finnish Medical Society Duodecim, Ann. Med. 2001; 33: 337-343.

[4] J.C.J.M. de Haes Ziekte/behandeling en de kwaliteit van het leven van kankerpatiënten (Disease/treatment and the quality of life of cancer patients) Kwaliteit van leven en zorg, L. Boon, Amstelveen (1988); pp. 39:43.

[5] Congregation for the Doctrine of the Faith, Instruction Donum Vitae (1987), Introduction, par. 1.

[6] Declaration of Helsinki (1964) and lately revised in 2000 (Edinburgh, Scotland).

[7] W.J. Eijk, Ethical models for health management, Dolentium hominum 37 (1998) p. 61, Vatican City, Rome.

[8] A.W. Musschenga, Kwaliteit van leven: een criterium voor medisch handelen? (Quality of life: a criterion for medical practice?) Ambo, Baarn (1987), pp 142:143.

## **NOËL SIMARD**

### **QUALITY OF LIFE AND AIDS PATIENTS**

#### **INTRODUCTION**

Before going into the heart of the subject, and by way of introduction, I would like to tell you about an experience I had when I was chairman of the HIV-AIDS Support Group of Sudbury, a mining town with 100,000 inhabitants located 400 kilometers north of Toronto. In 1996, on the first of December, which is World AIDS Day, the Sudbury HIV-AIDS Support Group opened a home, the House of Peace, to offer hospitality and lodging to people from the north of Ontario in the last stages of the AIDS illness. As a matter of fact, these people were supposed to go to end their days in Toronto far from their own family and social environments. The first resident welcomed to the House of Peace was Michel, a young man of 32. According to his doctor, he had no more than a few months to live because the illness had done so much damage to his lungs. Many felt at the time that Michel no longer had a quality of life and that it was preferable not to insist on treating him and to let him die. But Michel was a fighter and he loved life. Despite his very poor physical condition and reduced life expectancy, and despite his repeated stays in the hospital, through improved medical treatments and a "family" atmosphere of goodness, compassion and respect at the House of Peace, Michel clung to life and died four years later, leaving a testimony to a heroic struggle, a life of gentleness and tenderness, and an extraordinary gusto for life. This story is meant to show how with regard to AIDS, the idea of quality of life is complex and delicate. In this area, attention has to be given to the concrete persons, their particular situations, their living conditions, their hopes and plans in life, and also their social and spiritual environment. In this presentation, I will attempt first of all to clarify the concept of quality of life, then I will speak about the living conditions of persons affected by AIDS, and, lastly, I will take up some major ethical problems related to the idea of the quality of life among the persons living with AIDS.

#### **QUALITY OF LIFE: AN ATTEMPT AT CLARIFICATION**

What should be understood by quality of life? Do objective criteria exist for determining whether or not a life is worth living? Is it possible to judge the value of a life on the basis of some elements that are considered essential? Who can determine these criteria? Isn't it a personal, subjective question that cannot depend on the judgment of other people extraneous to the situation of the persons concerned? So can it be left up to healthy people to judge the quality of life of persons affected by AIDS? Even if the idea of quality of life is relative to the outlook on life of the men and women who are living this life, can it be said that the idea is only subjective? Isn't there a whole series of conditions that are essential and which we have the duty to build, favor and preserve for every human being? Isn't it up to every citizen, and even more so to every one of Christ's faithful, to take part in creating a living environment that is favorable to every human person's development?

The term "quality of life" appeared in medical and paramedical terminology in the 50s following the economic and social development after World War II that brought greater well being in Western societies. The quality of life also appeared at the time as a new criterion for defining health, which is no longer just the absence of illness, but calls for well being as an essential requirement.<sup>[1]</sup> But with the use of more and more refined technologies in the medical and scientific world, some new questions arose, such as the validity of insisting on saving a life through the use of these technological means or resources. To find a solution to the dilemma, researchers and doctors tried to establish some criteria to

measure the quality of life of patients, but they limited themselves all too often to physical and social well being. It got to the point that a life was not considered worth living, and the first ones targeted were babies with severe handicaps, and elderly, senile persons who had little or no awareness and interaction with their surroundings. One of the results of these attempts to measure the quality of life was a growing acceptance of euthanasia as a response to a life considered painful and useless.

In the public at large, the idea of quality of life takes on many connotations. Naturally, it describes a whole set of economic values needed to live measured according to parameters like production, working conditions and free time. But it also refers more and more to the quality of the environment - the rise of the "greens" in Europe attests to this-- the ideal of happiness, the possibility of pleasure, participation, harmony, social accord, etc. Here again, all too often this is limited to a materialist, economic view that easily leads to individualism, utilitarianism and hedonism, and overlooks the moral and spiritual dimensions. As John Paul II writes, "The so-called 'quality of life' is interpreted primarily or exclusively as economic efficiency, inordinate consumerism, physical beauty and pleasure, to the neglect of the more profound dimensions-interpersonal, spiritual and religious-of existence".[2]

These attempts to measure the quality of life and the different meanings that the concept of quality of life has and is taking on show the ambiguity of the term. Should it be abandoned, then, and risk falling into an extreme form of vitalism where everything must be done to save a life? As an expression of our era, the concept remains valid as long as all the dimensions of human existence, moral and spiritual as well as social and economic, are taken into consideration. The idea is acceptable if it is based first and foremost on the integral vocation of the human being and the dignity of the person. Moreover, it has to be well understood that this dignity is not tied to some particular characteristics, such as autonomy, self-awareness, the ability to have relations and communicate etc., but that it is innate and does not disappear with the eclipse of one or all of these vital characteristics.

In any event, the concept of quality of life cannot turn into an instrument for passing judgment and making comparisons on the value of personal lives, as if some lives are of greater quality and others of lesser quality. Such a comparison risks obliterating the intrinsic value of all human life. In this sense, it is utopian to want to establish the essential criteria for the value of a life or put them into a hierarchy[3] because an undertaking of this kind runs the risk of ultimately discriminating against persons whose intelligence is gravely affected or who are considered useless for society or incapable of enjoying life. It is obvious that when emphasis is put on the social utility of a life, on enjoyment or pleasure as a moral criterion, when no sense can be seen in suffering or when life is considered meaningless, then the choice to put an end to a life full of suffering that brings no joy or contributes nothing to society seems to be the only valid one. With regard to life, the idea of quality cannot blur the idea of its sacred character, which would no longer hold in the face of unbearable conditions. When separated from the principle of life's sacred character, the idea of quality ends up justifying assisted suicide or the voluntary assisted euthanasia of patients affected by AIDS who feel that their lives are no longer worth living and that they are entitled to demand that their lives be put to an end.

Lastly, to avoid any ambiguity, the expression of quality must maintain a balance, on the one hand, between the quantifiable, measurable objective criteria that can help in complex and painful situations, and, on the other, the subjective factor that is related more to the meaning of life and the perception people have of themselves and their living conditions. In this regard, the opinion that the sick persons have about themselves is revealing. In fact, most of the time they believe that they have a higher quality of life than what is assigned to them on the basis of objective measuring instruments.

## THE LIVING CONDITIONS OF PERSONS WITH AIDS

Before taking up this question, it is good to recall that HIV is always transmitted through unprotected sexual relations, sharing syringes or material for injecting drugs, pregnancy, delivery and breast feeding (by a mother infected with HIV to her baby), using unsterilized syringes for piercing, tattooing or acupuncture, professional exposure in a health center, and, although this occurs rarely today, the transfusion of contaminated blood.

AIDS continues to be a mortal illness because despite the progress made in treatment (which has made it possible - mainly in the Western countries - to prolong the lives of persons living with HIV/AIDS and to improve their quality of life[4]), now some treatments have no effect now since new strains of the virus are resistant to the drugs and tri-therapies are still only available to too few people around the world.In fact, while the proportion of persons infected by HIV who will later develop AIDS is not known with certainty, and despite the improved treatments and care, the majority of these people - and even more of them in the developing countries - will die from the illness.Prevention is still the only issue until a cure or vaccine is discovered.

