

# ETHICAL CONSIDERATIONS IN MODERN REHABILITATION MEDICINE: MODELS, THEORETICAL BACKGROUND AND PRACTICAL APPROACHES

## ETIČNA VPRAŠANJA V SODOBNI REHABILITACIJSKI MEDICINI: MODELI, TEORETIČNO OZADJE IN PRAKTIČNI PRISTOPI

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### Summary

The paper provides a short overview of ethical principles and models in modern medicine in general, and specific ethical and practical models in rehabilitation medicine. It highlights the various ethical issues in modern rehabilitation medicine and provides some general considerations on bioethics at present and in the future.

### Key words:

ethical principles, ethical models, rehabilitation medicine, ethical problems, bioethics

### Povzetek

Članek prinaša kratek pregled etičnih načel in modelov v sodobni medicini kot celoti ter specifičnih etičnih modelov in praktičnih pristopov v rehabilitacijski medicini. Izpostavlja številna etična vprašanja v sodobni rehabilitacijski medicini in obravnava nekaj splošnih vprašanj bioetike v sedanjosti in prihodnosti.

### Ključne besede:

etična načela, etični modeli, rehabilitacijska medicina, etični problemi, bioetika

*"Surgeons must be very careful  
When they take the knife!  
Underneath their fine incisions  
Stirs the Culprit---Life!"*

- Emily Dickinson

## INTRODUCTION

Francesco Petrarca (1304-1374), the founding father of the term "humanism", attacked doctors who defended scholasticism: he accused them of being "more apt to diminish the substance than the sufferings of their patients, and to lighten their purses of gold rather than their bodies of evil humors" ...

Modern rehabilitation medicine is characterized by its multidisciplinary team approach, the long-term and costly process and the absence of dramatic and immediate cure. Today, more complicated moral dilemmas appear, life expectancy becomes longer, quality of life and equal opportunity issues become prominent. It aims to overcome STIGMA – as an acronym: school, technology, integration, gainful employment, accommodation.

**Sapere aude** is a Latin phrase meaning “dare to be wise”, or more precisely “dare to know”. Originally used by the Roman poet Horace, it has become closely associated with the Enlightenment after being cited by Immanuel Kant in his seminal essay, *What is Enlightenment?* Kant claimed it was the motto for the entire period, and used it to explore his theories of reason in the public sphere. Later, Michel Foucault took up Kant’s formulation in an attempt to find a place for the individual in his post-structuralist philosophy and to come to terms with the problematic legacy of the Enlightenment (1).

On a daily basis, we have to use and implement these international guides:

- ICD – International Statistical Classification of Diseases and Related Health Problems,
- DSM – Diagnostic and Statistical Manual of Mental Disorders,
- ICF – International Classification of Functioning, Disability and Health.

