

# **EUBIOSIA: BIOETHICS OF CARE AND REHABILITATION**

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## Summary

Thanks bioethical sensibility in the world is developed the awareness that about the life should discuss with all who have something to say as well as about the quality of life in order that all together could build a culture of life and try to achieve a good life (**eubiosia**). In other words, "*it is shaped the moral awareness*" about the value of life, of the its preservation *as well as the inseparable connection between life and freedom*. Where there is life offends, offends as well freedom. Especially important for us is the ethical dimension today when they appeared *visually bioethical problems of sick, disabled and elderly* persons as well as their dignity.

To solve the problems of these persons are not only invited doctors, nurses and social workers, but all people and the whole society. All of us have to serve life and take care of him (life). Service to life is the basic ethos and principles of *bioethics care* what we call **eubiosia**.

**Eubiosia** is one of the newer term of clinical bioethics foremost used by prof. Dr. Franco Pannuti in 1978., and means "the quality which signifies the dignity of life, or "the good life" which means "life in dignity from the first to the last breath". The term (concept) consists of two Greek words (eu - good + bios-Life), a mentioned professor set the term as a basic principle of solidarity.

**Eubiosia** thus became a cultural term that has become a sort of *cultural life* which was not only a medical and bioethical concept, but has become a *theological-philosophical*, which means the *commitment to respect and protect life*. The very term of a *culture of life* in the modern thought was introduced by the Pope John Paul II. that it first time has pronounced on his trip to the U. S. in 1993. and again in the encyclical *Euangelium vitae* form 1995. The term *culture of life* was mentioned in American politics. First time was mentioned by former U.S. President George Bush during the presidential campaign on October 3, 2000.

Key words: Eubiosia, Rehabilitation, Bioethics, Life, Culture of Life

The awareness of serving life is raised up in the world due to the bioethic sensibility. Concurrently, the issue of life and quality of life should be discussed with all people who have something to say, in order to build the culture of life together and realize good life (eubiosia)<sup>1</sup>. On the other hand, the *moral conscience is shaped on the value of life, its protection and as unseparable bound between life and freedom*. Whatever threatens life threatens freedom.<sup>2</sup>

Ethic dimension has been especially stressed upon the emergence of *actual bioethical issues of the sick, the handicapped and the old*. Problem solving of such categories of people should not concern only physicians, nurses or social workers but all people and society. We all should serve life and safeguard it. Serving life is the basic value and principle of bioethic care known as *eubiosia*.

The term Eubiosia was first used in clinical bioethics terminology by prof. dr. Franco Pannuti in 1978 and it denotes “quality signifying dignity of life or “good life” i.e. “life in dignity from first to last breath. Prof. Pannuti created the term out of two Greek words (eu-good + bios-life) and set it as a principle of voluntariness and solidarity in Northern Italy.<sup>3</sup>

**Eubiosia** presents medical, bioethical but also cultural concept i.e. a sort of *the culture of life, and theological-philosophical concept meaning promotion of respect and protection of life*. The expression the ‘culture of life’ was introduced into contemporary reflections by Pope John Paul II who uttered it first during his journey to the United States in 1993: “the culture of life means respect for nature and protection of God’s work of creation. In a special way it means respect for human life from the first moment of conception until its natural end”.<sup>4</sup> The culture of life implicates a positive life attitude and the aspect of sacred life created by God. It opposes practices and approaches

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<sup>1</sup> Comp. Bellino F., *Eubiosia: la bioetica della „buona vita“*, Citta' Nuova, Roma 2005.

<sup>2</sup> Comp. Ivan Pavao II, *Euangelium vitae –Evandjelje života*, KS, Zagreb 1995.br. 96.

<sup>3</sup> Eubiosia Project initiated in 1985 by ANT (Associazione nazionale tumori) provides voluntary palliative care units for cancer patients at home. This organization also supports researches and projects referring to prevention in oncology and education in medicine (ECM) organizing workshops and trainings for the care-giving staff. Organizing life-long education this foundation theoretically and practically promotes the principle of Eubiosia.

