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THE ETHICAL DEBATE IN BIOETHICS: THE CONTRIBUTION OF PERSONALISM*

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The paper gives an overview of two main positions existing at present in the field of bioethics: the „secular” conception and the „personalistic” one. The former tries to justify the moral choice autonomously and empirically with reference only to man. Each individual makes his own moral (private) choice, without any reference to God, that is to transcendency. The secular method of analysis is „factual” (or „empirical”), as truth is related to the empirical verification of facts: truth (and, above all, moral truth) can only be physical (not metaphysical). It is also „calculating”, as rationality is reduced to the search for logical consistency and coherence of the arguments. The paper briefly comments on the most widespread philosophical trends of the secular perspective: sociobiologism, subjectivism, neoutilitarianism and neocontractualism. It then proceeds to characterize ontological personalism as a philosophical point of view that justifies respect for human life in all its aspects. The ontological personalism considers the „person” as the centre of bioethics. On the basis of the ontological concept of „person” it is possible to justify the fundamental principles of personalistic bioethics: a) the fundamental value of life; b) the principle of totality or therapeutic principle; c) the principle of freedom and responsibility; d) the principle of family; e) the principle of sociality and assistance. The most important philosophical contribution of personalism to contemporary bioethics (or better, to metabioethics) seems to be its ontological concept of the „person”: it provides a deeper understanding for moral and juridical reflections that are respectful of all human beings without discrimination. (Abstract writen by the editor.)

Key words: contemporary bioethics, meta-bioethics, ontological personalism, secular approaches in bioethics

The present scientific and technological advance in the biomedical field opens new possibilities of intervention on life (human and nonhuman) and, at the same time, it raises new moral questions. Anything that can be done, must be done anyway? Because an action can be (technically) undertaken, does it mean that this action is (morally) right? There is substantial theoretical agreement among scientists, moralists and jurists on the necessity of giving some sort of *limits* to technological researches and applications: there are only a few people left (as far as the

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theory is concerned) who accept the 'illuministic' conception of complete trust in scientific progress, asking for the absolute freedom of science. But, *which limits*? This is the specific question for moral philosophy. Contemporary philosophical thought is strongly marked by *pluralism*: moral positions differ as far as the choice of principles and values is concerned. There is no absolute unanimity in morality: different moral trends suggest (or better, justify) different principles and values that should be the boundary line between what is right and what is wrong in scientific practice.

In other words, moral philosophy does not deal with the epistemological question of justifying bioethics, but it deals with the justification of *metabioethics* (1). Metabioethics tries to give a rational explanation to the ethical choice of the principles and values which determine man's behaviour when he has to intervene on life (human and nonhuman) (2). It is obvious that if metabioethics is different, bioethics is also different: if the moral theory is different, its practical application is, consequently, different.

This is why the main question of the present philosophical debate is no longer: „is it necessary to give science and technology ethical principles?", but the question is: „which ethics for bioethics?". And it is just at this level (of metabioethics) that the role of philosophy is clear: it deals with discrimination between good and evil in the scientific field and with the right way of acting in the biomedical field.

Because of the existing moral pluralism, the values and principles which are proposed in bioethics are extremely diversified (3).

The question that follows is therefore inevitable: **which moral foundation in bioethics?**

Two of the main existing positions at the moment are: the **„secular" conception** and the **„personalistic" conception**.

1. The *secular conception* (which includes different theories) is based on *the foundation of moral principles and values „etsi Deus non daretur"*, that is, „as if God were not", or, „in absence of God" (4). In other words, the secular conception tries to justify the moral choice autonomously and empirically with reference only to man. Each individual makes his own moral (private) choice, without any reference to God, that is to transcendency. This kind of approach is, philosophically speaking, „factual" and „calculating" (as Heidegger refers to it), because it structurally denies metaphysics. The secular method of analysis is „factual" (or „empirical"), as truth is related to the empirical verification of facts: truth (and, above all, moral truth) can only be physical (not metaphysical). Like neopositivism, metaphysics is considered a nonsense: only facts are real and true. The secular approach is also „calculating", as rationality is reduced to the search for logical consistency and coherence of the arguments.

The most widespread philosophical trends of the secular perspective are: sociobiologism, subjectivism, neoutilitarianism and neocontractualism. Even though they are quite different from each other, they have in common the acceptance of the physical dimension only, and the rejection of any approach that will transcend the material aspect of what is real.

a) **Sociobiologism** considers the moral principles and values which belong to a particular society in a particular historical period, as the result of a sort of „natural selection" for the natural adjustment of human life to the external world (the „environment"). When man's behaviour encourages the evolution of the species, then, it is considered 'positive' (or, morally right): the tendency to sacrify respect for the individual in favour of the „adjustment" or „improvement" of the group (that is, the „human species") in its totality is clear (5).

b) The theory of **subjectivism** (or, **noncognitivism**) denies the existence of truth in ethics (the formula „ethics without truth" is well known). This trend falls into the most absurd irrationality: each moral choice can be neither true, nor false. In moral matters we cannot know what is true or false: every action may be, at the same time, right and wrong, since it cannot be empirically verified. The neopositivistic assumption is clear. Only what is (or can be) factually verified is true or false. As moral action cannot be verified, it is neither true nor false. Therefore the moral choice is a „decision" or, better, an act of arbitrary individualistic will. The moral judgment is, in the end, subjective: it is only possible to discuss the logical consistency, but the fundamental principle of the moral choice is irrational. From here comes the assumption of the absolute priority of the concept of „selfdetermination", meant as individual freewill. Individualism is softened by the suggestion of the concept of tolerance, meant, within the social context, in the „weak sense" of the respect for the arbitrary decision of others (6).

The theories of neoutilitarianism and neocontractualism try to overcome the individualistic tendency through the search for an ethical criterion that, if not universal, could at least be based on a mutual intersubjective understanding.

c) **Neoutilitarianism** is based on the ethical criterion of what is socially useful. The fundamental moral principle is the „principle of utility" or „the greatest happiness principle" (defined by J. S. Mill, like Bentham before him (7)): actions are right only if they tend to promote happiness (pleasure or absence of pain; satisfaction of desires, preferences or interests) and to avoid unhappiness (pain or privation of pleasure; frustration of desires, preferences or interests). This principle, applied to society, means that the greatest happiness (or good) is the optimization of what is pleasant and minimization of what is unpleasant for the greatest number of individuals. The cost/benefit ratio transposed from the egoistic to the collective level (this is the distinctive feature of this trend) leads to the identification of the measure of right and wrong in social utility (8).

d) The theory of **neocontractualism** allows the moral choice to coincide with the „contract", that is the agreement among the „moral agents" (or „moral actors") who constitute a „peaceable moral community": the moral content is the result of a decision shared by the community members. In this sense, the measure of right and wrong is conventional: it depends on the stipulation of the moral community (9).

From what has been mentioned here, a common feature of the secular conceptions emerges: the value of human life is not recognised in itself, but it is recognised only under some conditions (or better, under the factual verification of certain conditions). *Not all human beings are „persons"*, that is, are „moral subjects" (or, possessors of a valuable life) (10): not all human lives are considered worthy to be respected. Moral status is recognized only to some entities (human or nonhuman) who are endowed with certain „capacities". But what makes life (human or nonhuman) valuable? Which are the necessary conditions of personhood?

Sociobiologists recognise the value of human life only if it improves the evolution of the human species; subjectivists consider lives worthy of respect only if they show the capacity of selfawareness, autonomy and selfdetermination (that is the capacity to take a decision on their own); neoutilitarians acknowledge the moral status only to „sentient individuals", that is, to individuals that possess the sensory capacity of feeling pleasure or grief; neocontractualists identify moral subjects in selfconscious and rational entities, capable of understanding the notion of worthiness of blame and praise.

In other words, the respect for life is submitted to the verification of certain empirical conditions: the survival and improvement of the human species or the presence of certain capacities such as, perceptiveness, selfconsciousness, rationality and free will. But what if human life does not favour the evolution of the species? And what if human life has not yet developed or is no longer able to exercise its sensitive, rational and/or volitive capacity?

The practical consequence of the secular theories is a strong discrimination between human beings: according to the secular point of view, only some human lives need to be respected (in a moral and juridical sense). Not all humans are persons, and, paradoxically, not all persons are humans.