The history of AIDS is a history of struggle, combat, suffering, culpability and confrontation with time and death.[5] This explains why the living conditions of persons with AIDS are particular and painful.From the biological viewpoint, the virus attacks the immune system of the organism that has to continuously fight the destructive invader.From the psychological viewpoint, the infected individual has to struggle with the anguish of imminent death, combat the negative images projected by society threatening his mental health - even if this situation has improved after the discovery of HIV.e has to work without end for the psychical reorganization of his being, develop defense mechanisms to protect himself, etc.He has to overcome many psychological difficulties caused by HIV: fear of rejection and judgment, fear of suffering and agonizing, the shame of having a "dishonorable" virus, and guilt for having possibly transmitted it; a reaction of isolation, difficulty in communicating his condition to his surroundings, an absence of sexual contact or an overinvestment in sexual activities, overwork and exhaustion, etc.[6] He also has to fight to be respected in his dignity as a person, to defend his rights (to health care, decent housing, work, insurance, etc.), and to claim his place in society against all these attempts at rejection, exclusion or ostracism.Sometimes he has to battle with intrusions into his body (for research purposes or experimental treatment) and his private life (breach of confidentiality, exposure of his feelings, etc.).A person living with AIDS also experiences special difficulties in finding the energy needed to think and behave in a positive way when the illness becomes acute.He will have to face the secondary effects that are very hard to bear, especially over the long term.These effects are such that some patients are tempted to interrupt the treatment.

AIDS brings suffering.It puts the men and women affected by it in a situation of moral and physical distress.It not only affects the body and makes it vulnerable, but it also weakens the very foundations of existence.The men and women affected by this disease have to face many challenges.These people have to live with pain, fatigue and decreasing activity during a considerable period of their lives.They may also have to adjust to new treatments and the experience of many stays in the hospital.They have to battle with new emotions evoked by the disease and growing anguish and uncertainty about the future.Not only does the person with AIDS have to face the uncertainty about his/her future health, but he/she often has to suffer a number of serious losses.AIDS patients can gradually lose control over the daily activities in their lives and feel the painful loss of control over events.They also have to go through the suffering of being unable to work and financial difficulties.Since they often lose their independence, they find it difficult to depend on others for practical care and emotional support.They also have to go through the painful experience of abandoning the projects and plans they made for

themselves, such as having a family...People affected with AIDS can feel threatened in their image and self-esteem and face the additional suffering of rejection and discrimination.

Lastly, for most affected persons, the suffering of AIDS is experienced against a background of culpability. When their illness is revealed, the contaminated persons look for the cause or origin of their infection. Perhaps they discover that it was the result of a bad habit. But very soon they feel an overwhelming burden of guilt when they become aware of their contribution to the spread of the virus, whether this is to a partner to whom they are united or an unborn child, or through the blood they have given. This feeling of guilt is felt strongly by seropositive women, who are very often contaminated without knowing it, and may have transmitted the virus to a child they are bearing or breastfeeding.

In the developing countries the situation is even more serious and tragic. By the end of the twentieth century, HIV had already infected more than 50 million people and caused the death of 21.8 million. According to ONUSIDA estimates, [7] the number of adults and children living with HIV around the world rose at the end of 2003 to approximately 38 million (35-42 million), and AIDS was the cause of 2.9 million deaths (2.6-3.3 million) in 2003. More than 34 million people are living with HIV in the developing countries, representing 90% of the world total. Sub-Saharan Africa alone has 70% of all the persons living with HIV. In 2003, in that same region, it is estimated that about 3 million people have been infected, and that 2.2 million have died due to this scourge, i.e., 75% of the world total.

A lack of information, inadequate health care, and a poor diet - all linked to endemic, extreme poverty - make the poorest people in the most disadvantaged countries most vulnerable to HIV/AIDS. Therefore, HIV and AIDS have an even greater impact on the poor countries, and this is manifested, among other things, in a harmful slowdown in development. HIV and AIDS are not limited to the individual; they have repercussions on the family, the community, the region, the country, and also on the international community. In the developing countries, HIV and AIDS have made poverty worse and created new privations and needs. The impact on development is enormous and can be seen on all levels: the economy, the job market, demography, food security, health care, and life in society. [8] In these countries, where life expectancy is lower than it was before the emergence of the pandemic, this illness has become "the greatest challenge to development in our times", in the words of the Secretary General of the United Nations, Kofi Annan. In view of the alarming spread of the epidemic, most African countries, among others, now have to bear an economic burden that is disproportionate to their abilities to react. The deaths of many adults of working age, the infection of women, especially mothers, and the dramatic increase in the number of orphans thus raise enormous, unresolved problems to the governments of these African countries for the future. As we can read in an article by the ACDI, "When parents, teachers, farmers, construction workers, entrepreneurs, nurses and managers are dying by the thousands each year, families, communities and countries stop working. Children struggling to take care of their families by working or begging in order to earn their livelihood, have no time to go to school. The fields are not cultivated because the people are too sick to work in them. Basic businesses and services are upset, the economies suffer, and the communities become undone. Because of HIV/AIDS the people are unable to get out of poverty, improve their elementary living conditions, and avoid their vulnerability in the face of the illness". [9]

Because of grave economic problems, the developing countries are unable to allocate the necessary resources to care for the persons living with HIV/AIDS. The health services in these countries are obsolete for the scale of the needs, and they tragically lack adequate installations, personal protection equipment and other material that make it possible to care for the persons affected by HIV/AIDS. At present, in Sub-Saharan Africa, the local non-governmental organizations and the traditional network

of the extended family, friends and neighbors are filling the serious gaps in care. But this network is no longer enough for the task, and there is a limit to what these people can do in taking care of the persons in their charge and facing the expenses related to their illness and death.

## SOME OF THE MAJOR PROBLEMS RELATED TO THE QUALITY OF LIFE OF PERSONS LIVING WITH AIDS

The major ethical problems related to the idea of quality of life among the persons living with AIDS are also different in the Western countries and in the developing countries.

In the Western countries, the quality of life of the persons living with AIDS - with regard to socio-economic conditions and health care - has clearly improved after tri-therapies were perfected that have maintained their efficacy and made it possible to lower the mortality due to AIDS. Indeed, the antiretroviral treatments, together with good prevention measures and carefully conceived information campaigns, have prolonged the lives of these persons and enabled them to regain - despite the painful secondary effects - a certain quality of life. However, some problems are starting to be seen. The media's coverage of the benefits attributed to antiretroviral treatments has led to believing erroneously that they can cure AIDS, and that the preventive measures can be abandoned. In certain cities in the United States, there has been a reoccurrence of the spread of infection through HIV. Many prefer to have a better quality of life by doing without prevention - this is what they say and want - rather than a greater life expectancy. It is necessary for the Western countries to continue their prevention and information campaigns, aiming in particular at adolescents and vulnerable groups. It is urgent for an integral or holistic view of the human person to be adopted by the authorities and groups responsible for prevention, information and care. What is necessary is to work on the meaning of life and offer the persons living with AIDS reasons for living and not just good socio-economic living conditions, however important they may be. As Dr. Rafael Mazin stresses, "Our evaluation of the progression of this epidemic also shows that greater attention should be given to the needs related to the care of seropositive persons. These needs are not limited to primary medical care, but include the treatment of the person as a whole and make up a vast range of services including psychological counseling, emotional and social support, and recommendations regarding diet. In responding to these needs, not only the physical condition of the patients has improved, but also their emotional state and the quality of their existence, which allows them to live with dignity and self-respect". [10] It is too bad that Dr. Mazin did not mention the needs of a spiritual nature which, if not filled, leave a void and a lack of meaning in many persons living with AIDS.

It is not surprising when the antiretroviral treatments are no longer effective and the AIDS illness does its damage that people living with AIDS in the rich countries support the right to euthanasia to put an end to a life now considered useless and without value. [11] The right to die with dignity, i.e., without suffering, with awareness and when one wants, is demanded more and more, not only by the persons living with AIDS, but also by all the men and women who do not want to face the ravages of the final stages of cancer or Alzheimer's, for example. This growing support among the Canadian people and in other Western countries for assisted suicide for those in a terminal stage, whose hope of recovery is almost nil, shows the need to work not only to improve the living conditions of the sick, but also to offer reasons to live and to suffer.