<sup>4</sup> Jean Paul II, *CELEBRAZIONE EUCARISTICA NEL «CHERRY CREEK STATE PARK» DI DENVER, OMELIA, Solennità dell'Assunzione della Beata Vergine Maria Domenica, 15 agosto 1993.*

destructive of human life such as: war, abortion, euthanasia, capital punishment, contraception, assisted conception, cloning, experimenting and killing of human embryos, mutilation and torture.

Pope John Paul II mentioned it in his encyclical *Evangelium vitae*, in 1995: “ In our present social context, marked by a dramatic struggle between the culture of life and the culture of death, there is a need to develop a critical sense, capable of discerning true values and authentic needs.”<sup>5</sup> ‘The culture of death’, a concept in papal sense, refers to supporting of abortion and euthanasia and in its broader meaning it is used to denote genocide (the Nazi Communists against the opponents of the regimes).

The expression the “culture of life” was also used in American policy by American ex- president George Bush during his presidential campaign on October 3, 2000 , when he stated: “Surely this nation can come together to promote the value of life. Surely we can fight off these laws that will encourage doctors or allow doctors to take the lives of our seniors. Surely, we can work together to create a culture of life so some of these youngsters who feel like they can take a neighbor's life with a gun will understand that that's not the way America is meant to be.”

Moreover, we use the expression to *promote value of life and human dignity* especially in rehabilitation process. We refer to life in its value, from conception until death, consequently including medical bioethics, medical care, rehabilitation and palliative care as well. The expression therefore, encompasses all life values that should be provided to all people during rehabilitation or existence.

*Medical ethics* presents not only *knowledge* about diseases, prevention, diagnosis or therapies or *know-how* (expertise in individual cases), but also *knowledge on being* (a patient deserves treatment on the basis of equality and acceptance through understanding of his/her life values, respect of life, human rights and dignity).

However, therapeutic dimension of persons involved in rehabilitation should be introduced into bioethics, as well. It is a point of view of the whole society not an individual optional attitude.

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<sup>5</sup> *Evangelium vitae* (dalje EV), br. 28, Kršćanska sadašnjost, Zagreb, 2003.

## 1. Emergence

The emergence and development of general or global bioethics is followed by rehabilitation ethics.<sup>6</sup>

Western Christian theologians (especially those in the United States P. Ramsay, McCarty) participated and supported the emergence and development of bioethics, shaping its role in today's public discourse from its early beginning. Religious *activists*, especially those fighting for political and human rights have enriched society with religious and human values. Nevertheless, theologians, especially Catholic ones, started to talk about the *common good* pertaining to the traditional social truth of the Catholic social teaching and demand *integral* justice in the field of life and social security. In this context, the Catholics advocating the right of the unborn (embryos, fetuses) trace a path for the Catholic movement *pro-vita*.<sup>7</sup>

This important concept of the Christian tradition is introduced into the *health care parlance* (rehabilitation) and the *justified distribution of health resources*. According to the concept of justice, the right to *health* is an inclusive right of every human being. Christian justice emphasizes the equality of all human beings, regardless of their poverty or wealth, as well as their right to treatment. Christianity view also highlights that religious and moral values neither relate to the right political wing nor to the left one. In general, poverty can become common field of action for all partakers, conservatives or liberals.<sup>8</sup>

Christianity becomes aware of its inexhaustible resources on significance of life, man and his dignity that are included and affirmed in the Bible and the Tradition. Man is not any kind of being but rather being created by God as His collocator<sup>9</sup> and co-creator, in the "image" of God (His "likeness" in the Eastern Theology). Though, created, dependent and limited being a man still has an

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<sup>6</sup> Cf. *Archives of physical medicine and rehabilitation* (1980), *Hastings Center Report* (1987), see also *Encyclopedia of Bioethics* (1978. I 1995.).

<sup>7</sup> Pope Johan Paul II, founded Academy, *Pro vita Motu proprio* „Vitae Mysterium“ 11 February 1994., comp. [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/motu\\_proprio/documents/hf\\_jp-ii\\_motu-proprio\\_19940211\\_vitae-mysterium\\_sp.html](http://www.vatican.va/holy_father/john_paul_ii/motu_proprio/documents/hf_jp-ii_motu-proprio_19940211_vitae-mysterium_sp.html)

<sup>8</sup> Comp. Wallis J, *God's Politics: Why the Right Gets It Wrong and the Left Does't Get It*, (San Francisco, CA: HarpwrSanFrancisco, 2005.