There is a *restriction* of the meaning of the term „person", as this cannot be assigned to all human beings: as in fact, it cannot be assigned to subjects who could produce an „involution of the species" (this is the case with the defective newborn). It cannot be assigned to subjects who are not yet, or are no longer perceptive (zygotes and embryos until the nervous system is at least initially formed, as well as people who suffer brain damage that prevents them from exercising any kind of sensory functions; or patients in the last stage of illness who suffer too much) or to subjects who are not yet or no longer selfconscious, rational and autonomous (embryos, foetuses, infants, children, mentally retarded adults, hoplessly comatose, old people and the seriously handicapped). The deferment of the „beginning" of a person and the anticipation of the „end" of a person, with reference to their biological birth and death, imply a lack of respect within the so called „boundary conditions" (prenatal, neonatal and terminal life) and „marginal cases" (when life is seriously handicapped).

Paradoxically, the term „person" may be assigned to nonhuman beings, like animals (as they can „feel" and perceive) or robots and artificial intelligences (as they exercise rationality and selfdetermination).

The critics of the secular perspective point out that the definition of the line between humans and persons is arbitrary: the contribution to the improvement of the species or the factual verification of certain behaviours are, inevitably, *reductive criteria*.

Who decides what is evolutive or involutive for the human species? How could we objectify sensitiveness, which is structurally a subjective experience? How could we identify what is useful for society in its totality (what is useful for society could be not useful for an individual)? Why are individuals who no longer exercise (or never exercised) certain functions not worthy of respect? A sleeping individual or an alcoholic (who do not exercise „personal" capacities at the moment): are they persons or are they not?

2. Many questions remain without answer. This is why there emerges the necessity of a philosophical point of view that justifies respect for human life in all its aspects. Here is the role of **personalism** (11). According to the personalistic conception in bioethics human life must be respected from the moment of conceiving (the fusion of the gametes) until the moment of total cerebral death. We are talking about the **ontological personalism** that goes back to St. Thomas Aquinas, reconsidered by J.Maritain (12). This remark is important in order to avoid misundertandings with other personalistic conceptions like dialogical or existentialistic personalism, which tend towards subjective solutions.

Ontological personalism considers the „person" as the centre of bioethics. The clearest expression of the concept of „person" according to ontological personalism has been worked out by Boethius, and then reexamined by St.Thomas (13): the „person" is „individua substantia rationalis naturae". There are three elements that identify a person: I. substance; II. individuality and III. rationality. Each point requires to be analyzed.

I. Substance indicates the act of being that has in itself the reason of its own being: substance means the presence of an ontological substratum that trascends the mere joining of the parts and goes beyond the acts (it is the metaphysical principle: the whole is more than the sum of parts and acts).

II. The individual aspect specifies the principle of distinction of every existing human being: our body, or still better, our genetic code makes us unique.

III. Rationality refers to a feature which belongs to the essence (or the substance or „nature") of a human being, even if the human being is not able to exercise it at any given moment.

Simply because of the fact that a „human being" is (that is, exists), he/she is a „person", apart from the capacity of improving the species or of behaving in some particular ways, apart from the capacity of exercising perceptiveness, selfawareness, rationality and will at the moment. Human beings are much more than their own acts: the „person" is much more than the „sum of the acts" performed (perceptions, thoughts or wishes): the person trascends them. Human beings are one physical, psychic and spiritual totality: the metaphysical element is the condition of the physical and psychic element. In short, the theory of personalism justifies the identification between the „human being" and the „person". „All human beings are persons" is a statement that appears obvious, but, it needs to be philosophically justified, as the secular positions have opened a discussion about it.

According to the theory of ontological personalism all humans have a personal status: zygotes, embryos, foetuses, the newborn and children are all „persons", as they all possess in nuce (potentially) all those elements that develop and allow them to become accomplished human beings. In the same way, the elderly, the handicapped, the insane and the terminally ill are all „persons", even if they do not perform some particular actions. The biological cycle of human life is an expression of the personal human life: every single expression of human life must be respected and protected.

The personalistic theory, based on the ontological foundation of the concept of „person", assigns the personal ordinance to the human being as it recognises the existence of a unitary and permanent centre that transcends outward manifestations and behaviours. On the contrary, the antipersonalistic (or secular) approach recognises the personal ordinance of some human beings only (and, of some nonhuman beings) on the basis of an empirical verification of behaviours.

On a practical and applicative basis, the ontological personalistic conception (in the metabioethical field) makes possible the respect for human life in all its aspects. On the basis of the ontological concept of „person" it is possible to justify **the fundamental principles of personalistic bioethics**: a) the fundamental value of life; b) the principle of totality or therapeutic principle; c) the principle of freedom and responsibility; d) the principle of family; e) the principle of sociality and assistance.

a) **The fundamental value of physical life** indicates that life is not at our disposal and is sacred. This conception is strictly connected to the ontological conception of corporeity: our body cannot be simply reduced to an instrument or an object (Korper); it is not a group of cells and neutrons. The physical and psychic dimensions do not complete the human being. Our body is subject (Leib), as it is where the person, considered as one transcendent totality, is revealed. Our mind organizes our brain and our soul gives life to our body. The rejection of any form of suppression of human life (abortion, euthanasia, suicide ecc.) is strictly related to the conceptions expressed here above.

b) According to the **therapeutic principle**, the medical act (or any other act which interferes with human life) must consider the patient in his totality. If our body is a unitary whole, any intervention on the „part" must keep in consideration the „whole" (which is, qualitatively speaking, more than the sum of the parts). The therapeutic principle justifies intervention on human life only if the intervention is directed to the actual disease (or to the active cause of the disease), which otherwise could not be cured, having not only the concrete hope of a positive result, but also the patient's consent. The therapeutic principle is not only applied to surgical operation, but also to the gene therapy of tests on human embryos, sterilization and organ transplants.

c) **The principles of freedom and responsibility** derive directly from the fundamental value of life. To be free does not coincide with selfdetermination: to be free does not mean the possibility of exercising free will in an absolute way. On the contrary, an absolute freedom coincides with an imposition of force which inevitably causes violence and conflicts. Every act of freedom is real only if it is based on the idea of responsibility in the sense of „respondere" or being responsible for our own acts towards ourselves and towards all other human beings.

Freedom can be proved true only if other human beings are respected in their right to be free, but this means that also their life must be respected as well as their freedom. Man cannot be free if he is not alive: freedom presupposes life. To be free does not mean that we can decide to have children „at all costs" (accepting an indiscriminate use of artificial techniques) or decide that our life is not worth living (signing the „Living will"). To be free means to make responsible choice for ourselves and for others.

d) **The principle of family** refers to the necessity for each individual to live in the family to establish his/her identity. Family, in the Aristotelian sense, is the natural community in which the individual can recognise his/her specific role. Family is the first community in which the individual relates to others, acquiring his/her identity. Heterologal insemination and ectogenesis are techniques which operate against family in this sense.

e) **The principle of sociality** consists in promoting life and health in our society through the promotion of life and health of every single human being. The concept of sociality is aimed at reaching the common good through the consideration of the individual good. The principle of sociality is supported by the **principle of assistance** towards whoever needs help and support. The principles of sociality and assistance come from the duty of mutual respect based on the dignity of others as human beings: the „person" is the source and aim of society and the act of being a person is revealed by taking part in the common good. The principles mentioned here are related to the problem of health and economic policies (allocation of resources etc.).

Personalism gives a very important philosophical contribution to bioethics (or better, to metabioethics): the ontological concept of the „person" provides a deeper understanding for moral and juridical reflections in bioethics which are respectful of all human beings without any discrimination.

Notes and references

(1) We can not talk „of" bioethics only, but, before that, we must talk „about" bioethics. Bioethics presupposes *meta-bioethics.*

(2) E. Sgreccia: *Manuale di bioetica.* Vita e Pensiero, Milano 1991, Vol. I-II.

(3) M. Stocker: *Plural and conflicting values.* Clarendon Press, Oxford 1990.

(4) It is a statement which goes back to Grotius, who is considered the first „modern" and „secular" philosopher.

(5) E. O. Wilson: *Sociobiology: the new synthesis.* The President and fellows of Harvard College, Harvard 1975.

(6) Non-cognitivism is a radical subjectivism, which gave rise to two trends: „decisionism" and „emotivism". The first may be identified with H. Kelsen and, in Italy with U. Scarpelli; the second with A. J. Ayer and C. L. Stevenson.

(7) J. S. Mill: *Utilitarianism.* First published in 1861, reprinted in A. Ryan (ed.): *Utilitarianism and other essays.* Harmondsworth, Penguin 1987, p. 278.