In the developing countries, the major ethical problem related to the quality of life is improvement of the socio-economic living conditions and access to care. From July 13-16, 2003, Paris hosted the Second Conference of the International AIDS Society on HIV, pathogenesis and treatments. On the

occasion of an extraordinary plenary meeting, Nelson Mandela, the former President of South Africa, made an exceptionally strong appeal to the conference participants:"We have failed to transform our scientific advances into actions where they are most needed in the communities of the developing countries, the poorest regions of the globe.This constitutes a world injustice that cannot be tolerated.It is a sham of human rights on the world scale".In the framework of that Conference, a community forum took place on Sunday which enabled the participants to exchange their views regarding their expectations from research both on the medical level and in relation to access to care.The forum highlighted once again the blatant inequality in access to treatment and care between the North and the South, which Marie-José Mbuzenkamwe did not fail to denounce. She is a physician, co-president of the community liaison committee of the conference, and an activist in the National Association to support persons living with AIDS from Burundi.[12]

There are surely some projects that are bearing fruit, but they are too limited and reduced given the scale of the situation.We can think of the involvement of persons living with HIV/AIDS in the non-governmental bodies, which has beneficial effects for them, such as preventing isolation, greater knowledge about HIV/AIDS (including treatment and greater access to care), better acceptance of serpositivity and greater self-esteem, a job or material benefits essential to their well-being and that of their families, a change in sexual behavior, greater family acceptance: in a word, a general improvement of their health, both physical and psychological.[13] Some sick persons from the developing countries get antiretroviral treatments which enable them to regain a certain quality of life and prolong their life expectancy.But this work is more symbolic than significant because it only reaches a very slight minority of the people affected by HIV/AIDS in the developing countries.What is needed is access for all, in line with the theme of the XV International Conference on AIDS that took place in Bangkok from July 11-16, 2004.The objective of that Conference was to promote access to the essential scientific discoveries concerning HIV, prevention, treatment and different resources for the people of the whole world.Some initiatives have already been made in this sense, in particular the World Fund to Fight AIDS, Tuberculosis and Malaria, the Emergency Aid Plan for AIDS Victims (PEPFAR), proposed by President Bush to offer treatments and care in fifteen of the countries most affected by malaria; and the "Three million from now to 2005", an initiative of the World Health Organization, a program that aims at offering antiretroviral therapy to three million persons living with HIV/AIDS from now to the end of 2005.This is all very praiseworthy, but more funds and technical assistance are needed to reinforce the health care capabilities in the developing countries.On the part of the rich countries, this means supporting the national strategies that aim at creating care givers, setting up distribution and supply systems for medicines, and controlling and evaluating the programs related to HIV/AIDS.This means support for these initiatives, like the Canadian legislative bill C-9, which makes less costly versions of patent medicines available to the developing countries.As long as access to multi-therapies and care is not generalized in the countries most affected by the AIDS pandemic and not limited to just a small group, the gap will not cease to widen between the North and the South and will reveal ever more acutely the situation of those outcast by the pandemic.It is urgent to respond to this question of justice and solidarity if we want to stop the spread of HIV/AIDS and reverse the trend.This cannot be done without pursuing other development objectives such as the struggle against poverty and hunger, the improvement of education, and equality between the sexes.It is only through concerted action and real commitment on the part of the rich countries that the developing countries will be able to respond to the challenge of AIDS.What is at stake is not so much the improvement of the quality of life, but rather the survival of millions of our human brothers and sisters.

## CONCLUSION

This brief reflection on the quality of life of people living with HIV/AIDS shows us the importance of understanding the meaning of the term well. It is essential to maintain equilibrium between the objective criteria and the subjective dimension of perception about life, as well as between socio-economic living conditions and moral and spiritual values. To achieve this equilibrium, an integral view of the human person and his destiny are needed, respect for his fundamental dignity, and a concrete commitment to the well-being of all the members of the great human family.

Even though there are some similarities, the living conditions of persons with AIDS are not the same in the North and in the South. We could speak about improving the quality of life in the North and degradation in the South. The difference is also manifested in the major problems related to the quality of life: in the rich countries, the major problem seems to be linked to the perception about life and its meaning, while in the poor countries this is expressed more in terms of socio-economic conditions essential for living with dignity.

If the Church wants to carry out effective action to improve the quality of life of persons living with HIV/AIDS, it must know these problems and bring a remedy to them that will be adapted to the circumstances of time and place, and respond with discernment and courage to the specific and different needs of persons, all within a real concern to incarnate Christ's Gospel of charity, justice and compassion.

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[1] For a brief study relevant to the concept of quality of life, see: Paccini, Renzo, "Qualità della vita" in Pontificio Consiglio per la Famiglia, LEXICON Termini ambigui e discussi su famiglia, vita e questioni etiche, Edizioni Dehoniane, Bologna, 2003, pp. 763-768.

[2] John Paul II, Encyclical Letter *Evangelium Vitae* on the Value and Inviolability of Human Life, No. 23.

[3] The search for or preparation of instruments to measure the quality of life, however, is not useless. In the health area this can help to define life better and to understand its determinants. On this subject, it is useful to read the book, *Mesure de la Santé Perceptuelle et de la Qualité de vie: méthodes et applications*, under the direction of Alain Leplège and Joel Coste, De Boeck, 2002 edition, 336pp.

[4] The EuroAids study, which brought together more than 9,800 patients followed in 70 centers in Europe, Argentina and Israel, revealed that after the prescription of tri-therapies and the appearance of new anti-AIDS molecules (the new generation of anti-retrovirals), the incidence of AIDS dropped by 50% and mortality from AIDS decreased spectacularly (naturally, in the countries where these therapies are available). *The Lancet*, July 4, 2003.

[5] For this part, I was greatly inspired by Charter 3 of my book *Le Sida Enjeu éthiques et spirituels* (Mediaspaul, Montreal/Paris, 1995), *Le sida et les situations-limite de l'existence*, pp. 115-163.

[6] On this subject, read the article by Johanne de Montigny: "Aspects psychosociaux" in Olivier Clément and Thomas Réjean, *Le sida: un nouveau défi medical*, Association med médecins de langue française du Canada, Montreal, 1991, pp. 256-270.

[7] Summary table of the epidemic of HIV infection and AIDS around the world, end of 2003. XV International Conference on AIDS in Bangkok

2004, [www.unaids.org/bangkok2004/GAR2004\\_pdf\\_fr/GAR2004\\_Graphics.fr.pdf](http://www.unaids.org/bangkok2004/GAR2004_pdf_fr/GAR2004_Graphics.fr.pdf)

[8] The Canadian agency for international development published a very pertinent article on the impact of HIV/AIDS on development showing that it is more than just a health problem. (*Les priorités de développement social de l'ACDI*, September 4, 2000, <http://www.acdicida.gc.ca/sida.htm>)

[9] *Les priorités de développement social de l'ACDI*, July 14, 2004, <http://www.acdicida.gc.ca/sida.htm>

[10] When he wrote these lines, Dr. Mazin was the Regional Counselor on the prevention and treatment of HIV/AIDS of the World Health Organization Regional Bureau for the Americas, Pan-American Health Organization. Mazink, Rafael, La prevention et le traitement du VIH/sida dans les pays en voie de développement, Dossiers mondiaux, Dec. 2001, Sommaire/Revues

IIP, <http://usinfo.state.gov/journals/itgic/1201/ijgf/gj-4f.htm>

[11] In the early 90s, David Lewis, a counselor on AIDS from Vancouver, Canada, who was also affected by AIDS, caused a scandal and a discussion of an ethical and legal nature when he publicly admitted that he had helped more than eight male friends with AIDS to take a lethal dose of medicine. Even though assisted suicide is a crime in Canada, Lewis was never prosecuted.

[12] In a militant speech, after recalling the promises of the rich countries and their leaders, and after mentioning—as a ray of hope—the strategies and actions set in motion locally in the field for a global responsibility in the reality of AIDS, Marie-Josée Mbuzenkawme denounced Western hypocrisy: “There are two realities: one made up of words, which end up having no more meaning, fueled by announcements that are never effectively followed up, and the other reality, which we live, where the number of deaths and contamination are increasing a little more every day”. The complete text of her speech can be found on the controversial website of Act Up Paris—  
[www.actupparis.org/article1205/html](http://www.actupparis.org/article1205/html)

[13] On this subject, read the article, “Vers une implication plus significative des personnes vivant avec VIH/SIDA” published in the Canadian review, VIH/SIDA et DROIT (volume 7, Nos. 2-3, December 2003) and based on an exposé by Christophe Corne at the Barcelona Conference in 2002.

## **LUIGI POSTIGLIONE**

### **QUALITY OF LIFE AND ENVIRONMENT**

#### **ENVIRONMENT – GREENHOUSE EFFECT**

The environment represents the physical part of the ecosystem “Earth”, and consists of the land and oceans as well as the gaseous belt that envelops it (the atmosphere). Exchanges and interrelations between the land masses, the oceans and the atmosphere are continuous and unceasing. Within such a scenario there is the intervention of living creatures (plants, animals and man) which, in turn, interact to a major degree both with each other and with the phenomena occurring on a physical level.

Among the different components an equilibrium is always established, and when for various reasons one of the elements undergoes a variation, the whole ecosystem, thanks to its self-regulating power, finds new equilibria.

Today, however, the human component has managed to seriously upset the relations between the various elements, first with the use of fossil fuels and then, gradually, with the development of new technologies, especially in the chemical sector: pollutants, i.e. substances that may have harmful effects on human health or on the environment overall, are emitted directly or indirectly into the system.