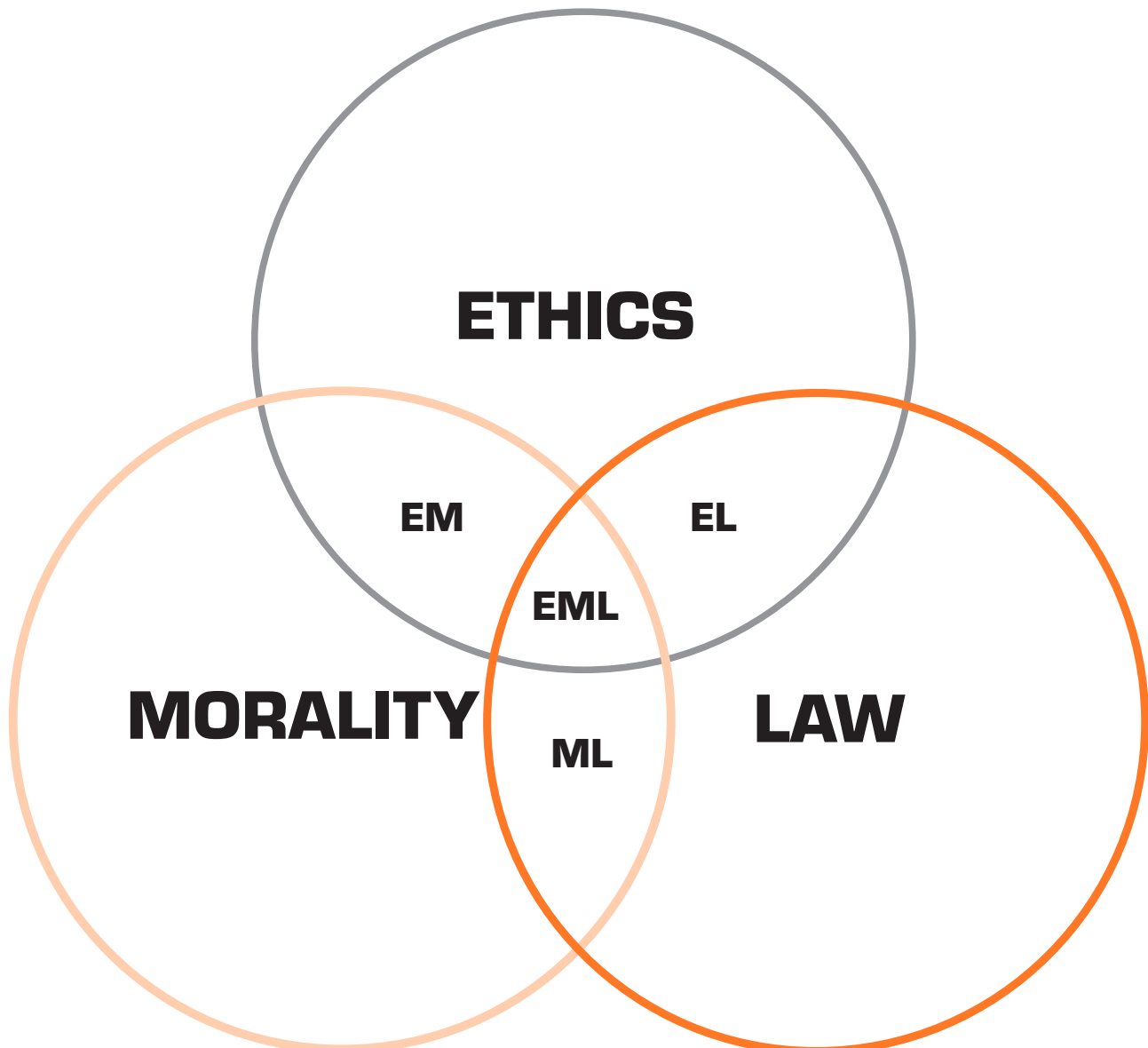
Rehabilitation medicine (RM) experts are aware of the fact that chronically disabled persons are prone to progressive changes and premature aging process (2-3). These phenomena, the “wear and tear” processes which are naturally slowly progressive, have no mention in these books. These aspects raise new ethical and medico-legal questions.

### MODERN MEDICINE AND ETHICAL MODELS

The ingredients of modern medicine are: cost-constraining, scientific and less artistic, evidence based on prospective placebo-controlled randomized studies, DRG and not fee-for-service, the hospital is not anymore a “refuge” but rather under the eyes of the social, legislative, ethics and media.

The traditional four major corner-stones of medical ethics are:

- The principle of beneficence: kindness, charity and doing of good, the moral obligation to help people.
- The principle of non-maleficence (“*primum non nocere*”):



*Figure 1: The three dimensions within which a modern physician acts.*

to refrain from harming.

- The principle of patient's autonomy (contrary to previous paternalistic approach): respect for the values and beliefs of other people. Clients (former "patients") are entitled to privacy and to make decisions about their lives.
- The principle of making justice.

Thus, the modern physician acts within three dimensions (Figure 1).