(8) P. Singer: *Practical ethics.* Cambridge University Press, Cambridge 1973; *Animal liberation: a new ethics of our treatment of animals.* New York Review Random House, New York 1975; *Applied ethics.* Oxford University Press, Oxford 1986; J. Harris: *The value of life: an introduction to medical ethics.* Routledge & Kegan Paul, London 1985; M. Tooley: *Abortion and infanticide.* „Philosophy and Public Affairs", Fall 1972, 2, No. 1.

(9) T. H. Engelhardt: *Foundations of bioethics.* Oxford University Press, New York 1986; D. Parfit*: Reasons and persons.* Oxford University Press, New York 1984.

(10) The concept of person must be seriously examined in bioethics as the moral and juridical debate of our days is based on determination of it. The assiological and juridical meaning to be assigned to the term itself is unanimously accepted: the „person" must be morally respected and juridically protected. But there is disagreement about the meaning of the concept itself. M. Goodman (ed.): *What is a person?* Humana Press, Clifton (New Jersey), 1988.

(11) E. Sgreccia: *Manuale di bioetica.* cit.

(12) St. Thomas Aquinas: *Summa Theologica.* J. Maritain: *Les droits de l'homme at la loi naturelle.* Editions de la Maison Francaise, New York 1942.

(13) S. Boethius: *De persona et duabus naturis.* Contra Eutychen et Nestorium, III, 4 – 5.

L. Palazzani: The Ethical Debate in Bioethics: Contribution of Personalism/Etická debata v bioetike: príspevok personalizmu, ME&B, 2(2)1995, p. 1 – 5. Práca podáva prehľad o dvoch hlavných smeroch prítomných v rámci súčasnej bioetiky: o „sekulárnej" a „personalistickej" koncepcii. Prvá sa snaží zdôvodniť morálne rohodnutia autonómne a empiricky, odvolávajúc sa výlučne na človeka. Každý jednotlivec prijíma vlastné (súkromné) morálne rozhodnutia, bez ohľadu na existenciu Boha alebo transcendencie. Sekulárna metóda uvažovania je „faktická" (alebo „empirická"), keďže podľa nej pravda závisí od empirickej verifikácie faktov: pravda (a nadovšetko morálna pravda) môže byť len fyzická (nie metafyzická). Je tiež „kalkulačná", keďže racionalita sa redukuje na hľadanie logickej konzistentnosti a koherencie argumentov. Príspevok v krátkosti komentuje najrozšírenejšie súčasné smery vychádzajúce zo sekulárneho prístupu: sociobiologizmus, subjektivizmus, neoutilitarizmus a neokontraktualizmus. V ďalšom sa venuje charakteristike ontologického personalizmu ako filozofického prístupu, ktorý odôvodňuje rešpektovanie ľudského života vo všetkých jeho aspektoch. Pokladá „osobu" za ústredný bod bioetiky. Na základe ontologickej koncepcie „osoby" možno zdôvodniť základné princípy personalistickej bioetiky: a) základná hodnota ľudského života, b) princíp totality, alebo terapeutický princíp, c) princíp slobody a zodpovednosti, d) princíp rodiny, e) princíp sociality a pomoci. Najdôležitejším filozofickým príspevkom personalizmu pre súčasnú bioetiku (alebo, lepšie, meta-bioetiku) je ontologická koncepcia „osoby": umožňuje hlbšie pochopenie morálnych a právnych postojov, ktoré rešpektujú všetky ľudské bytosti bez diskriminácie. (Abstrakt redakcia.) *Kľúčové slová: súčasná bioetika, meta-bioetika, ontologický personalizmus, sekulárne smery v bioetike*

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> **"A doctor must always bear in mind the obligation of preserving human life."**
> **"A doctor owes to his patient complete loyalty and all resources of his science."**
>
> *International Code of Medical Ethics, WMA*

VÝUKA MEDICÍNSKEJ ETIKY

TEACHING OF MEDICAL ETHICS

PATIENT AS A PERSON

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Abstract

The paper presents a didactic model of a lecture on a concrete medical ethical problem, which is given to the medical students. The goal of the teaching programme is to improve the ability of students in understanding the problems of oncology patients, as well as other patients with incurable diseases. On the basis of a moral reflexion while facing an extreme life situation of the patients students are encouraged to find their own ways with respect to possible personal contribution to the welfare of their patients.

Key words: the patient as a person, spiritual dimension of human life, patient's feelings, spiritual needs

> *"Where is the love of man there is also the love of art."*
> *(Hippokrates)*

We present here briefly the scheme of a programme on medical ethics developed for medical students, which tries to expose more specifically the needs of patients with malignant, or other incurable diseases. The programme is given as a lecture followed by discussion.

The aim of the programme: (1) To help students in understanding better oncology patients and patients with other serious incurable diseases on the basis of own moral reflexion of an extreme life situation. (2) To provide the students with a model ethical framework for determining doctor's general and specific obligations, as well as for finding their own personal ways of contribution to the welfare of these patients.

Programme overview: 1. Introduction. 2. How the person can be described ? 3. The spiritual dimension of person. 4. Topics of discussion. 5. Conclusion.

1. Introduction. The diagnosis of cancer, or other life threatening disease may often provoke a serious life crisis in the patient. The apparent loss of meaning and future perspectives of life frequently undermines previously unquestioned trust in reality. Self-esteem, self-confidence, and also religious faith might be shaken, while relationships to other persons could be broken or hampered by the uncertainity of patient's future. Many of the formerly effective coping strategies become inadequate in the new situation. Concurrent diseases, progress of the malignant disease itself, as well as the therapies used are more or less connected with a considrable distress, pain, other physical symptoms and the stress of repeated hospitalizations. All this together usually aggravates a rising sense of aloneness, unhappiness, hopelessness; bringing about a deep multifaceted personal crisis (including spiritual one) (2).

2. The person can be described as a complex entity, that means an integrated (human) being, who altogether is more than just the sum of his/her biological, psychosocial, and spiritual dimension. Each dimension is a reflection of the whole person and can be defined as a set of universal human needs. When all the needs are met the result is a complete health. When some needs are not met properly, the result might be the sickness, or at best the absence of an actual illness (2).

3. The spiritual dimension of person can be defined as the human capacity to transcend self, which is reflected in basic spiritual needs:

a) The need for **self-acceptance**, a trusting relationship with self based on sense, purpose and meaning of life. Human attitudes are based on value systems, that are influenced by their enculturation, and also on the experience gained during life, that are interpreted in terms of that enculturation. In our culture, the basic value and personal priority is to be successful, to have the achievement of an aim or purpose. Self-acceptance is connected with a self-respect and the conception of dignity.

b) The need for the **relationships with others**, characterized by a non-conditional love, trust and forgiveness. The isolation of patients from their families and communities make their suffering worse.

During the time when a person is assuming the role of a patient, other role relationships, such as those of a parent, spouse, employee or a student, may temporarily become interrupted. Occasionally, role reversals occur. For example, a self-supporting independent father may suddenly have to be cared for by his children. Patients must learn a new role, a new language /"hospitalese"/, a new life-style. Often they will have to find a new meaning of their life.

c) The need for **relationship with a supreme other** (e.g. God).

Patient in a spiritual crisis, which is connected with a serious disease can loose his or her religious belief. On the other hand, the crisis could make the religious belief more strong.

d) The **need for hope**, that is the need to imagine and participate in the enhancement of a positive future. Many patients have negative expectations from their future. They are suffering from an anxiety of different origin (2, 3).

4. Topics for discussion: a) Moral dilemma: Conflicts between beneficence and autonomy. **b)** Disclosure of information, understanding. How information is to be conveyed to the patient? **c)** Sources of anxiety (biological, social, moral and spiritual).

5. Conclusion. A more contemporary version of ethical questions concerning medical profession has shifted from the one of its character to the one of a practical conduct - "What should a doctor do?" Autonomy, information and respect, all together, form the crux of current ethical views of the doctor-patient relationship. Morality requires not only that you treat the persons autonomously and refrain from harming them, but also that you contribute to their welfare. An outcome which now or in the future would be regarded by the patient as worthwhile (1). No ethical or legal requirements concerning the attitudes of health professionals to the patients will be effective without the willingness of those who have the knowledge and power to be constantly critical of their own practice and always open to a perception of the needs of the individual patients (1). As a traditional medical saying puts it: "To cure sometimes, to relieve often, to comfort always."

Training devices: slide projector, desks: Vincent van Gogh and his pictures (a spiritual crisis explained by the story of his life).