The best-known example of human-induced system perturbation is the continuous increase in the atmosphere in the levels of carbon dioxide and other gases due to fossil fuel combustion in car engines, for industrial purposes and for domestic heating[1]. This increase leads to the greenhouse effect, by which the earth's temperature gradually rises, according to the various models, from 1.5 to 4.5 °C (Kerr, 1984) until 5,5 (Adams et al., 1990), and from 1,4 to 5,8 in the period 1990 to 2100 according to IPCC. As a result, part of the ice caps will melt, the sea level will rise (5 – 8 metres, Abelson, 1984) and hence coastal plains will disappear together with the low-lying parts of urban areas. The greenhouse effect will essentially cause a climate change that will also entail a considerable variation in the rainfall regime, thereby affecting crops and livelihoods.

To reduce carbon dioxide levels in the air, we would need to limit the use of fossil fuels to obtain energy. A major contribution may be made by vegetation (agricultural, forestry, ornamental) since plants absorb CO<sub>2</sub> during photosynthesis to various extents according to species, age and growth, and return pure oxygen to the atmosphere (one-third of CO<sub>2</sub> absorbed). On average, a hectare of shrubs and ornamental trees absorbs 114 kg of CO<sub>2</sub> per day. All land available would thus need to be covered with trees, shrubs, pasture and various crops, i.e. create a “greenery culture”.

Thus, the production of combustibles from plant biomass will also have to be promoted. With their use as an energy source, there is the great advantage of emitting into atmosphere only part of the CO<sub>2</sub> absorbed by the plants that produce them, and a minimal amount of pollutants that are produced during fossil fuel combustion.

#### **AIR POLLUTION**

Currently, the most serious aspect of fossil fuel combustion lies in the continual emission into the air of chemical substances which are highly harmful for the health of humans and other organisms, including gas products and smoke from factories. It is also worth noting the contribution of harmful substances coming from urban waste management: landfills, waste-to-energy plants and incinerators.[2]

As regards atmospheric pollution, the chief culprits are the various nitrogen oxides, sulphur dioxide, hydrogen sulphide, carbon monoxide, ammonia, lead and volatile organic compounds (VOCs); we should add most pesticides and weedkillers used unnecessarily in agriculture. All these are called primary pollutants; there are then some secondary pollutants, such as ozone (in the troposphere), and

peroxyacetyl nitrate (PAN), resulting from O<sub>2</sub>, NOX and VOCs due to photochemical reactions. The term “secondary” applies to their formation, but not to the damage produced (Gasparini et al., 2002). In general, such compounds pollute the air, causing certain diseases which chiefly affect the lungs. In combination with rainfall, they then pollute the soil and crops, adversely affecting food hygiene. When they fall directly on fruit or vegetables, or penetrate via the soil, they cause gastro-intestinal complaints[3]. Moreover, in some circumstances they lead to “acid rain”, extremely hazardous for vegetation. Finally, very often, they reach the groundwater via the soil, making water unfit for drinking[4].

In the air, particles between 0.005 and 50-150 µm may be suspended, forming “particulate”[5]. The particles consist of various substances: chiefly dust from various metals and incompletely combusted carbon particles; there may also be cement and construction waste due to the decay of buildings and sometimes monuments.

These and other forms of pollution are frequent especially in cities where, due to the concentration of vehicle traffic, heating plants for buildings and the presence of factories, there are very high emissions of CO<sub>2</sub>, nitric products, sulphur compounds and VOCs. Moreover, due to the excessive residential density in such cities, the presence of very tall buildings and narrow roads (cement canyons), pollutants and particulate lingers and creates greater damage to health. We should also recall the damage produced by asbestos, the use of which has now been banned.

#### Pollution in closed environments

Particular pollution occurs in closed environments ranging from chemical laboratories to factory workshops: the latter problem ranges from an excess of particulate and toxic substances, according to the type of industry, to excess humidity in premises for processing tobacco and foodstuffs, with specific pathologies for each type of pollution. Thus in greenhouses in which, to sustain production of two or three crops per year, very high rates of fertilisers and chemicals are applied, such products pollute both the protected atmosphere and the exterior, often being found in the fruit and vegetables grown therein.[6]

A further hazard consists in all the equipment that uses radiation, found especially in hospital laboratories but also in doctors' surgeries. We should recall the damage (lung cancer, chiefly) arising from exposure to Radon[7], affecting those who work in tunnels, underground railways, subways, catacombs, caves, public baths and mines, as well as flight personnel. Lastly, there is our daily exposure to pollution from electromagnetic waves, waves between radio- and TV-masts and cell phones, believed by many to be the cause of serious disease.

For workers in closed environments there is the additional problem of noise pollution, which reaches a peak in the heavy manufacturing industry, with values that often seriously affect the auditory apparatus. Noise pollution is also frequent in urban areas due to heavy traffic loads and the often unnecessary use of horns, as well as the excessive noise from motorcycle engines.

### CLOSED ENVIRONMENTS

Separate mention should be made of discotheques and the like, frequented at night-time. At these venues the air is usually a mix of tobacco smoke, alcohol and often drugs, whether natural or synthetic. In addition to poor-quality air is the music, which exceeds comfortable noise thresholds, as well as psychedelic lighting. The combination of these factors results in an environment in which dulled sensibilities are the minimum damage experienced by disco-goers.

An aggravating factor is that those who frequent night-spots late at night and leave at dawn are frequently involved in fatal car accidents. However, even if the end results are less dramatic, regular

disco-goers experience a change in their biorhythms: living by night without enjoying the benefits of solar radiation will impact negatively upon health.

## SOIL POLLUTION

Soil contains not only toxic substances resulting from air deposition or water transport, some of which are mentioned above, but also heavy metals such as iron, lead, manganese, zinc, chromium, copper and nickel. Some of these come from the weathering of rocks, though most are produced by engine exhausts, or with smoke and scrubbers from factories (Adamo et al., 2003). However, when one of these metals exceeds its limit value for safety, and is absorbed by plants, it may be found in foodstuffs and cause various diseases.

## WATER QUANTITY AND QUALITY

One of the main emerging problems worldwide is the use of water for domestic, industrial and agricultural purposes. This resource, which is essential for life and health, has begun to grow scarce worldwide; in equatorial countries, and especially in dry climates, seasonal droughts occur. It is the search for water, chiefly from the subsoil, or its transport from water-rich areas by means of long channels and tunnels, that are necessary for ensuring albeit minimal living conditions for various peoples worldwide. It is not only a question of water quantity but also quality: apart from the various forms of pollution mentioned above, water contains a slow yet progressive increase in salt content both due to the rise in temperature that increases evaporation and hence leads to a greater concentration in salts (only the solvent evaporates (water) while the solute (salt) does not), and because water is extracted from the subsoil almost everywhere for domestic, industrial and especially agricultural purposes. Overextraction of groundwater lowers the water table, wells have to be sunk deeper and often saline layers are reached. This is cause for great concern as the use of saline water causes crop damage and leads to soil salinisation which is the first step towards desertification (Postiglione, 2002).

On the subject of water, two pollutants should be mentioned, namely phosphates and nitrates: their excessive presence in water-courses and hence in marine and lake waters gives rise to eutrophication, which makes the shoreline unproductive for fishing and unfit for bathing.

The second form of pollution concerns the presence of highly toxic substances (lead, mercury) in wastewaters reaching the sea, making coastal fish and other marine animals unfit for consumption.

## SOIL CONSERVATION

Soil, an essential resource for the production of major food crops and hence for human life, is today facing serious threats. A phenomenon of particular severity is desertification, which affects much of the land surface to differing degrees and was recently estimated to render as much as 12 million hectares of farmland uncultivable every year (Desertification, SOLIDEA, 2002).

This is a phenomenon that starts in lowland areas, as stated above, with water and soil salinisation and is aggravated by other concurrent causes, such as drought, deep tillage, excessive fertilisation, monocultures and the lack of organic matter. The first step is soil degradation which weakens the soil's physical, chemical and biological potential, and ends up making crop production impossible, hence threatening the very survival of the people living there.

In Mediterranean regions, the phenomenon also occurs in the hills, and in general on sloping land, due to the rainfall which is poorly distributed and often of great intensity. Such rainfall, even if short-lived,

causes erosion first and foremost, i.e. the detachment and removal of smaller soil particles. These are generally the most fertile and, as they are the richest in organic matter, are those that contribute to maintaining soil stability.