The classical codes of ethics according to Veatch (4) include:

- The J. Bentham and J.S. Mill's *utilitarian* approach with commitment to maximizing good health.
- The moral obligations and rights – the *deontological* (duty) approach.
- *Equity* is a concept related to the moral principle of justice and fairness, and efficiency is related to utility.
- This idea of distributive justice was first conceived in the Magna Carta (1215), later- on reemphasized in the American Declaration of Independence (1776), The French Revolution (1789) and finally by The Human Rights Committee – UN, 1948.

Veatch described the classical models for medical ethics:

1. The engineering model: the patient has all the power in which doctor-patient relations are conceived or modeled.
2. Paternalistic (Priestley) model: the doctor has all the power and makes all the important decisions.
3. Collegial model: power is shared by doctor and patient as social equals.
4. Contractual model: power is shared through contractual negotiation, which ideally does not violate the moral integrity of either physician or patient.

The key words of bio-ethics in RM are the same, but, as we shall see later-on, they do contain more specific issues (5-9). Sir Douglas Black (10) defined problem oriented medicine as an approach which elicits and categories the patient's problems, both those described by him/her and those discovered on physical examination or in the course of investigation.

Evidence based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about care of individual patients. This fact requires continuous professional development and "keeping up to date" with the available information. Are these issues applicable to RM?

We live in a cost-constraining medical atmosphere rather than cost-ignoring medicine. Can we supply proper modern comprehensive RM to the disabled people in this atmosphere?

In general, the problems of the aged and the disabled are: deprivation, inaccessible world, continuous needs, continuous aspiration to recovery, fairness justice, and equal opportunity, and shared values.

"The emergence of rehabilitation as a social movement may be a significant contribution of the twentieth century to human development. Each step toward freeing human potentiality from the limitation of disability contributes to the dignity and growth of all mankind. The rehabilitation goal is helping the disabled person to attain his/her maximum level of adequacy in work, love, play and social relations." (11)

"Can we afford, however, to consider rehabilitation apart from all other preventive, developmental, curative and conservative measures? For rehabilitation is not a discrete moment in time, but a series of connected events in the life process of development, maturation and decline" (12).

We need trust in the rehabilitation medicine setting:

- patient-focus of health care providers;
- macro-level policies having no consequences for patients (overcome system hassles);
- expertise of health care providers;
- quality of care;
- information supply and communication by care providers.

At the end of the acute stage of their medical or traumatic problems, patients are referred to rehabilitation facilities. At this moment some questions are asked: where to refer the patient - to general RM ward or to specialized center like spinal unit or stroke unit etc.? For how long the patient will stay at the rehabilitation ward? What is the policy of the insurance company or sick-fund? Should we screen/select the patient prior to his admission according to disability, circumstances of injury, age? When RM ends and geriatrics starts? Are obvious obstacles to successful rehabilitation, like severe cognitive dysfunction, previous poor social-vocational integration or pre-morbid multiple diseases, deter from admittance to RM facilities? Non-medical factors also carry weight: insurance status, personal finance, social and family situation.

RM is the meeting point of medical sciences, psycho-social sciences, physical education, education, legislation, allied health fields, and bio-engineering. All the efforts of the large rehabilitation team is directed and "orchestrated" toward one goal: to fight physical pathology, to prevent disability, to relieve pain and distress, to try to cure disease, to care for illness, and to promote life. This is usually unrealistic. RM tries therefore to restore the patient's emotional well-being, maintaining residual function, preventing secondary and tertiary complications of the existing disability, and developing compensatory functions.

These specific aims of RM are obviously subject to varying interpretations when they are translated into day-to-day action into the search for an optional therapy. What about quality of life? How to define it? Who decides a life lacking the attributes to this quality is not worth living anymore? These questions, although relevant to all fields of medicine, are crucial in all major decisions of the rehabilitation process. Though there are no completely satisfying answers, RM specialists are usually able to deal with these questions. They rely on their professional expertise, experience,

knowledge of existing conditions to help them solve this kind of dilemma. The challenge lies reaching an agreement between the patient, the family, the hospital directors and the care/payer provider on what is an acceptable quality of life (13-19).