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Table: The patient as a person - framework of the problem

THE PATIENT AS A PERSON

Sociocultural context of behaviour :	Jewish - Christian tradition (Islamic or Eastern traditions)

SOCIAL

SOCIAL ROLES	STYLE OF LIFE	SOCIAL STATUS
patient	inactivity	often lower
parent, spouse	isolation	
employee	violation of privacy	

SPIRITUAL

		self-conscious	I
E	Center	self-control	N
M	of Person	self-respect	T
O			E
T	Self-importance:		L
I	attitude - to death		L
O	- to life	sense of life	E
N		purpose in life	C
S	value system and meaning of life		T

the will

BIOLOGICAL (body) [3]

PATIENT'S FEELINGS:

fear and anxiety	hopelessness	hope
sadness	disgrace	faith, belief
uneasiness	dishonour	trust
restless, disturbance	misprision	
	pain, suffering [3]	

MATERIÁLY Z KURZOV ÚMEB

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PARENTHOOD AND CLINICAL GENETICS

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It is natural for parents, and potential parents, to be concerned about the health of existing children, and of the children they may have in the future. However, the way parents act on this concern will differ widely, depending, first, on their view of the moral demands of the parent–child relationship, and secondly, on their beliefs as to when the parent–child relationship, with the moral demands which form a part of that relationship, can be said to begin.

In this talk, I will be referring to one model of the parent–child relationship as the 'gift' model. In referring to the 'gift' model I am referring to a view according to which children are seen as gifts to be accepted unconditionally by their parents at every stage of their lives, and not at any period of their lives as products subject to quality control and rejection. I will argue that the attitude of parents tends increasingly to be closer to a 'product' view of children, at least for some period of their lives, then it is to the 'gift' view according to which children are to be accepted at every stage of their lives.

Many people, if asked how parents should behave towards their children, would say that parental acceptance should not be conditional on the state of health of their children – or indeed on neutral feature of their children such as sex, height, etc. That is, children should not have to meet the expectations of their parents before they are treated as the children of their parents, with the rights which that relationship entails. On the 'gift' view children of all ages are seen as having a moral status not inferior to that of their parents, or of any other human being. Immature human beings must be accepted as the individuals they are, just as mature human beings must be accepted as the individuals they are. Of course, all would agree that seriously ill children will sometimes need to be cared for by adoptive or foster parents or even institutions, if the birth parents are simply unable to meet the needs of these children. However, a choice to give up one's child on the grounds that one cannot meet his or her needs should be seen not as rejection of the child whose needs one is unable to meet, but rather as the delegation of responsibility for that child. A mother who gives up a child for adoption because she cannot meet the needs of that child together with those of the rest of her family is not rejecting her child, or treating her child as less than human, but providing for her child in the way which best responds to the needs both of that child and of the rest of the family.

Most people feel some inclination towards the view that children should be treated 'as children' by their parents: that is, that they should not be rejected, or treated as less than human, on the grounds that they do not meet their parents' expectations.

However, while most feel strongly drawn to take this view with regard to later phases of the parent–child relationship, there is a growing tendency to take another view with regard to earlier phases of the parent–child relationship, or to postulate some other exception to the principle of unconditional acceptance of children by their parents.

Clinical genetics is itself very largely responsible for this shift in attitude on the part of parents. For while it is true that clinical genetics responds, to a certain extent, to pre–existing desires and fears on the part of parents and potential parents, it also creates a demand for the services it offers, some of which are, and some of which are not, compatible with the unconditional acceptance of all existing children.

Parents are not encouraged by the widespread availability of prenatal diagnosis to regard the unborn as children to be unconditionally accepted. The availability of prenatal diagnosis with a view to abortion if the foetus is found to have some handicap presupposes that the pregnant woman has a right to exercise a very high degree of control over her unborn child, or over what is sometimes called the 'products of conception'. While it is possible to undergo prenatal diagnostics with a view to prenatal or postnatal treatment of the child, it is usually with a view to possible abortion that prenatal diagnostics is undergone. Since many prenatal tests involve a not inconsiderable risk of causing a miscarriage, it tends to be those parents who would contemplate abortion if the foetus were found to have some handicap who make use of these tests. Parents sometimes feel that they are morally obliged to make use of whatever tests are available, although many parents – particularly mothers – experience considerable stress in relation to these tests. Other parents, while they do not feel obliged to make use of prenatal tests, will nonetheless desire to make use of them in the interests of ensuring that the mother does not give birth to a handicapped child.

There are three main arguments put forward in favour of prenatal screening with a view to possible abortion. The first argument (often found in combination with one or both of the others) is that the embryo and/or foetus is a 'product of conception' which is being used to make a child, so that the embryo or foetus need not be treated as if it were already a child, but instead should be treated as what it is – a product in the making. Those who claim that parents have unlimited control over the process of producing children may also claim that the control of embryos and/or foetuses constitutes control over the production of children, rather than over existing children.

The first objection to this view is that parents should not feel they have unlimited control even over the production of children. Indeed, they should not think of themselves as producing children at all, but rather as receiving children as gifts which result from their unreserved giving of themselves to each other. In cases where children are literally produced by the putting together of biological materials, as in vitro fertilization, it is harder for parents to treat these children as human beings with human rights, when they have come into existence in a way more appropriate to manufactured products. In contrast, when children result not from an act of production, but from an act of committed love, and there has been no attempt on the part of the parents to prevent this act from generating life, parents will find it easier to welcome any child they do conceive. In other words, some forms of control over the generation of children are more in keeping with the dignity of children than others – and this is true whether the child originates at fertilization, or at some later time.

The second objection to the view that the embryo is a 'product in the making', and therefore can be rejected if found to be defective, is that the embryo is not, in fact, in the process of being used make a human being, but is already a human being, because it is already a human organism. For a human being, or person, is not something other than a living human organism – a living human whole. A human being is not something like a car, which comes into existence by degrees: rather, it is a living human whole, which is either there or not. Nor is a human being some non–bodily entity which joins or replaces the human organism during some stage of its life. A human being is an organism: something which is, at least in part, a *bodily* entity. As soon as there is a living, self–organzing whole, of a kind which may grow to be an adult, there is a being with *morally significant interests* in his or her long – and short–term fulfillment. There is now sufficient evidence that most human beings, or human organisms, come into existence at fertilization, although a small minority come into existence later as the result of identical twinning. If we accept that human beings are human organisms, and that human organisms begin, in most cases, at fertilization, then we must either accept that human embryos are *human beings with human moral status*, or say that *some* human beings have human moral status, while others do not. But to recognize human moral status only in those human beings who have reached some arbitary level of development is to be arbitrary about who are the *subjects of justice* – an arbitrariness which fails to recognize the very *nature* of justice as a non–arbitrary system. Human beings are *equal* in their basic human dignity: there is no such thing as a human being with subhuman moral status.

If the unborn – including the handicapped unborn – are human beings with basic human rights, certain lines of argument often used to defend the rejection – that is, the destruction – of the handicapped unborn are clearly doomed to failure. One such line of argument is that which focusses on the needs and wishes of the parents: for example, on the strain a disabled child may cause to his or her parents' marriage, or to their life–plans in general. It may be claimed that if the parents are not obliged to care for the child who will be handicapped, they will be enabled to have another, healthy child, so that the abortion of the child who will be handicapped is a means to *replacing* that child with a child who will be healthy.

However, it is clear that this kind of reasoning is entirely inappropriate if the unborn are human beings with basic human rights. To kill a child with a handicap, in order to spare his parents the burden of and/or to 'replace' that child with another one would be a violation of the human rights of the handicapped child. For human beings are not replaceable, in any real sense of the word, but have rights and interests which cannot be transferred, and which moral agents must respect. The rights of moral agents themselves are limited – here as elsewhere – by the rights of those who will be affected by their actions. The humane response to the heavy burden of care which may be faced by the parents of a handicapped child is to help the parents with this burden of care, rather than to end the life of the child. Moreover, to regard the handicapped child as *nothing more* than a burden to its parents is to fail to recognize the fact that a handicapped child also offers a new opportunity for family love and parental fulfillment.

If an unborn child is a human being, it will not be possible to defend abortion for handicap to spare the parents the burden of his care. Similarly, if the unborn child is a human being it will not be possible to defend abortion for handicap on the grounds that this will spare *society* a significant *financial* burden. Certainly, the care of disabled children can be expensive, as can the care of older people, terminal patients, AIDS patients, etc. However, if the unborn child is a human being the proposal to abort it in order to save money is clearly unworthy of consideration by a civilized society.