<sup>9</sup> Dogmatic Constitution of II. Vat. Council, „Dei Verbum“, no. 10.

immense dignity. However, in the Bible, a man perceives himself as an active, creative and responsible being. He is not an absolute master, neither of himself nor of worldly life but merely responsible manager. So, the Christian teaching points out that God created the world and man and all He created has been left to man's governance. It is interesting that God didn't give man any *working* programme, but rather reason and freedom to find out and follow the laws and way of life. Man is therefore an integrated part of nature, he is immersed into it.

The Christianity has also introduced into bioethics one of its specific concept of *love*. Love is namely, the source of moral Christian life and the essence of the very Christian proclamation of Christ. Actually, God was first to love us freely, so we are to love each other (1 John 4, 10), and the culmination of such love was shown by Christ Himself when He laid down his life for others (John 15, 13). Therefore, He is real „measure“ of love for any Christian. According to such law of love Christians have to recognise each other (John 13, 35) and deeds of love should be their truly Christian preoccupation. Thus, Christian love is taken as a form of all virtues. Consequently, this idea is closely connected *bioethics of care* which has been mostly developed through the practice of clinicians, especially in *rehabilitation*, and had impact on treating a patient as man/person and his inherent dignity.

## **2. Rehabilitation: bioethical understanding**

Rehabilitation issue is in the focus of *clinical bioethics* i.e. bioethics referring to a person in need of treatment and cure and clinician who provides it. Their relationship can not and should not be only professional but rather specific of other features. Medieval theology and spirituality regarded a patient as *Christus patiens* and physician as *Christus medicus*.<sup>10</sup> Present understanding of rehabilitation overpasses the frame of clinical treatment, cure and bioethics and requires a *human approach in caring for a disabled person*. A patient primarily needs human kindness, polite words, pleasant reception and physician's expressed willingness to help.

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<sup>10</sup> Comp. Tomašević, L., *Bioetika u kršćanskoj tradiciji i sadašnjosti*, u: Filozofska istraživanja, 71, God. 18, Sv.

Rehabilitation has become bioethical issue only in recent decades. There are two reasons:

1. it is a complex matter because there are different types of *persons with disabilities, disability types*, but also *rehabilitation approaches*;
2. A *systematic review* of disability issue started in 70-ties of the past century, actually when the first edition of Encyclopedia of Bioethics appeared. Namley, rehabilitation area started to focus on *the patient's autonomy, the quality of life and justified distribution of health resources*. A great number of persons with disabilities caused by traffic-related accidents and the prolongation of life etc., contribute to the rehabilitation issue.

Furtherly, the issue of the *disabled* was a taboo subject for a long time. At present, the person facing some physical challenges is treated on the basis of his/her *personality, dignity, needs and rights*. The view on such people has changed: regardless of their disabilities and defects, they are *humans and persons*. Disability is no longer taken as a *negative condition of others objectively*, as it also concerns us and becomes *our problem* i.e problem of the society and all people. Therefore, we are all invited not to think of their disability but to consider their *ability or possibility to create good life in community* because they are like all others, members of the same society.

Certainly, this shift in consciousness leads to better comprehension of a *new, truthful and human rehabilitation* targeting health care improvement for persons with disabilities. By caring for other we commence to *recognize other's values* and treat people around us differently, especially *persons with disabilities*.

Understanding of rehabilitation has changed gratefully: it encompasses *cure and surgery* but also acceptance of the other *as a person* in need of global way of rehabilitation aiming at the *quality of life* he/she would be satisfied with.

