

Obligations for Care in Severest and Hopeless Neurological Conditions

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Introduction

In the third millennium modern human beings in industrial society demand that all possibilities of modern medicine have to be available to them. Everybody expects to be released of physical or mental illness as fast as possible, simultaneously everybody wants to be certain that all results of modern research in medicine are being applied to grant him a longer life. The modern human claims his right to be treated everywhere and at any time, even in advanced age and suffering from incurable diseases as well as mental decline. The modern human appeals to the progress in diagnosis and therapy, on which he has to be informed constantly. He demands his presumed right to have access to all resources, assuming them being intended for him as a member in the social welfare system. The phrase "Freedom of the Human Individual" is being used as an important pawn. This special feeling of freedom is equalized with the presumed right of personal wellbeing, but unconnected to the wellbeing of the community.

From a historical point of view the origin of this "misunderstanding" of individual rights goes back to the French revolution. The freedom of human individuals was transferred to all mankind by the revolutionary idea, the wellbeing of the individual was separated from the communities wellbeing. The concept of human rights defined in 20th Century was starting to serve as a regulator in concepts of modern Western community and is utilized as an integral part of democracy. The basic principles of modern western society were initiated with the onset on the Judeo-Christian tradition based on the 10 Commandments of Moses by establishing special ethical and moral rules.

Based on Greco-Roman culture a life form predominated by Christianity

evolved in Europe, refined by the philosophical work of Saint Augustinus and his construct of the State of God, critically analyzed by Thomas Aquinas, student of Albertus Magnus, this great European philosopher and initiator of the Gothic period in architecture. An obligatory ideology for the "Western Way of Live" was founded during the industrial time with all its errors, fights and attempts to find a harmonization till recent days using democracy as a fundamental stone of a God-given construction, claiming the whole world to follow Western ideological pathways.

Coevally, during centuries different civilizations have been developed with different moral and ethical basic rules. In China Confuzianism was founded, directing all parts of life, being the ruling law until now, experiencing a renaissance in the "Neo-Confuzianism" of modern China. More than two thousand years ago Buddhism was established as a moral institution, denying in his basic rules the Western materialistic ideologies and their demand of a missionary democracy. The Islamic religion was formed as an assimilation of Judeo-Christian thoughts, in the fundamentalistic way claiming the right to build up a new ideological basis for the whole world. As the main insight of the recent time it has to be accepted that ethical rules of the Western World in their present form cannot be transferred to other cultural communities, neither in the Islamic World nor to the "Neo-Confuzianism" with its basis in Marxistic-Leninistic ideology or to Hinduism or Buddhism.

At the present stage modern medicine in daily practice as well as in research has to be based on ethical laws, in harmonization with the ethical rules of different ethnical, historical, geographical and climatic regions, accepting social and biological validity. Ethical rules in modern medicine are based on the Human Rights, declared 1948, in practical use and in research on the Helsinki Declaration (1964). The UNESCO Declaration of Paris (2005) is a further step to a harmonization taking into account social, legal and environmental dimensions and requiring patient's autonomy, individual responsibility and informed consent. The Paris Declaration does not include the upcoming tendencies of religious and ethnical based ethical principles. Only the article 12 "Respect for cultural diversity and pluralism" is in compliance with these aspects.

Bound by the Hippocratic Principles every physician is obliged to heal, he has to treat the diseases of his patient, but he has to interrupt the treatment of a patient who suffers from incurable illness, from advanced age or mental disabilities. To prolong the life over hours and days in untreatable conditions using special therapeutic measures is not justifiable, neither morally nor ethically. In accordance with the content of the Hippocratic Principles the physician has the obligation to reduce suffering. The ancient maxim for physicians never to hurt and always to help has a normative weight until nowadays.

The patient has to be informed about all details of his disease and the foreseen diagnostic and treatment programme by his responsible physician.

The patient has to decide if his relatives shall be informed. In state of “unable to consent”, the solicitor has to get information from the responsible physician. Every patient has the right to refuse the planned diagnostic and treatment programme as well as to interrupt such programmes. In this situation, the physician has the obligation to inform his patient about all related consequences for his health in full detail.