It is interesting that even those who argue for a high degree of control over unborn children on the part of their parents will often admit that unborn children are children: that is, that there is *some* kind of parental relationship between the parents and their unborn child. For example, it is increasingly accepted that abortion for handicap can cause lasting distress to the woman who has the abortion, who is often described – even by those who *defend* abortion – as *grieving* for her *child*. This recognition of the fact that the unborn child is a *child* for whom the mother *grieves* is not easy to reconcile with the way in which the life of the unorn child is thought to be at the mother's disposal.

The most persuasive attempt to reconcile the view of the child as a *child* with the view of the child as disposable is found where it is claimed that in agreeing to the abortion, the mother is acting, like any good mother, 'in the best interests of the child'. There are those who believe that it is sometimes the *duty* of a mother to abort her unborn child, if the child is diagnosed as suffering from some very serious disease. On this theory it is not simply up to the mother whether or not she has an abortion: rather, her decision must make some kind of reference to the 'best interests of the child'.

This brings us to the third reason often put forward in defence of abortion for handicap – a reason also used to defend euthanasia of older human beings. This is the reason that life with certain handicaps is, on balance, 'not worth living', so that it is an act of mercy to end the lives of those affected by these handicaps. Sometimes it is claimed that those affected are so badly affected as *not to be human beings* with human moral status; other times it is claimed that those affected *are* human beings with human moral status, but human beings whose *life has no value*. Those who advocate euthanasia for those – including rational adults – whose prospects are sufficiently poor may claim that they are not refusing to recognize the *humanity* of the foetus by allowing what amounts to foetal euthanasia. For unlike those who see the human being as disposable only at some early stage of his or her life, such people see the human being as disposable at *every* stage of his or her life, providing that human being's prospects are sufficiently poor.

Defences of abortion and euthanasia on the grounds that some human lives have no value generally fail to make an important distinction between the *subjective* value of the life of the person – the value *to that person* – and the *objective* value of the life of that person. The difference between subjective and objective value can be illustrated by reference to the case of a person who is suicidally depressed. *Subjectively* his life seems *to him* to have no value; however, his friends and family may believe that his life has nonetheless an *objective* value, which they want him to appreciate. In other words, they may claim not that *they* value the life of this person, but that his life is *objectively valuable*, even though he does not *feel* its value.

In the case of prenatal diagnosis, the *subjective*, as opposed to the *objective* value of the life of the unborn child will not be easy to predict. Care should be taken not to make predictions which are unduly pessimistic. A life which a healthy adult regards as intolerable – for example, a life confined to a wheelchair – may be valued *by the handicapped child* no less than the life of anyone else. Where the child has a *mental* handicap, there may be still less reason to suppose that the child will find his life unsatisfactory. Abortion is frequently carried out on children with Down's Syndrome: a condition compatible with a very happy life on the part of the child with Downs, who may have a greater or lesser degree of mental handicap.

But more importantly, quite apart from the *subjective* value of the life of the child – the extent to which *he values* his life – there is also the *objective* value of the life of the child. For it can be claimed that *all* human life has a certain 'core value' – even in the most unpromising conditions: that it is part of what we mean by 'human dignity' that the *very existence* of the human being is in itself valuable. It seems incongruous to claim both that human beings are *equal* in their basic moral dignity, and that some human *lives* have no value, and perhaps a disvalue. It is more natural to accept that the the existence of those with human dignity has value in itself, although some human beings have more, and others less, of the other goods of life. To say that all human beings are equal in their basic dignity is to say, first, that the very existence of all human beings is *objectively good*, and secondly, that all human beings have an interest (though this interest may not be fulfilled in their lifetime) in the *additional* objective goods which a human life can offer.

Parents who recognize that their children, at any age and with any form of handicap, have lives of value, are recognizing that their children are equal in dignity to themselves. Those who recognize before their children are born that their children have this basic dignity will find it easier to recognize this dignity after they are born. For this reason, those who argue in favour of abortion for handicap, but who want children after they are born to be accepted by their parents and society, are attempting to promote two incompatible attitudes – conditional and unconditional acceptance – on the part of parents and society. The rejection of handicapped children will not only affect the way in which the older handicapped are regarded, but it will also affect the way in which all children are regarded. Parents will be encouraged to think of children as acceptable only in so far as they happen to want them, rather than being prepared, even in advance of conception, to welcome any child they may conceive.

Children need the security of knowing that their parents accept them as the individuals they are: a security which they are more likely to find if their parents have always been committed to accepting and caring for them – from the time they were conceived. The parents themselves will benefit gretaly from making this type of commitment. They will benefit in the very deepest sense, in that they will strengthen in themselves the dispositions which make them good and loving people. If their children do have some handicap, the parents will have a more difficult task in life than many people; however, they will also have opportunities to develop as human beings which others do not.

I have focussed so far on prenatal diagnosis and rejection of handicapped children: an area which, it must be said, looms very large in clinical genetics. However, this is not, of course, the only possible application of genetic knowledge. It is perfectly reasonable to take certain steps to diminish the incidence and/or reduce the gravity of serious genetic diseases. The fact that something good – such as personal growth – can come out of something bad, such as genetic disease, is no reason not to seek to prevent what is undeniably bad in itself.

The first way in which this can be done is, of course, by carrier diagnosis, so that those diagnosed as carriers can use this information to choose their marital partners – or plan their families, if they are already married. A couple who decide to avoid the conception of a child who will be seriosly handicapped need not believe that, if they did conceive a child with this handicap, the life of this child would have no value. Rather, the couple may believe that, despite the value of the life of the child, this life will involve or bring about disvalues (for example, pain to the child, sadness to the parents) which they are justifed in avoiding, through avoiding the conception of that child. Such a couple may realize that if, despite their efforts, such a child is conceived, the value of the life of that child demands their unconditional respect.

Does a couple ever have a duty – not simply a right – to seek, by ethical means, to avoid the conception of handicapped children? The moral right to have children should not be thought to be absolute – to apply to absolutely anyone. Rather, it should be seen as applying to married couples who are committed to each other and to caring for the children they conceive. All married couples should be willing to meet, as far as they can, the postnatal, as well as the prenatal needs of any children they conceive. If a couple is planning to conceive a child who is very likely to be seriously handicapped, they should ensure that they are able to meet the needs of the child to some reasonable extent (with the reasonable assistance of society).

However, even if it is the case that couples may sometimes have a duty to take ethical steps to avoid the conception of a child for whom they cannot care, this is not to say that pressure may be brought to bear on couples to do this on the part of the State. The State is not entitled to put pressure on people in this area, for various reasons. One reason lies in the fact that such pressure may result in people being driven to take unethical steps to avoid the birth of a handicapped child – for example, sterilization, or (on the worst case) abortion. The second reason is that the couple will normally be those best qualified to decide if they are justified in conceiving a child they know will be handicapped. It is the couple who are likely to know best what are their own needs and resources – that is, both the strength of their desire to have a child, and their ability to care for that child.

It is sometimes said that no reproductive decisions should be subject to State interference. However, it seems obvious that the State has a duty to protect the lives of existing children – as it has a duty to protect the lives of other innocent human beings. Certainly, parents should not be coerced by the State either to conceive, or not to conceive a child; however, once a child exists the parents have a duty, which should be legally enforced, to look after that child at least until someone else can take over. This is a matter of justice, and therefore an appropriate subject for State intervention. It is perfectly reasonable for parents to be prevented both from killing their children, even with the best of motives, and from abandoning their children, with the result that they die.

However, the duty of the State does not, of course, stop at preventing parents from harming their children. Parents have a right to assistance from the State in performing an important social task: caring for vulnerable human beings. Parents should not be left alone with the responsibility of caring for handicapped children, but should be helped to take up the responsibilities of parenthood. If parents could be given sufficient help and encouragement on the part of the State and society in general, many would never consider rejecting their children, before or after they are born.

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DYING PERSON IN THE FAMILY: PROBLEMS AND CONDITIONS FOR A REAL ACCOMPANYING

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1.Socio–cultural reality of dying today

Nowadays the fact that most people die in hospitals is usual in all European countries and, in general, in the Western world. Statistics gives us percentages of 60–70% about this phenomenom, while the remaining 30% is about sick persons who die in rest homes, at home or in other places.