Rehabilitation includes a set of therapeutical activities and cure; care in order to reach full or partial recovery of lost abilities (mild, medium or complex) because of the inherited or acquired disorders (neurological, cognitive) and the assessment of actual abilities (perceptual, motor, mental) aiming at the best and the most efficient integration of the person with disability into the family or

community.<sup>11</sup>

It actually denotes the procedure disabled person is involved in order to reach better quality of life on physical, functional, social and emotional level, through care and education, so that his/her disabilities are minimised. Rehabilitation includes not only clinical but also psychological and social activity referring to: *patient's autonomy, improvement of his/her quality of life, his motor ability, talk and acquisition strategies* (self-therapy skill). Moreover, it includes rehabilitation staff, tools and techniques therefore, it is also *medical discipline* characterised by its theoretical principles and practical implementation.

In this context, medical rehabilitation (prevention, partial or complete recovery from disability) is closely connected to *social* rehabilitation aiming at reducing the burden of disability and helping person to regain his/her dignity, life respect, and to adjust to the demands of family, community, and occupation.<sup>12</sup>

The document entitled “*Il Provvedimento Trento and Bolzano*” – Italy, focuses on practical implementation of rehabilitation strategies aiming at cost-effectiveness and repeated surgeries prevention. It also highlights the importance of making necessary medical supplies based on research of local and regional needs and possibilities. It refers to any rehabilitation procedure which should be subjected to assessment and scientific evaluation before it is broadly accepted. Nevertheless, persons and their families should not be given false hopes or asked for financial support for surgeries which have not been thoroughly researched. Rehabilitation as a global process of the integration of sanitary-social sector turns to be the essential requirement, valid for all people.<sup>13</sup>

Rehabilitation procedure includes two levels: the first level is directed to a body and the defective organ and the second level is much broader and

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<sup>11</sup> See articles in: *Archives of physical medicine and rehabilitation* (1980), *Hastings Center Report* (1987), kao i one u *Encyclopedia of Bioethics* (1978. I 1995.). At the international level see: The Declaration on the Rights of Disabled Persons of the United Nations from 1975., and Council of Europe – Ministerial Conference in 1884.

<sup>12</sup> Comp. *Provvedimento Conferenza Permanente per i rappresentanti tra Stato, Regione, Provincia di Trento e di Bolzano*, 7 maggio 1998, u: *Gazzetta Ufficiale del 30 maggio 1998*, n.124. This document deals with rehabilitation procedure, professional competencies, service provision function, and the integration of sanitary and social activities.

<sup>13</sup> *Ibid.*,



encompasses entire person and his/her integration into family, community and occupation. Four rehabilitation aspects are stressed and they refer to:

- a) a defective organ and its dysfunction;
- b) secondary and tertiary damage;
- c) a complete person i.e his/her physical, psychological, moral and spiritual aspect;
- d) society invited to support prevention, to provide resources, staff and facilities for the needed and to promote willingness of its citizens for solidarity.<sup>14</sup>

Nevertheless, rehabilitation mostly refers to physical disability and therefore it does not include sensory impairment directly (blind or deaf people) nor psychological and mental patients, drug or alcohol addicts.

### 2.1. *The basis for ethical requirements*

The existence of various patients and diseases contributes to the complexity of rehabilitation issue. Certainly, all human *disabilities* are specific regardless of their categories, from blind to mentally impaired patients. Consequently, the first *bioethical-personalistic* requirement states: *every disabled person should be treated individually, in acceptable and adequate way*. From bioethical point of view every man is entitled to fundamental right, the *right to be treated as a person*. This right is based on general human rights.

- a) *the disabled person's right to human dignity* simply because of the fact that he/she is a member of mankind. This fundamental human right is explicitly quoted in United Nations *Declaration on the Rights of Young People* from 1975, as well as in the *Declaration on the Rights of Mentally Retarded Persons* from 1971 where it is clearly stated: *Mentally Retarded persons are equal in all rights the other people have.*"

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<sup>14</sup> Comp. Sgreccia E., *Bioetica, handicap e riabilitazione*, u: Manuale di bioetica. Aspetti medico-sociali, vol. II, Vita e Pensiero, Milano 1991., p.379-380.

b) This fundamental right includes some other rights such as:

- *the right to integration* into family life, social, political, economic and religious life;
- the right to the *normalization* of life aided by science and medicine;
- the right to *autonomy* so that any individual is treated specifically and evaluated by his/her skills and abilities in the society.<sup>15</sup>

## 2.2. Requirement for ethical engagement

One of the first ethical engagement should be *disability acceptance*. It should refer both on a patient and medical worker who has to create an atmosphere of successful rehabilitation and recovery of the lost ability.<sup>16</sup>

The fact that human body refers to the *principle of self-directedness* means that any injury or defect in the human body reflects to his/her own concept of self<sup>17</sup>. However, self-acceptance and integration does not occur immediately. In case of failure of a complete recovery from disability, it is important that person accepts imposed limitation and to broaden his/her creative potential. In this context, one should think and reconsider the significance of health. It is especially important matter today when health is regarded as our *responsibility and the task* of society.

Health means not merely the *absence of disease*. If it were so, a sick man would lose his dignity and become useless. Consequently, the task of medicine is to cure him and to bring back his ability to do work. In this sense, disability is an unpleasant life experience one should get rid of.

The World Health Organization (WHO) attempts define and determine responsibilities “for health of all”. It defines health as a state of complete physical, mental and social well-being and not merely the absence of disease.

Medicine of the past was more concerned of patient’s recovery and a way to *combat illness at any cost* than of him. Insisting on *cures* at any cost was

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<sup>15</sup> Comp. Ciccone L., *Anziani e handicapati: due sfide alla societa' civile e alla communita' ecclesiale*, Elle Di Ci, Torino-Leumann 1987; Ciccone L., *Salute e malattia. Questioni di morale della vita fisica*, Ed. Ares, Milano 1986.

<sup>16</sup> Williams R.S. jr., *Ability, disability and rehabilitation: a phenomenological description*, u: „J.Med.Phi.“, 1984, 1, pp. 93-111.

<sup>17</sup> Comp. Melchiorre V., *Il corpo*, La Scuola, Brescia 1984.

medical approach at that time. Today this approach is gradually changing: cure refers to a patient not disease, and patient is a person having his/her body, feelings and spiritual dimension. Person therefore need *rehabilitation* or integration into life of family, friends and community.<sup>18</sup>

Based on such approach the other broader view on man and his life has developed. According to this approach health and disease are immanent to life and everyday experience of all people. Moreover, health is regarded as a sort of *inner-body equilibrium*, rather dynamic than static and disease is regarded as disturbance of such *equilibrium* which is not merely *incident* but rather a new *opportunity* to search for own equilibrium through personal growth, conscience, self-responsibility and self-improvement.

In this context, recovery presents a new capacity to evaluate regain life energy, consciously and freely. It is not merely gift but property that anyone can lose, but always search for and reach it again. Furthermore, health is considered everyone's *task and duty*, particular life style enriched by its ethical dimension which integrates the following ones: *organic, psychological and ecological*. Key factors which influence health are: nutrition, working conditions, housing and basic needs satisfaction which are no longer in the focus of medical sciences.

According to such approach to health, disease represents its integral part requiring medical diagnosis, adequate therapy and care, as well as rehabilitation of patient which lead to prevention directed to such behavior which can and should prevent any pathological condition.

Health protection and health promotion should become *duty* both on personal and social level in order to transform into the real *health education*. The paradigm "*health as equilibrium*" does not question medical development, scientific evaluation or rehabilitation success. On the contrary, this paradigm sheds new light on medicine: *it is human acceptable answer to medical needs which shouldn't be theoretical but rather adjusted to human needs and 'flexible' for the development of other 'personal' possibilities*.

Finally, bioethics has introduced some new non-medical concepts into health and rehabilitation sciences emphasizing necessary distinction between

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<sup>18</sup> Comp.Lozano Barragan J, *Teologia e medicina, EDB*, Bologna 2001., pp. 11-20.

disability and disease.

Disability (WHO) is the subject matter of the human race and it should not be merely approached from the *medical* point of view (therapy and cure) but also through social obstacles which impede integration of the disabled persons into life. This is right bioethical approach which refers to something in one's possession, something personal, someone's commitment not conditioned by life circumstances but one's own approach to disability and help.