With more intense rainfall there may be landslips that often cause large numbers of fatalities. In upland areas the problem is aggravated by the abandonment, on the part of smallholders, of such land as it is less productive: the soil is no longer managed and no crops are harvested, which previously contributed to soil conservation.

## FOOD HYGIENE

Lastly, there is the issue of food hygiene which, given its effects on health and the extent of the problem, merits treatment that goes well beyond the scope of this paper. Suffice it to mention the presence of some pollutants in foodstuffs, the frequent lack of some elements such as iron, zinc, iodine (some in high doses are toxic) or of compounds of high nutritional value, such as Vitamin A.

Moreover, in foodstuffs preserved in jars and cans, widely used now that our lifestyles have changed, mention should be made of toxic organisms such as Clostridium, mycotoxins, and, with more serious consequences, Salmonella. To limit hazards and product genuineness, there are now regulations on the traceability of the whole product chain from seed purchase and cultural technique to industrial processing and commercialisation. However, both the deficiencies and the presence of pollutants and toxic micro-organisms cause various pathologies, in some cases lethal.

Important newcomers on the scene are GMOs, whose benefits and possible hazards are widely discussed, and the constitution of plants that supply “functional food” designed to be rich in healthy ingredients (antioxidants, vitamins, etc.).

## PROSPECTS AND ALTERNATIVES: TECHNIQUES FOR AID, PREVENTION AND ADOPTION

In an attempt to safeguard the future of the Planet from the consequences of climate change due to the greenhouse effect, and from the various forms of pollution, several world conferences have been organised on the environment. In particular, in the Kyoto Conference (December 1997) a protocol was drawn up by which signatories[8] undertook to reduce, by 2008-2012, CO<sub>2</sub> emissions by 5% of their 1990 level estimated at about 353 ppm. However, at the next conference (New Delhi, October 2002) it was confirmed that in no part of the world had such a reduction begun.

The subject of the CO<sub>2</sub> increase in the atmosphere is intrinsically linked to the pollution due to the emission of nitrogen and sulphur compounds, carbon monoxide, volatile organic compounds, and so many other pollutants that arise from fossil fuel combustion. Naturally, pollution is aggravated by the emission of toxic products from industry and the irrational use of fertilisers and pesticides in agriculture.

Therefore, so as to limit the greenhouse effect and pollution, one would need to eliminate or at least reduce the use of fossil fuels in vehicle engines and in industry as well as for domestic heating. In their place “alternative” sources of energy should be used, such as:

- clean energy: wind, solar, hydro (micro), marine, geothermal;
- renewable energy: from biomass, hydrogen;
- energy with high risk: nuclear.

In reality, clean energy sources are already used in many countries, as is biomass: wood used with modern technology, plant-based oils for biodiesel and bioethanol for combustion engines. The results are favourable, yet their contribution is still modest compared with the total energy requirement.

Much is now expected from the adoption of hydrogen. However, its economic production is still being studied, as is its use in vehicle engines.

The generation of power from nuclear energy is banned in Italy, so this is an ethical matter, rather than a technical question. However, the matter should be re-discussed especially at the international level. Moreover, to limit the damage from air pollution, the factories that produce toxic substances or harmful emissions or particulate should be relocated far away from large urban areas, and there should be rigorous compliance with the laws on mechanical and chemical filters and those on water treatment systems. The same goes for landfills, waste-to-energy plants, and all the plants for processing and eliminating solid urban waste.

In particular, to safeguard health, those working in closed industrial environments at risk of specific pathologies must undergo appropriately frequent medical check-ups to avoid the onset of certain diseases, while face-masks, special overalls, air conditioning, showers etc. should contribute to hazard prevention. In this context scientific and medical equipment that uses radiation, now found in all large urban centres, should be rigorously checked at regular intervals, as should the health of the operators concerned.

As regards water resources, there should be a far-reaching publicity campaign to reduce waste. A good example is given by agriculture in which, with modern drip irrigation, a considerable saving is obtained and, with other devices, used water can actually be recycled. Moreover, with various channels and tunnels, water could be transported from areas of abundance to those of scarcity. Using wells, the subsoil could be further exploited. There remains the problem of pollutants in some aquifers which, together with salinisation, makes their use impossible.

Correlated with salinisation is the progressive increase in desertification, which results in the migration of entire populations from the areas concerned. The same holds for erosion and for landslips on sloping land. For desertification and landslips, attempts can be made to limit damage by using sound agriculture. However, in such cases the farmers or landowners should be considered stewards of the land and compensated accordingly.

As for food hygiene, rigorous controls should be carried out not only on the end product but also at each phase in the production chain.

Last but certainly not least, there is the problem of urban areas. It is to be hoped that they will be built in future with a human dimension. There should be no more enormous agglomerates with millions of inhabitants, skyscrapers, narrow roads, a lack of basic facilities and urban green spaces. Small interconnected urban centres would be desirable, with some high-rise blocks but no cement colossi, with wide roads for vehicle and chiefly air circulation, with sports centres and swimming pools surrounded by greenery and an abundance of parks, gardens, tree-lined avenues, and with flower-beds in the middle of every square.

With the planting of parks and gardens, the vegetation will absorb much of the CO<sub>2</sub> and will return pure oxygen in the ratio of 3:1, it being thus possible to limit the damage from air pollution. There will thus be an improvement in the quality of life, together with considerable social and ethical benefits.

The system outlined above will ensure that children can spend hours in the open air, breathe clean air, play together with other children in the neighbourhood, and hence socialise; learn to recognise, respect and love plants, become familiar with birds and small animals that will inevitably be found in such parks. Accompanying parents and child-minders will also begin to socialise and get to know one another. The elderly will be able to meet one another and spend time with their peers, have a game of cards in the shade of a pergola of vines, and play bowls on a pitch surrounded by leafy trees.

Thus a proper living system will be created (humans, plants, animals, nature). Residents of a neighbourhood will no longer be nomads that do not even know each other but will form a genuine community of living people.

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- [1] In reality, gas exchange between the atmosphere and the oceans also leads to variations in CO<sub>2</sub> levels, especially in the CO<sub>2</sub> absorbed in water and the “sink” activity of marine organisms. We should also note the contribution of forest fires, mostly resulting from arson (from 25,000 to 100,000 hectares per year in Italy).
- [2] In some areas the problem of urban waste management has reached alarming proportions (Senior and Mazza, 2004).
- [3] Two years ago, in an area of Campania, due to a high air concentration of dioxins, part of which was deposited on forage, the chemicals ended up in cow's stomachs and hence in milk, making it unusable.
- [4] Due to nitrate pollution, water from wells in the Agro-Nocerino basin near Salerno cannot be used even to wash fruit or vegetables for export to EU countries.
- [5] Particulate larger than 2.5 µm damages the aerial pathways (nasal cavities, pharynx and larynx), while smaller particulate (breathable dust) reaches the bronchial tubes and the lungs, causing serious disease (Arpart, 2004).
- [6] To sterilise greenhouse soils the use of methyl bromide is permitted "for a few more years" . This product immediately breaks down into the highly toxic methyl group, which pollutes greenhouses and the surrounding atmosphere, and into bromine, which remains in the soil and is then found in excessive doses in vegetables.
- [7] A radioactive, colourless, odourless and chemically inert noble gas. It is formed in some rocks (in Italy chiefly in tuff deposits), and is ubiquitous insofar as its source, uranium, widely occurs in nature. It decays with a half-life of 3.85 days, giving rise to a series of products which are actually responsible for health effects (Orlando et al., 1999).
- [8] This protocol has not been ratified by the USA, Russia or China (the two latter countries recently stated their intention to ratify it). Some developing countries are also reluctant to ratify.

**GIAN LUIGI GIGLI,  
MARIAROSARIA VALENTE**

## **QUALITY OF LIFE AND VEGETATIVE STATE**

### **INTRODUCTION**

We are living a time of an authentic revolution in Medicine. In the time span of a generation, we passed from an Experience based medicine to an Evidence based medicine. Now the same generation is confronting with another important change, the development of a Technology based medicine.

Technological development has certainly created new wonderful possibilities for better diagnoses and treatments. But the applications of marvellous discoveries can be diverted, without strong moral issues, into instruments of oppression against human beings.

The technological era assumes most of the old axioms of scientism, but develops them much further: 1) The refusal of God (Nothing exists out of the universe), is pushed to the point of transforming technology itself in an omnipotent God, with unlimited power of ameliorating the quality of life, of course also in the medical domain; 2) Neutrality of science (Science is neutral by definition) becomes for technology the lack of any responsibility for the applications of the discoveries. It pretends to be amoral, but actually it becomes immoral, denying any personal responsibility for the consequences of actions; 3) Man, declassified to an animal species among the others, becomes in the technological era a disposable object and can be submitted to selection processes.