The process of dying is more and more a ‘hospitalized’, ‘medicalized’ process which is managed by medical workers (doctors and nurses); a terminaly ill person runs the risk of being dispossessed of his own death and of losing „the right to supervise the event of his death” (I. Illich, p. 223).

Certainly, a hospital offers high standards of medical care and assistance, especially hygienic and technological ones. But the problem is how to grant the sick person a global assistance, which would be able to take care of him even when he is at death’s door. The problem is that of going a real, human escorting way in the terminal phases of a person’s life by considering death not simply as the end of an illness or a trauma, but as the final event of a life; as the person’s ‘leave’ to his existence, to his family,... It is a question of seeing how that all is lived in a family context, how a family reacts when one of its members is on the point of dying, and how it can assist him, either in hospital or, and especially, at home.

2. The dying person and his family

A patient in a 'terminal phase' is a sick person who is going to his death in an irreversible way. The person is affected by a disease which requires no more neither complex diagnostic investigations nor advanced therapeutic treatments, and the course of the illness shows moments of stasis or slight remission followed by swift worsenings, with a gradual decay. The patient mainly needs a treatment aiming to control the symptoms and the psychophysical alterations rather than one being directed to his or her basic pathology. Various psychological reactions, alternate feelings, anxiety, reflections, are associated with and sometimes come before the gradual physical decay.

Death is not simply a biological event, but it is a reality which concerns the whole person who finds himself/herself at the end of his/her worldly existence and who has to face the experience of sorrow, leave, loneliness, and the unknown. All the subjects variously linked to the terminally ill patient (the family, doctors and nurses, friends, etc.) are involved in all that, and share his going to death.

Certainly, the family plays a fundamental role by living with a person near to death and standing by him during these phases, both in the hospital and, also more specifically, if the dying person is at home. At this point it is worth mentioning the psychological reactions of a person who is facing his/her death.

2.1 Psychological phases of dying (E. Kübler–Ross)

I suppose that everybody knows the work by Elisabeth Kübler–Ross, On Death and Dying (McMillan, New York, 1969). The researcher distinguishes there five psychological phases which a patient goes through during his mortal disease. I will just briefly remind them:

1) *denial:* a feeling of refusal and denial: „it is not possible!";

2) *anger:* be enraged against everybody and everything;

3) *bargaining:* a compromise is looked for; the sick person makes some promises, especially to God;

4) *depression:* that feeling of grave loss that approaches along with death;

5) *acceptance:* a certain rest before the ultimate journey.

Kübler–Ross's observations have been criticized and confuted by some scholars (A. Kastenbaum, R. Glaser–Strauss), who affirm that Kübler–Ross falls into simplifications and schemes which do not take into consideration different variables such as the kind and intensity of pain, the quality and quantity of support given by the family, age, sex, culture and place (home, hospital, hospice,...), etc. (Kalish).

In practice, it has also been pointed out that Kübler – Ross's study presupposed that the sick person would be informed about his real condition, as it usually happens in the USA. In Latin countries, on the contrary, this piece of information is not commonly given to the dying person, so the psychological process would be articulated as follows (Cf. P. Sporken, Ayudando a morir, Sal Terrae, Santander, 1988):

1) *unawareness:* the sick person does not know anything of his real physical condition, this causes a state of incommunicability with his family, who on the contrary, knows the unfavourable prognosis;

2) *uncertainty:* the sick person begins to be uncertain and asks for explanations the people around him who 'reassure' him;

3) *implicit denial:* the sick person perceives the real situation, but implicitly denies it and 'rejects the idea';

4) *communication of the truth:* the moment to tell him the truth arrives. These phases would be followed by those described by Kübler–Ross.

From all these considerations, without falling into strict and oversimplified schematizations, emerges an importance of recognizing and, in some way, sharing the experience lived through by the dying patient. It is in this way only that one can really accompany him/her towards the crucial moment of his/her life. Furthermore, I would like to remind here, that it is not only a matter of giving him/her a psychological support, which would imply the risk of a 'psychiatrization' of the event of dying and of the creation of new specialists to whom delegate the accompanying. The problem is, on the contrary, to be able to offer a real global assistance which could fulfill the hygienic, medical, psychological and spiritual needs of the dying person.

2.2 The family

The family is intensely and immediately involved in one of its members's proces of dying. The problems, the psychological reactions, the attempts of answers that the family has to face in this new situation are of different kinds; and different are also the variables which depend on: who the dying person is (a consort, a son,...), what age he is, the kind of disease and its course, the composition of the family, the hospitalization, etc. It is also necessary to consider the 'quality' of relationships among the members of the family, the capacity for dialogue, the knowledge of symbols and rites on life and death, the experience of faith and the spiritual one.

In the case of a patient who is near to death the following psychological dynamics can be noticed in the members of his family:

– the grievous avareness of the approaching death of their relative;

– the feeling of guilt which comes from their powerlessness before the uncontrollable evolution of the disease;

– the possible concerns over the future of the family life, including the economic aspect;

– the relations to carry on with relatives, friends, neighbours, etc.;

– the psycho–physical stress which a weary assistance of several months may cause (M. Petrini, 1990, p. 62).

The family is asked to face death directly, as the family knows well that it is the death of one of its members and that this process will last a certain period of time (while it is not the case of a sudden death or an accident). Many questions might arise: How should we react and be a family, a „community of life and love", in this situation? What kind of assistance should be guaranteed? Which further help is necessary and how should it be integrated? (Particular problems arise for a sick person with a cancer; another different situation is that of a person who is affected e.g. by AIDS, taking into consideration the ways of infection's spread, the course of the illness, and all the necessary precautions...).

3. Conditions and prospects for a real accompanying of the dying person in the family

Even though the dying person is in a hospital, the family is asked to fullfil a very important role of assistance and psychological and affectional support which should be more and more enhanced. But we would like to linger, in particular, on the experience of the 'home care' outlining some indications and pointing out the most urgent ethical efforts.

3.1 Current problems (Cf. G. Di Mola)

There are a lot of difficulties faced when the family wants to render an efficient home care to the seriously ill person and to accompany him/her throughout the dying process.

– In our society, and consequently in families, there is a strong propensity to delegate care and assistance to institutins, doctors, and to the power of modern medicine, renouncing the 'human', homely element of assistance.

– A cultural climate which induces the 'refusal' of sorrow, death and the event of dying. Dying at home sometimes seems strange, almost shameful, something to keep rather hidden.

– Psychological difficulties in speaking of death within the family, in bearing the separation, in conversing on the fundamental themes of human existence.

– Family groups are more and more restricted (3–4 people), and for this reason they are often unable to fulfill the needs of a sick relative. A man is usually nursed by his wife; a woman, often already a widow, by her children who are already adults and occupied with a families of their own.

– We are not any more in the condition of the large families in the rural world. The life in a big city – in the huge blocks of flats – has become anonymous, characterized by a negative privacy: it is difficult to enter into such a relationship with neighbours which could permit to obtain a help from them in the case of need. The working rate, the stress of the city life, makes it difficult to find a time, patience, organization among the members of a family in order to look after the sick person.

– In the families, where a sense of cohesion among the relatives does exist, the presence of a seriously ill person may give rise to the situation of crisis, but it may also turn out positively by strengthening the relationships among their members. The family gathers around the weakest and the most suffering relative, and recovers deep links while showing, almost symbolically, to be capable of sympathy, sharing and mutual comfort.

– But the situations might appear, in that the sick person causes such psychological and organizational difficulties, that inconvenience and unbalance the group (family) he belongs to. In this case the tensions and the isolation from the outside world may increase. The sick himself may feel ill at ease for the problems he causes the family. The wish to die at one's home is very strong, but one also feels that this fact may cause a greater distress to the family, some difficulties for the commitment of assistance, and inconveniences in relations.

3.2 Prospects and ethical issues

The family must „think over itself in another way" when one of its members is dying; it also must draw from its own energies and try to be a community that helps a person to die with dignity and surrounded by warmth. The connection with the hospital, the hospice or other organizations may be variously interrelated, and it seems that, nowadays, an accompanying the dying person at home is easier in the very final phases (for example during the month) as it is a more bearable situation for the family and it allows the ill to spend the last moments of his life with the people and things he loves the most.

A) We can suggest the following prospects in order to:

– Make possible a real and efficient home care service, which could enable the family to exercise its function as a vital environment, rich in values and sympathy and which fits well to the person who is passing away.

– To this purpose, elaborate a close and harmonious cooperation among the family doctor, nurses, social workers, clergy, volunteers, etc.