The care in severest and hopeless neurological conditions, medical and nursing care

Patients with following diseases have to be classified as severest neurological patients in a hopeless condition: patients suffering of progressive brain processes (Creutzfeldt-Jakob Disease, Neuro-degenerative diseases, including Amyotrophic Lateral Sclerosis), end state of progressive inflammatory processes of the nervous system like Multiple Sclerosis, defect states after severe acute brain damages like Apallic Syndrome, Locked-In-Syndrome, all defect states after severe damage of the central and peripheral nervous system showing no remaining capacity in a neuro-rehabilitation programme.

In addition patients with an a priori untreatable condition (brain metastasis etc.), patients with a severe defect state after an acute damage of the nervous system without further possibility in a neurorehabilitation programme, without prospect of further remission because of no remaining rehabilitative capacity have to be transferred to a special nursing home, but only after a re-checking with specialists. This especially concerns patients with an apallic syndrome, showing no remission or no further improvement in an early remission state, patients with an locked-in-syndrome without remission, patients with severe defects after an acute traumatic brain damage or after encephalitis and stroke.

All patients without any possibility of an improvement after a neurorehabilitation programme or in a declining course of a progressive neurological disease and patients in an a priori untreatable condition need intensive medical care with a special supporting programme. The main principle for these patients is to be cared in a special nursing care centre, which is fully equipped and supported by an experienced medical and para-medical team. A “continuous activating programme” has to be installed.

Nancy Roper created 1953 a special scale for the daily activities of a human being in the modern industrial society called ADL, further developed by Liliane Juchli in 1993. Listed are wake and sleep, moving, bathing and dressing, eating and drinking, excretion, regulation of body temperature, respiration, care for safety, to keep busy, communication, feeling as woman/man and sense of life. All these needs are the basis of a human being in the “Western World” and an in a full healthy state. The Basic ADL (BADL) was created by Mc Dowell and Newell 1996, in addition consisting of the ability to bathe, dress and undress, eat, transfer from bed to chair and back, maintain

continence, and use of the toilet as a self care task. The BADL- evaluation is used as a measurement for patients with chronic and untreatable diseases to decide the individual's necessary programme in the care. The instrumental ADL (IADL) gives the basis for an independent life in a community,

The organization of a nursing unit has to compensate the lack in the basic ADL. The different individual assessment level of a patient has to be taken into account with the recognition that each patient needs his individual caring programme.

After Wikipedia the definition of nursing care declares nursing as a profession focused on assisting individuals, families and communities in attaining, maintaining and recovering optimal health and functioning. Modern definition defines nursing as a science and an art which focuses on promoting quality of life as defined by persons and families throughout their life experiences from birth to care at the end of life. After this definition the nursing care has the obligation to preserve the life of a patient needing help. The main demands of patient's care is to deliver best nursing care besides best medical care with the tendency to avoid needless pain. To preserve the personal identity and social contacts of a patient as well as providing the possible resources are an obligatory demand. A basic necessity for patients in untreatable conditions is the availability of methods for life support. Any discussion about financial resources should be avoided, a discussion of end of life decision is an act of inhumanity and ethically unacceptable.

As a different chapter the palliative care needs a separate discussion. The WHO defined palliative care in 1990 as the active total care of patients whose disease is non- responsive to curative treatment. A control of pain and of other symptoms as well as of psychological, social and spiritual problems is paramount. The call of palliative care is the achievement of the best possible quality of life for patients and their families. Palliative care affirms life and beholds dying as a normal process, neither hastening nor postponing, providing relief of pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, offers a support system to help patients to live as active as possible until death. But palliative care offers too a support system to help the family during the patients illness and in thier own bereavement. Radiotherapy, Chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures have to be kept at a minimum.

One of the most important facts in the nursing care of untreatable and hopeless patients being in a severe neurological condition is the demand for the amelioration of quality of life. This new movement in neurological obligations can be called the third leg in Neurology besides acute neurology and neurorehabilitation. The main intention of the idea of Movement for Amelioration of Quality of Life is the support of nursing care institutions with a special programme to improve the environment of a nursing care centre and its surroundings.