Faith in the omnipotent power of technology of being able to ameliorate the quality of life and lack of moral principles combine together. The technological power, although being intrinsically amoral/immoral, feels nevertheless a moral due to accomplish: everything that can be done must be done. Recurring often to linguistic engineering for obtaining social approval, the technological power has its own ethical code: every action is ethical if it is the result of free choice (so called "liberal theory"); every action is legitimate if socially useful (utilitarian theory); what is grounded on common and accepted costumes is legitimate (contractualistic theory, based on the consensus of the social body of adult people).

The result in the medical field is the emptiness of bioethics.

However, in medicine, perhaps more than in other disciplines, being without moral principles brings the risk of becoming more and more dependent on civil powers or on policies for the control of costs. The last decades have been marked by a dramatic fall in the birth-rate of all Western societies.

Associated to the progress of medicine, this led in time to the aging of the populations, and inversion of the demographic pyramid. Both aging and the increased possibilities of survival offered by modern therapies (in particular resuscitation techniques) are causing an important increase in the global burden of aged, chronic disabled (particularly neurologically disabled) persons.

While these important epidemiological changes were taking place, we also observed a weakening of the concept of sanctity of life and a decrease in the strength of social solidarity, the combination of which made unacceptable the financial burdens caused to society by the presence of large numbers of chronic, totally dependent patients. Added to limitations (and lack in some countries) of sufficient support to families to cover the costs of prolonged care for their relatives, this caused a gradually increasing pressure to take off the burdens of those whose lives are apparently meaningless, but who create costs and subtract resources for other purposes.

Among the chronic, neurologically disabled, totally dependent persons are the patients in vegetative state, who are not terminally ill and can remain in their condition of apparent unawareness of self and of the environment even for years, if good nursing, nutrition and hydration are constantly provided. Vegetative state is a condition that still lacks a clear understanding of its pathophysiology and can be linked to various anatomical lesions[1]. Rudimentary perception of pain cannot be excluded, with

noxious somatosensory stimulation activating midbrain, contralateral thalamus and primary somatosensory cortex in each and every vegetative patient, even in the absence of detectable cortical evoked potentials[2]. Similarly, auditory stimulation activate bilateral primary, but not associative, auditory cortices in vegetative patients[3]. There are reports as well of some modalities of stimulus recognition and discrimination, both auditory[4] and visual[5], indicating the possible persistence of elementary forms of communication. In the absence of a generally accepted neural correlate of human consciousness, it remains very difficult to interpret functional neuroimaging data from severely brain-injured patients as a proof or disproof of their ‘unconsciousness’[6].

This condition is still affected by important clinical uncertainties, leading to frequent misdiagnoses[7],[8]. There are no clinical differences between vegetative state (plain) and persistent vegetative state and it is actually impossible to predict, on an individual basis, those patients who are candidates to recovery. For these reasons, the use of the term persistent, meant to imply the irreversible nature of VS, has been discouraged. However, more recently, the term permanent to imply an irreversible state has been recommended. A patient in VS would be defined permanently vegetative when the diagnosis of irreversibility is established to a high degree of clinical certainty, that is when the chance of regaining consciousness becomes extremely unlikely[9]. However, there are well documented cases in whom the recovery of consciousness has been reported after the criteria for permanence had been met[10],[11],[12], while there are atelencephalic infants who are not vegetative despite the complete lack of the telencephalic structures[13].

This prolonged status of vigilant, but apparently unaware life has been challenged from the ethical point of view, proposing the withdrawal of assisted nutrition and hydration, once the condition of vegetative state could be considered permanent.

However, this attitude can be very dangerous for its psychosocial consequences and for the changes it can provoke in the integrity of the medical profession. In addition, although well intended among physicians and public opinion, this attitude is actually promoted for intentional reasons by currents of thought which have much wider views and intentions.

The analysis of the consequences that this kind of approach (which is supported by several scientific societies, by too many hospitals and by some families) would cause on the ethical and juridical status of the medical profession, and the impact that it could have on the society at large are the scope of this article.

Chronically (especially neurologically) disabled patients are increasingly considered as better off dead. However, the right-to-die groups which promote this kind of solution are aware of the fact that it is difficult to bring the general population to accept this view, unless the attitude of physicians in favour of preservation of life is not changed first. The turning point for this change of attitude was the definition of assisted nutrition and hydration (ANH), i.e. nutrition and hydration not administered through natural ways, as “artificial” and no longer a form of basic ordinary care (as they had always been considered), but as a form of “medical treatment”[14], which, in analogy to other forms of life-sustaining treatments, such as the use of the respirator, “may be discontinued in accordance with the principles and practices governing the withholding and withdrawal of other forms of medical treatment”[15].

Having been defined as a form of medical treatment, ANH could also be refused by the patient. Since VS patients are unable by definition to communicate their decisions, treatment could be refused by a surrogate or by somebody entitled to a permanent power of attorney. At the beginning, it was intended that the ideas previously manifested by the patients in vegetative state had to be screened in order to ascertain their will about “artificial” treatment, preferably by means of formally written advance directives, but also by means of any available evidence of previously expressed opinions about this form of “treatment”. Later on, it was accepted that the surrogate could interpret the will of the patient, trying to act in search of the best interests of the sick person.

Patients in vegetative state, if chances of recovery are unlikely, are seen by those who are in favour of the withdrawal of nutrition and hydration as dying naturally of their underlying condition (which includes a partial or complete inability to swallow food the ordinary way). Intervening to stop this natural dying process requires special justification, such as the prospect of reversing the condition. From this perspective, simply sustaining life in a state of unawareness is not beneficial, because it maintains only a "biological existence" that cannot pursue the higher "spiritual purposes" to which earthly life is directed. This theory states that once a vegetative state is diagnosed as "permanent", there should be a presumption against assisted feeding. In these cases, in fact, "treatment" by means of ANH should be considered ineffective and futile, as it sustains life whilst being unable to cause the recovery of the patient, extraordinary, i.e. disproportionate to the desired aim, and burdensome for the patient, the family (psychological stress of a slow dying process without a perceived benefit to the patient, and financial burden) and the society (consumption of resources for health care, which could be allocated for more beneficial aims).

According to this view, the ensuing death by dehydration and starvation should be regarded as a natural death, resulting from the patient's inability to take food normally, a kind of death that should be permitted as the end of the natural process of the underlying disease. For these reasons, withdrawal of ANH should not be considered an euthanasic procedure. On the contrary, according to them, it is the "artificial" administration of nutrition and hydration that is not respectful of human dignity. However, it is important to make clear that nutrition and hydration are in fact very effective (in maintaining the body homeostasis) and patients do not die because of the vegetative state (there would be no reason in stopping fluids and food if this was the case), but of malnutrition and renal failure, which are exactly the intended consequences of the withdrawal. The outcome (death) is fully intended. In addition, the same kind of procedures for nutrition and hydration are well accepted for prolonged treatments in other clinical conditions without being considered by any means offensive for human dignity (such as in case of pharyngeal and oesophageal stenosis, of amyotrophic lateral sclerosis or of prolonged posttraumatic coma).

Families who reject the feeding-treatment equation and claim that feeding is a fundamental interpersonal caring transaction are seen as denying illness, afraid of death, engaging in primitive thinking, or even as violating the autonomy of their loved one.

Based on these considerations, it became possible that decision to withdraw nutrition and hydration could be taken always, upon the request of the surrogate, unless there were explicit intentions manifested by the patients in favour of the continuation of assisted nutrition and hydration. Withdrawal is assumed to be licit, when the real will of the patient is unknown, in order not to force him/her to an artificial treatment of indefinite duration. It would only allow the patient to end his journey, letting him/her die. This circular and autoreferential reasoning has been extensively criticized in previous articles[16],[17].

The cases for whom withdrawal of ANH has been considered, especially those that have been discussed in U.S. Courts, were patients either in the VS, or suffering severe stroke which impaired swallowing, or senile and demented and thus too difficult to feed. In these cases, regardless of what we think of their "quality of life", the only reason they will die if we remove the tube feedings is from dehydration and malnutrition. In other words, death is the inevitable consequence of the withdrawal of ANH. Obviously, the purpose of removing the feeding-tube is to hasten a death that is presumed to be unacceptably late for the patient, it is therefore a genuine form of "euthanasia by omission", that is practiced only to shorten the patient's life that is considered worthless.