– Support the family and equip it with greater responsibility, also concerning the hygienic–medical treatments and the psychological approach.

– Promote the dialogue within the family, encourage the members to share the problems, and to get over the mechanisms of self–defence.

B) The family's ethical attitudes may be expressed in:

– Offering the terminally ill patient the possibility of disclosing all his feelings, being able to listen and share them in a real empathic relationship, also encouraging the verbal and nonverbal communication.

– Comparing oneself with one's own death evoked by the presence of the dying person.

– Sharing fears and self–defences among relatives, or also with the help of somebody else, trying to formulate and overcome them. In this way it will be possible to establish a more real and deeper communication with the dying person.

– Allowing the sick person to come to his truth avoiding the „conspiracy of silence" and the solitude into which the sick person runs the risk of falling.

P. Verspieren states, that encouraging the dying person to open himself/herself may make anguish less burdensome, and that „human presence allows many sick people to improve and reach a real acceptance of their condition, and sometimes even a true serenity. Some people become reconciled with their relatives after years of discord and separation; others take their leave of their family in sorrow or in tears, but not without a certain joy to be surrounded by their dear ones and to be able to communicate, probably for the first time, in a deep way with them. Somebody else overcomes the feeling of guilt and failure and discovers that his past life had a meaning he had not understood up to that moment; others make a real spiritual progress... The family as well, if it succeeds in accompanying the dying relative until his/her end, lives through a period of deep intensity and, afterwards, it will be able to elaborate its mourning with less feeling of guilt" (pp. 173–174).

Thus, the family will prove to be an authentic community of life and love, which is able to make a better disclosure of the meaning of „the life that does not die".

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WHAT CAN PALLIATIVE CARE OFFER ?

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PALLIATIVE CARE has been defined as: The active total care of patients whose disease is not responsive to curative treatment, where the–control of pain, of other symptoms and of psychological, social and spiritual problems is paramount, with the achievement of the best possible quality of life for patients and their families as the goal.

Patients needs with time: Many patients cannot be cured at the time of diagnosis (e.g. cancer of the lung or pancreas). Therefore treatment aims to control the cancer and the symptoms, but will not greatly prolong life. This is palliative treatment. As disease progresses the symptoms often worsen and new symptoms emerge so the patient needs more and more palliative care to maintain quality of life and to be enabled to live actively until death.

Palliative care works

- alongside acute specialties,
- to care for those with progressing disease,
- to care for those approaching death,
- as a multidisciplinary team of doctors, nurses, physiotherapist, occupational therapist, social worker, chaplain, etc.

Palliative care aims to

- improve the quality of life,
- stop patients dying of exhaustion through poor symptom control (e.g. vomiting, singultus, pain, etc.),
- help patients complete their life tasks (e.g. mother making arrangements for care of her children after her death),
- improve communication between the patient, family and professionals,
- support the patient's family as they face bereavement,
- always believe the distress and respond appropriately; the patients do not exaggerate or invent their pain,
- improve communication, the majority of complaints from patients relate to poor communication skills of the health professionals,
- teach other professionals to deliver better symptom control and to improve the communication.

Palliative care provides

- symptom control – common symptoms include pain, nausea and vomiting, dyspnoea, bowel problems, weakness, mouth problems,
- emotional/psychological support to the patient and the family – fear worsens the distress from unrelieved symptoms,
- social support,
- spiritual care,
- bereavement care.

Palliative care is delivered to the individuals. We have to understand, as much as possible, the people who are our patients. As doctors we must remember that each patient is a unique individual. For example a young mother who knew she was dying, had severe pain which was total pain of her whole self. She had **distress** made up of physical pain from bone metastases and amplified by social problems – who would care for her children? Her emotional pain was the pain of knowing she would not see her children grow up and the pain of departing from them. Her spiritual pain focused, as it so often does, around problems such as „what have I done to deserve this?", „is this divine retribution?"

The relief of symptoms. Every doctor should be able to help with some of the common symptoms and problems that patients have. Pain occurs in 2/3 of patients with cancer, nausea and vomiting in about 1/3 and weakness, anorexia, constipation, dyspnoea, mouth problems are also common. Underlying all these are the patients' fears.

How do we control the symptoms? This usually does not require high–technology medicine but the doctor's best diagnostic skills to adequately analyze the symptoms to determine the cause. Symptom relief is obtained through **appropriate prescribing** of drugs and other therapeutical measures. The doctor who guesses and prescribes will fail the patient. For example different antiemetics are required for different causes; the doctor who prescribes by guesswork will miss diagnoses such as hypercalcaemia or bowel obstruction and provide no relief of symptoms.

The process of symptom analysis for patients with pain requires a good medical history. Simple questions in the assessment of pain reveal the cause, eg: site and nature of the pain and what the patient thinks about their pain.

It is important to remember that distress has physical, emotional, social and spiritual components. The patient with pain who is frightened by their pain will feel it as „agony" where the patient who understands that pain and how it can be controlled will only have an „ache".

It is important to help patients communicate as the more frightened a person is, the less likely he/she is to talk about his/her fears. Often patients find the answer is much better than they had been imagining. Many patients with cancer fear the pain, but 90% of cancer pain is easily controlled; many fear a distressing death when a peaceful death can be provided by a good palliative care.

The World Health Organisation has provided a very easy guide to analgesic prescribing. **Analgesics** fall into three main groups, non–opioids, weak opioids and strong opioids. Morphine is a very safe and effective opioid analgesic when carefully titrated up to control the patient's pain.

It is the duty of the physician to provide the good symptom control for patients to enjoy the life that is left, even when with advanced disease.

Dame Cicely Saunders said that **dignity** is having a sense of personal worth. It is the way that we behave towards our patients, the respect we show them and our commitment to care that enhances their sense of dignity. Patients need our help to complete life's tasks. Careful symptom control can enable patients to do a great deal of living and actively contribute to those around them, even when in the last days of life.

Patients need more than only a physical care from the professionals. They need **continuity of care** with adequate information about their condition and the options for treatment. Doctors should be prepared to refer to alternative services to provide help for patients and there must be a good communication between services.

Patients and their families can gain much **support** from being able to talk about their problems; patient support groups can have an important role. No professional should be too proud to ask for help from the another; no–one can know all the answers!

The need of hope. But above all we need hope. Patients, however ill and however close to death need some hope; this cannot be the hope of cure or of remission but it may be the hope of a good night's sleep, a peaceful death, or of living long enough to enjoy a visit from a son or daughter. Hope must be realistic – we must not lie, as we will never be believed again. We cannot provide cure but we can provide comfort. We, as professionals, must never abandon hope for it is the hope of providing comfort and care that spurs us on in our daily work and in research efforts. Good palliative care should enable patients to live to the full rather than wait in unrelieved distress to die.

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WHY HOSPICES OPPOSE EUTHANASIA

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This paper is given from the perspective of a clinician faced with applying the ethical principles in everyday practice. There are some simple („*prima facie*") ethical principles that can be applied to each decision and can help guide the decision–making process. These are the principles of autonomy, beneficence (to do good), non–maleficence (to do no harm) and principle of justice. I will comment on each of them briefly.

Autonomy

Autonomy means self rule/self governance (from the Greek). It is important to remember that the autonomy of the individual can only exist if the individual is able to exercise or implement his/her autonomy – so autonomy and personal freedom are linked. However, at times the autonomous wishes of one individual may conflict with the autonomous wishes of others in society who interact with that individual, so one person exercising autonomy can endanger (or constraint) the autonomy of another. As a simple example, the person who wishes to drive home after drinking can endanger the lives of other road users.

How can we as physicians show respect for patients' autonomy and therefore allow them to exercise it?

The first and essential step is to allow the patient access to adequate information. Discussing treatment options allows the patient to voice opinions and the treatment plan evolved is one agreed with patient and carers. The need for information means that we cannot withhold information that patients ask for because of a third party. For example, a patient's son or daughter may request that we do not tell the patient their diagnosis. However, the patient may ask directly or indirectly about their condition and we must meet the patients's need for information when they request information. If we lie to a patient, we will never be believed again. We must also respect a patient's wish to decline treatment when they have made an informed decision. Some patients may decline treatment for religious reasons. E. g. a patient who is a Jehovah's Witness may decline a blood transfusion, but others decline for personal reasons, such as the female patient who does not want to lose her hair may decline palliative chemotherapy, preferring her children to remember her as she is. We must continue to care and support the patient in their informed decision, remembering that the patient's decision depends in great part on the quality of the information given by the doctor.