Summary

Neurology is the speciality in medicine with the greatest rate of development. Neurology has earned the profit of advances in modern techniques as well as in physics and biochemistry. Despite of all of these advances, the modern neurological research is just at the beginning, but many questions are open and in a great number of neurological problems we have to capitulate nowadays. Modern diagnosis and all the modern therapeutic knowledge have to accept that nature is stronger than all our wishes to help. On the other side we have to confess that in some directions we do not use all of our capacity in modern neurology and we have to confess too, that wrong decisions, misunderstanding, personal errors, lack of respect for the greatness of nature and jealousy in professional cooperation are disturbing the abilities of modern medicine. A part of our patients does not get a well organized treatment. Last not least economic intentions are opening mercantile interests, influenced by pharmaceutical and electronic industry. We have to accept that in a great number of neurological diseases all our modern possibilities have no effect despite of our well meant intentions. Finally nature is asking for its tribute.

As physicians we have to accept that every human being has the right to live (Paris Declaration 2005), every human being has the right to exert modern medical treatment and best nursing care (Paris Declaration 2005). The patient has to be cared according to the basic human rights and the ethical principles. As a physician we have to follow the rule that no economic consideration is acceptable in medical decisions (Hippocratic Principles, Helsinki Declaration). According to the Hippocratic maxim, patients have to be treated in dignity, but not over-treated by using all modern possibilities. In all defect states of neurological diseases patients without hope of any improvement, we are responsible for the best medical care and for a modern nursing care to be provided in special nursing care centres, with the demand of a continuous activating programme. In upcoming complications the renunciation of maximal therapy is acceptable in accordance with the Hippocratic Principles.

According to the ethical rules a decision for end of life is not acceptable and there is no place for such thoughts in the ideology of a physician. A decision backed by legal institutions (Supreme Court, etc.) can not be realized by physicians and by medical personal according to the ethical rules.

The patient in a hopeless condition after a neurological disease needs our special care taking all of our energy and medical experience accompanying this human being till the end of his life with a personal resonance. A special field is the palliative medicine, which needs intensive education and special training.

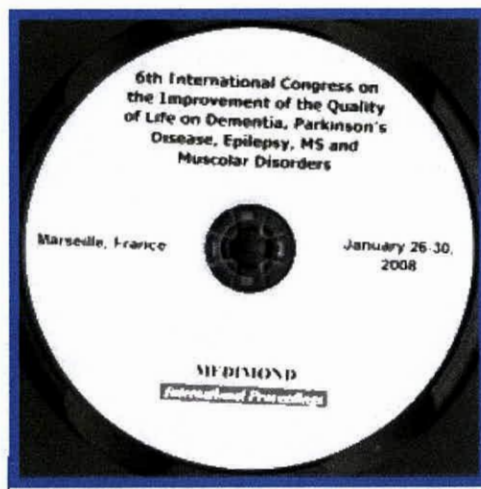
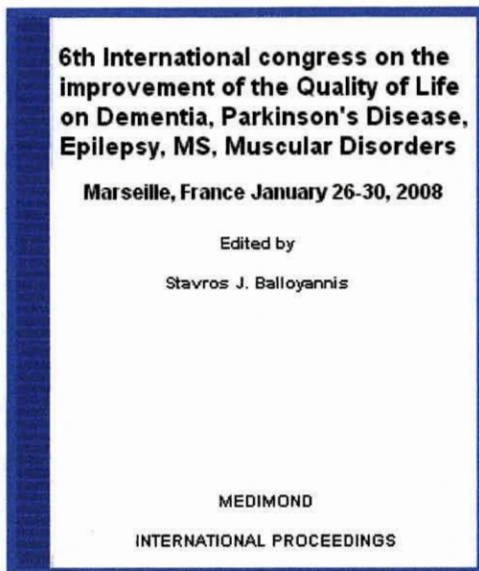
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