In a letter to the editor, commenting an article by R. Cranford[18], who developed the concept that the withdrawal of tube feeding does not constitute assisted suicide or euthanasia, Andrews wrote: "It is ironic that the only reason that tube feeding has been identified as "treatment" has been so that it can be withdrawn. Much of the debate has concentrated on the argument that tube feeding is futile treatment. I would argue that tube feeding is extremely effective since it achieves all the things we intend to do.

What is really being argued is whether the patient's life is futile--hence the need to find some way of ending that life. Once this decision is made then whatever means we use to end that life must have the definite intention of doing so--that is, euthanasia. The medical profession's desire to avoid seeming to support euthanasia has produced a tortuous argument to show that we are not responsible for the death. In doing so we commit the patient, family, and caring staff to a slow dying process. If we are to act to end the life then it would show greater respect for the patient and family to do so quickly"[19]. In accordance with Andrews, we believe that the real, but not always expressed, reason for the withdrawal of ANH is neither the respect of the natural course of a fatal disease, nor the indignity of tube-feeding in itself, but the indignity of tube-feeding ability to keep alive patients whose lives are considered to be of insufficient quality to deserve treatment. For this reason it is important to reflect more extensively on the issue of quality of human life.

## THE QUALITY OF HUMAN LIFE IN SEVERELY NEUROLOGICALLY DISABLED PERSONS

Although medicine as a whole, in addition to being a science, is in itself an art, considerations about the quality of life of a patient are certainly subject to an intrinsic lack of objectivity. This is true, without any reasonable doubt, among different external raters. More importantly, as stated by Andrews, "the severity of the disability as perceived by the observer may have little correlation with the opinion expressed by the disabled person himself. The embarrassment demonstrated by able bodied people in trying to communicate with a severely neurologically disabled person is often expressed as a feeling that the disabled person would be better off dead"[20]. "Quality of life is subjective and, therefore, no matter our views about the level of the quality of someone else's life, the only test is what that person feels. In my experience of working with severely disabled people, I have been surprised by their acceptance of, and ability to cope with, conditions I would have thought to be almost intolerable"[21]. In our opinion, the discussions about quality of life often hide a kind of evaluation typical of the interpersonal relationships in our society, based on the ability to produce and to be useful. In this society, not only the lives of patients in VS, but also those of gravely disabled patients and of every person marginalized out of the productive system are considered less worthy. This applies also to the use of health resources, which are considered well invested if they rehabilitate patients for productive, or at least independent lives, but are considered wasted when they only prolong a dependent chronicity. This is especially true for our western societies, where any increase in expenditures related to health is subject to anathema and which include affluent countries with significant proportion of the population deprived of any kind of health assistance.

According to Andrews, "The present attitude to 'value for money' and that financial resources should only be used for demonstrable clinical gain, further leaves the disabled person dependent not only on the help but also the good will of able bodied people"[22]. This attitude can provoke in the disabled person, or in the person foreseeing a severe neurological disability, not only lack of self esteem, but also concerns for the economic burden he/she is going to cause to society or, even worse, to the family, especially in those societies who do not offer sufficient support for the costs of disability. In the view of Andrews, "The ethical problems in chronic disablement are, therefore, not so much to do with the severity of physical disablement but with the ability to accept the handicap resulting from the impairment or disability and the influence of society's, usually negative, attitude to disablement. This, however, does give the opportunity, if not the duty, to take every effort to provide facilities to improve the quality of life of even the most severely disabled person. It is ethically essential to give the opportunity to live (in all meanings of the word) before providing the facilities to die"[23].

The question is the following: is the opportunity to live asked by Andrews always given to patients in VS, or are families under pressure to end a life considered by our society as worthless? Going back to the initial definition of ANH as a burdensome treatment, we could even ask ourselves: is the

“treatment” burdensome or are simply these patients (and many other kind of disabled after them) a burden for our societies and for the (limited) money we want to invest in our health systems?

## INFORMED CONSENT AND QUALITY OF LIFE

This leads us to the problem of the consent for the withdrawal of ANH. For VS patients the consent should be expressed by surrogate agents, acting on their behalf by means of advance directives or in force of judicial decisions. However, are they always free from pressures and, therefore, do they always act in the respect of the legitimate interests of the patient? When patients are incompetent, their medical-and-nursing best interests, rather than their relatives' wishes, should be decisive, although, of course, relatives should be consulted. In fact, differently from competent persons, whose death is imminent and who decide to accept their death, the cases of severely neurologically disabled patients represent incompetent persons who are not otherwise dying, but whose death is hastened because they are not going to die naturally.

Not only, even if out of financial or psychological pressure, the surrogate (and the judge) can erroneously claim that it is in the best interest of patients to be left without nutrition and hydration using the criterion of a presumed lack of quality of life.

We have already seen that the appreciation of life's quality can be different between disabled persons and able-bodied observers (including relatives): this difference can create serious biases in the family at the moment of making decisions regarding end of life issues in a disabled member. In addition, there are psychological pressures that can be perceived by a disabled person's family. These two considerations raise the suspicion of a possible conflict of interests when the family, or any other surrogate in the decision making process, decides to put an end to the life of a person because of a poor quality of life. In other words, we can question whether a patient in a very prolonged vegetative state does actually have any interest (except for life and very little hope of recovery) rather than asking what is his/her best or worse interest. According to Andrews, “If this is the case, then the decisions are being made for the benefits of others, a dubious decision making process”[24].

Certainly, when the consent is expressed by means of advanced directives, it can help at least to identify the wish of the patient. On the other hand, there is always the suspicion that this consent is not fully informed, there is often a lack of specificity of directives. Furthermore the decision could have been made by the patient while suffering mentally, in particular from depression, in which case his/her decision may not be rational.

In addition, in case of progressive diseases (e.g. vegetative state resulting from degenerative dementia), the decision could be biased by the kind of pressure that we have tried to describe above, notwithstanding the fact that the disabled person could have changed his mind, but is no longer in the possibility of expressing his/her last will. In fact, as noted by Andrews, it is frequent to observe “people who stated, whilst able-bodied, that they would not wish to continue living if they developed severe disabilities but who have changed their mind when they found themselves in such a situation.”[25].

Finally advance directives, which are seldom precise about severity and duration of the required condition, may have been given many years before the actual decisions about therapy and care, without sufficient consideration of changes that might have taken place in scientific knowledge and treatment opportunities.

In summary, the debate about the withdrawal of assisted nutrition and hydration in vegetative state is undermined by several factors: a) a prognostic evaluation about outcome has been transformed into the diagnosis of a clinical condition characterised by permanency; b) basic health care has been transformed into a medical treatment, subject to refusal by the patient; c) consent about decisions affecting human life has been made disposable for surrogates, without considering that life has long been considered juridically as an undisposable good; d) evaluations about quality of life have been

transformed into judgments about the indignity of human life to be lived. These premises have been taken to justify a conduct which is actually characterised by: a) the denial of basic health care to patients, resulting inevitably in their death, b) the aim to hasten their death, because their life are considered no longer worth living. More unacceptably this could happen for a clinical condition, such as VS, the pathophysiology of which is unclear, the diagnosis of which is inaccurate, and the prognosis of which only probabilistic.

## THE SLIPPERY SLOPE OF CONSEQUENCES

Patients with severe neurological disabilities are incompetent persons who are not dying for other clinical reasons, whose death is hastened just because they do not intend to die naturally. This attitude and the messages that are implicit in it are not without consequences. Those denying the consequences of withdrawal of nutrition and hydration should consider how our perception of these problems has already changed in the past ten years and how much it could change in the future.

In the era of Quinlan and Cruzan, the burden of proof lay on those who would deny basic care to the severely cognitively impaired. Today, the burden of proof is on those who would continue it. If that isn't a slide down the slippery slope, what is? [26].

### The withdrawal of ANH to generalise euthanasia by omission

"In the United States a number of highly publicized court decisions regarding patients suffering from a variety of illnesses established a legal precedent for withholding or withdrawing ANH. At the same time legislatures enacted laws further enshrining this practice as a legal right. Today, advance medical directive statutes (providing for the execution of a Living Will or Durable Power of Attorney) are common throughout the United States. These statutes allow patients to forgo life-sustaining interventions, including ANH, if they should be incompetent and diagnosed with a qualifying condition. Initially, the only qualifying conditions were terminal illness or a persistent vegetative state. Predictably, however, other vaguely described conditions such as serious debilitation and the lack of meaningful consciousness were eventually added to the list. Consequently, some have advocated withholding or withdrawing ANH from patients with Alzheimer's disease and other forms of dementia" [27]. As a neurologist, I would only like to recall a landmark article published twenty years ago on the NEJM, in which it was considered "ethically permissible" to withhold "nutrition administered by ... gastric tube" from "severely and irreversibly demented patients" as well as from those who are "pleasantly senile" [28].