Beneficence and non maleficence

„To do good" and „do no harm" are probably the most useful concepts in practical day to day patient management. The risks of treatment must always be less than the predicted benefits so that we „do good". The burdens of the treatment must also be less than the benefits; some low risk treatments are very burdensome. Two clinical examples from my own practice illustrates this. In one patient feeding was burdensome and of no benefit. He had a resistant hypercalcaemia, nausea and vomiting, multiple bone metastases, liver metastases and hated his nasogastric feeding tube which gave him a sore throat. He just wished to rest in peace. So we removed the nasogastric tube, gave him analgesia and antiemetics and he died peacefully within 48hrs, but he would have died in that time anyway. The nasogastric tube was of no benefit and was a burden to him. The feeding was futile.

Another patient was similarly unable to swallow, but his general condition was better. He also had carcinoma of the oesophagus. A simple gastrostomy allowed him to put fluid, liquidised food and drugs down the gastrostomy tube himself. He became stronger with good nutrition and was able to go out to meet family and friends and he enjoyed his remaining life. For this man the benefits outweighed the burden of the tube.

Justice

The fourth key principle is Justice. Justice to the individual patient means we do make judgements on generalisations such as age or pre–existing disability. The individual's personhood must be justly respected. The individual has the right to the highest standard of care within the resources available. Of course resources are finite and limited, so justice demands we allocate and use them fairly for the benefit of all our patients.

We must respect the sanctity of life. We must never kill our patients, but we do not have to continue futile treatment (e.g. ventilating a patient who is metabolically dying). We must accept death; it is the inevitable end to life and we must not pretend we can play „God" and provide immortality.

Euthanasia

Now I must address the specific difficulties with the concept of practising euthanasia. Euthanasia is the direct intentional killing of a person at his/her request as part of the medical care being offered.

– Why ask for euthanasia rather than commit suicide?

The person may be physically unable to commit suicide, either because of a stable disability such as a motor disorder or because he/she is too ill and weak. However, it may be that the patient is really looking for a response other than a lethal injection; the patient's physician may have removed any hope of symptom control or of dignity, but the patient desperately seeks confirmation of personal worth or hope of improved quality of life. I have had patients who clearly state „I wish to die", yet are delighted when offered control of their symptoms and they go on to enjoy life again.

– Who might be a candidate for euthanasia?

The groups usually considered in debates on euthanasia are those with advanced cancer or progressive neurological disease. But what of those with non progressive disability or the competent patient with severe injury? How are we sure the non–competent patient does not simply have an expressive disorder? In Holland a patient with severe depression who refused standard antidepressants was killed by her physician at her request. We all know that the socially destitute feel worthless, but can return to being active contributors to society with a little help. Should euthanasia be available to anyone who asks? The spectrum of human conditions and diseases means that the line cannot be firmly drawn.

– How else can we respond to the patient requests for euthanasia?

We do not have to kill the patient who asks for euthanasia. We should take their suffering more seriously and make efforts to relieve distress. No one person can have all the answers and the doctor whose patient's distress is unrelieved can find it helpful to seek advance from colleagues. All efforts at symptom control must maximise dignity, minimise dependence and affirm a patient's personal worth and value as an individual.

Some doctors fail to recognise that euthanasia, where the intention is to kill, is fundamentally different to symptom control. To obtain symptom control the minimum effective dose is the right one, whereas to kill a patient you would intentionally aim for a maximum dose. Of course, any medical intervention involves risk; sometimes drug therapy may cause sedation and therefore may, for example, increase risk of chest infection as the final event. But the intention is to relieve symptoms and not to kill. No evidence exists to show that symptom control shortens life and it may often prolong life as the patient is not exhausted by pain or vomiting, etc.

A lady was referred to us who wished to die. She lay in bed, weak, depressed and could not sit up. Symptom control required careful prescribing. Her body image was restored by doing her hair as before she was ill, helping her dress and most importantly showing respect for her intellect and knowledge. She had a new lease of life. The lady then started to help other patients by welcoming them to the hospice and being optimistic about the help we could give. She told us that when she was admitted she only wanted to die and could not have believed life could once again have much value.

– But why not give the injection?

There are consequentialist arguments that euthanasia would increase uncontrollably. This is the „slippery slope" argument that today we might only give euthanasia to the terminally ill, but tomorrow we might practice euthanasia on any unwanted person (e.g. the elderly). There is evidence from Holland that euthanasia decisions are sometimes made by the family or even just by the physician without clear discussion with the competent patient. This is no longer the autonomous wish of the patient that is being exercised, but allows the possibility of murder for personal gain going unnoticed.

– So is there an answer to this euthanasia question?

Mencken said that „for every difficult question there is an easy answer – short, simple and wrong".

The experience of people working in palliative care with patients who have advanced malignancy is that rational requests for euthanasia are very rare and that the potential for misinterpretation and abuse of permissive legislation or of well-intentioned but hasty inappropriate action is such that voluntary active euthanasia should remain illegal.

Euthanasia requests are certainly a cry for help and demonstrate a sense of hopelessness and come from a philosophy of despair. They reflect failed care and required a doctor to understand what is the worst thing at that moment, why life is so unbearable, where the patient can find realistic hope and the doctor must know how to relieve the distress. Requests for euthanasia do not persist when there is good palliative care.

– What is the role of the Law?

The Law protects the vulnerable, clarifies the doctor patient relationship and reinforces trust. The Law prevents actions by those who would willingly volunteer to kill on request – in every society there are people who will easily be executioners or torturers or even simply enjoy watching death. The Law is there to detect medical error rather than to encourage cover-up. It would be easy to encourage a patient towards euthanasia when an error of drug dose or wrong diagnosis had occurred. With death and cremation all evidence is destroyed. The Law also ensures that the disabled are respected rather than discarded.

In Great Britain there has been a parliamentary enquiry set up to examine the topic. The Select Committee from the House of Lords examined ethical issues surrounding euthanasia and they concluded that there should be „No change in the Law". Euthanasia remains illegal in Great Britain. This committee took evidence from many people including doctors and visited Holland. They accepted evidence from doctors that pain can be controlled in dying patients, that research into palliative care is increasing. They fear there would be excess pressure on the most vulnerable in society and that society has a duty to care. They were concerned that the Dutch Guidelines are already being abused.

Doctors must respect the sanctity of life and cannot be allowed to hide mistakes by killing patients or use killing patients as an easy way to solve a challenging clinical problem.

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OZNAMY REDAKCIE

NEWS FROM THE EDITOR

● **Z finančných a organizačných dôvodov** časopis ME&B **v roku 1995** vychádza **štvrťročne**. **Pôvodná cena predplatného sa nezvyšuje**. Prosíme o láskavé ospravedlnenie oneskoreného vydania tohto čísla časopisu (technické dôvody).

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● **Človek medzi životom a smrťou (A Man between Life and Death), an interdisciplinary conference with international participation**, Martin (Slovakia), December 7 – 9, 1995. Témy/Topics: * Medicínske a ošetrovateľské aspekty starostlivosti o nevyliečiteľne chorého a zomierajúceho pacienta/Medical and nursing aspects of the care of incurably or terminally ill patients * Etické, psychologické a právne aspekty nevyliečiteľne chorého a zomierajúceho pacienta a človeka vôbec/Ethical, psychological and legal aspects of incurably or terminally ill patients * Otázky utrpenia, umierania a smrti vo filozofii/Problems of suffering, dying and death in philosophy * Náboženský a teologický pohľad na „posledné veci" človeka/Religious and theological view of the „last things" of a man * Problematika nevyliečiteľne chorého človeka a obraz smrti a zomierania v literatúre a umení, vo folklóre a ľudovej tradícii/Problems of incurably ill and the picture of death and dying in literature and arts, in folklor and folk tradition * Smrť a zomieranie ako predmet demografie a sociológie/Death and dying – view of demography and sociology * Prihlášky/Applications: Ústav ošetrovateľstva JLF UK, Sklabinská 26, 037 53 Martin, Tel: 0842/38167.

● **International Conference: „Reflexions on relationships between the physicions and patients."** (V spolupráci s/in collaboration with International Association of Law, Ethics and Science), 5. – 7. 10. 1995, Bratislava, kontakt/contact address: Dr. J. Klepanec, Prof. L. Šoltés, ÚMEB – Katedra medicínskej etiky IVZ, Limbová 12, 833 03 Bratislava, Tel: (+42-7)374560/ext. 222, or 223.

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