In the United Kingdom, there is extensive debate on the Mental Capacity Bill, which was presented to the UK Parliament on 17th June 2004, following a period of public consultation and examination by a Parliamentary Scrutiny Committee [29]. Although aimed to clarify legal procedures for medical and financial decisions for those unable to make decisions for themselves as a result of illness or accident, it legally opens the door to starvation and dehydration of those suffering from dementia, stroke or traumatic brain injury, as well as other illnesses.

### Social acceptance of active euthanasia

Active euthanasia is illegal in the entire world, except in the Netherlands and in Belgium. Withdrawal of nutrition and hydration could be the key to open the still strong existing barriers which oppose the legalisation of euthanasia in the majority of countries. Pro-euthanasia bioethicists have been fully aware of this for many years. As early as Sept. 1984, at the 5th Biennial Conference of the World Federation of Right to Die Societies held in Nice, Australian bioethicist Dr. Helga Kuhse explained the strategy of the euthanasia advocates: "If we can get people to accept the removal of all treatment and

care—especially the removal of food and fluids—they will see what a painful way this is to die and then, in the patient's best interest, they will accept the lethal injection".

Distinguished scholars are aware of the consequences of decisions on nutrition and hydration withdrawal[30],[31]. "Whatever semantics are used, withholding or withdrawing treatment will have the same outcome as euthanasia, i.e. the clinician will have taken a decision that the patient should die"[32]. Death by starvation and dehydration "denies the respect we have for the dying person. Even a dead person is treated with respect and we would not carry out acts on a dead body simply because they would not be felt. Society is, therefore, in a dilemma – it is of the opinion that the patient should die, but it does not want a quick death because that would be seen as euthanasia"[33]. The conclusion of Andrews is very stringent in its logic: "Once the decision has been made by patient, family and clinical team that it is inappropriate that life should continue, then the quality of the dying process should be of the highest standard. The present attitude of ending the patient's life by withdrawal of nutrition and fluids is highly unsatisfactory, if not inhumane, and the option of euthanasia would be a far more satisfactory solution"[34].

We believe that, although unintended, the withdrawal of nutrition and hydration to patients in vegetative state and its extension to other patients with neurodegenerative diseases and with severe mental retardation can actually turn out to be, in the long term, the Trojan horse to make active euthanasia acceptable to societies and health professionals.

#### VS patients as possible organ donors

An even more disturbing expansion of our dealing with patients in VS as with lives unworthy to be lived, regards the field of organ harvesting for transplants. Authoritative authors begin to suggest that continued life in a state of unconsciousness should not be considered of commensurate value to organ donation and that this decision can be taken by the patient himself (before becoming unconscious), or by a surrogate. (Unconscious) life becomes a disposable good, which can also be administered by a surrogate[35]

#### Decisions on quality of life and pressure on health professionals

Despite Nurnberg, it seems that today the doctor is called again to decide on the value of human lives and to hasten the death of those lives that are believed to have insufficient quality to be considered worth living. In the long term, this could destroy the relationship of trust between the patient and the doctor. In fact, the relationship of confidence that must prevail between doctor and patient would be undermined by the former's power to legally end the latter's life.

Not only, it is possible to start observing pressures exerted on physicians (both as individuals and as a profession) to act against their conviction and to act against the Geneva Human Rights Convention which states that the mandate of the physician is for him to maintain "the utmost respect for human life from the time of conception, even under threat" and not to use his "medical knowledge contrary to the laws of humanity"[36]. As it already happened to obstetricians-gynaecologists in some countries with reference to abortion,

there is the risk that the exercise of the medical profession will be precluded in the future to physicians, who will not accept to perform euthanasia or physician assisted suicide.

The possible division of doctors and nurses into those who do and those who do not participate in these procedures is the source of great fears. However, more terrible is the perspective of a consensus on the opinion that withdrawal of nutrition and hydration are not to be considered a form of passive euthanasia, but rather just procedures decided according to good clinical practice. In this case, doctors and nurses who respect sanctity of life and integrity of health professions should probably face charges of malpractice, having no right even to conscientious objection. Doctors, and nurses especially, will be under pressure from families, hospitals and Courts. They will be called to justify their refusal of

hastening death in a condition for which there is no apparent reason to live, being the right to life based on the recognition from outside of a sufficient level of its quality.

Society itself could pretend to have a right on human life

The first risk is that doctors, having become the real judges of the quality of life of the patients, could decide to go beyond the desire itself of the patient. This is already happening in Holland. Although reliable statistics are almost impossible to obtain from the Dutch situation, many credible reports of doctors killing patients who had never requested euthanasia, and of patients being refused medical care after having refused euthanasia have come to public attention. Regarding the drift towards the so-called involuntary euthanasia in Holland[37],[38], the least to say is that in the Netherlands “patients or their surrogates do not always give informed consent; physicians acknowledge that their intent is to end life and do not uniformly seek less drastic approaches to alleviating suffering”[39].

If it is dangerous to give the power to kill to medical professionals, it is even more dangerous to give these rights to the society. Many patients in VS can live with a PEG for years. This is viewed as an indication of a “burdensome” treatment. However, the argument could be reversed. In fact, if a “treatment” can be continued for years without any trouble, it should be classified as non-burdensome.

It appears that is the life of the patient that is considered burdensome by society and (sometimes) by relatives. Families should be supported (financially, morally, psychologically), and societies should accept the “burden” of their frail members, if they do not want to become inhuman and to lose the standards of our civilization. For society, the burden is not PEG, but nursing care which could become expensive. However, if this were the real reason for stopping feeding, it would apply equally to stopping even food and water administered by mouth as well as all nursing care, for that is what costs so much. As a matter of fact, there is a general opinion that the increasing age of the community will make this a greater problem in the future. Those who look at the ageing of society as a catastrophe and those who do not want to spend in health converge in foreseeing hospital beds blocked by chronic patients who survive for years with PEGs, and unable to help those who would benefit in a real way by hospital admission.

From both a logical and a practical point of view, it is impossible to provide a framework that will prevent abuse. Pressure may be exerted on the doctor to end the patient’s life on non-medical grounds, including lack of hospital beds, the prospect of financial gain, or even political reasons. There will inevitably be a slide down the “slippery slope” to involuntary and non-voluntary euthanasia. People will be killed who never asked to die and who could have been helped by palliative care. Doctors (considering what they think is the best interest of the patient) and health authorities and tribunals (considering the best interest of the society) will take the decisions, without problems, unless reluctant families will create them, as it happened in the famous case of Terry Schiavo.

## CONCLUSIONS

The issue at stake is that withdrawal of ANH will inevitably desensitise society toward euthanasia. In fact,: “if there is no sense for this kind of life, why continue feeding?” But if so, why do we have to keep them alive? Society will inevitably face a confusion between the quality of human life and the inherent dignity of every human being: is it human what is useless, purposeless, unable to have a social relationship? Once we accept that humanity may be weighted upon quality of life, and subject to evaluation based on usefulness and possibility of relationship, it is the concept itself of what is human that will be challenged. The consequences can be very extreme, like in the criteria for recognition of personhood proposed by Engelhardt[40].

The confusion between the quality of human life and the inherent dignity of every human being, can only be the cause of a selective attitude in the recognition of human rights. This would be certainly a

regression for mankind. Today we again feel under pressure for a graduality in the recognition of human dignity, but we should be sufficiently wise to remember that every time we humiliated human dignity, conferring it in different degrees and creating discriminations, we have only created the premises for new violence and death.

Why should we be concerned by the attitudes towards patients in the VS?

The entire story of withdrawal of nutrition and hydration is a turning point of our civilization, it is paradigmatic of the direction in which we want to orient our mutual relationships, of the way in which we want to care for and relate to elderly, handicapped and unconscious people for the years to come. There is the concrete risk of further weakening the ties of solidarity inside families and inside the social body.

In conclusion, nutrition and hydration should always be provided to patients (including patients in VS) unless they cannot be assimilated by a person's body, they do not sustain life, or their only mode of delivery imposes grave burdens on the patient or others. If PEG feeding can be continued for years, it cannot be considered burdensome for the patient. The burdens of ANH to society should not normally arise in developed countries. Our world is increasingly opposed to spending anything much on the elderly, handicapped, comatose, the VS, etc. Medical doctors and nurses should not support the general trend towards a selfish society, but rather re-affirm the intimately compassionate nature of their professions, taking a preferential option for caring for the frailest among our fellows. That does not mean over-treating them. But it does mean very consciously resisting the equation of chronically dependent patients as improper bed occupants and as burden to public finances.

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