## ETHICAL AND PRACTICAL MODELS IN REHABILITATION MEDICINE

The classic expression of the traditional model of medical care was the Hippocratic Oath, which stresses the physician's duty to help patients and not to harm them. This was considered a sufficient moral basis for the paternalistic doctor /patient relationship. The physician alone decided which course of treatment was the best for the patient, how much information he will get, without involving the patient's personality or values. The contractual model is based on a contract between patient and physician. They are considered to be equal partners in a relationship. It is the doctor's duty to provide care, but in accordance with the patient's wishes. The key to equality in this relationship is the patient's informed consent. The physician, however, can refuse to carry out the patient's wishes if they contradict his/her medical opinion. In the early stages of the rehabilitation process, much time is spent for informing and explaining the patient and his family about the disability, diagnosis, prognosis and about the process itself. Sometimes understanding the full meaning of the disability is delayed and the patient not entirely "accepts the verdict", so it will be unfair to consider the patient as an equal partner.

The educational model is a much more flexible one. From the parent-like approach at first [the patient and his family going through emotional shock when they confront the trauma of the impaired condition, and at this point the professional team can opt for a parent-like behavior towards the patient which includes the right to temporarily disregard the patient's or family's wishes] to gradually becoming a partnership, this approach is better adapted to the relatively long rehabilitation process. It is an attempt to adapt the care provided to the changing needs of all concerned. Although family involvement is essential, our duty is to ensure the patient's privacy and confidentiality. We must get the patient's permission to share his private information to third persons. It is my belief that the patient should become an integral part of the rehabilitation team. During the period of "parenting", patient autonomy is gradually restored and an atmosphere of mutual trust should be created, so that when the patient becomes a partner to his care providers, the ideal of a common decision-making process can be pursued. In this last model patients have to know who coordinates and directs the team. They are entitled to ask for replacements among the staff, insofar as it is feasible. They should be consulted on the degree of involvement of their relatives in decisions concerning their treatment and their future.

The main three leading clinical guidelines towards proper patient's management are: it must be clear who makes the decisions, creating as soon as possible, an efficient and sensitive communication with the patient, and finally, the rehabilitation team must realize early in the course of the process, what are the patient's beliefs, and his views on quality of life.

## SOME OTHER ETHICAL PROBLEMS IN MODERN REHABILITATION MEDICINE

Some other ethical problems faced in modern rehabilitation medicine include the following:

- While there is a lack of acute-rehabilitation beds, who will select patients for rehab-program?
- When is plateau reached?
- When is the right moment for discharge or transferring the patient into community-based rehabilitation facilities or to day-care program?
- Does the patient select or prefer therapies and avoid others?
- How should we deal with conflicts of interest: between patient's goal setting and the staff's one; between the insurance company and the hospital staff; between the family and the patient, etc.?
- To whom should the team be loyal?
- Different compensation fees according to type of insurance, different equipment etc.

Ethical issues that were identified by American rehabilitation-medicine clinicians (20) are:

1. Issues related to changing health care reimbursement:
  - lack of insurance benefits for needed services;
  - allocation of scarce hospital resources;
  - "3 hours rule pressures";
  - suboptimal or inadequate discharge plans due to lack of financial resources;
  - reimbursement documentation (truth telling);
2. Goal setting – conflicts between patient, treatment team, or families;
3. Questionable decision-making capacity of the patient:
  - informed consent issues;
  - surrounding refusal of team recommendations;
4. Confidentiality issues
  - of patients' medical or personal information with staff, families, employers;
  - of medical records;
5. Withdrawing life-sustaining treatment for patients with disabilities;
6. Unsafe/suboptimal discharge plans due to competent patient's refusal of team recommendations or family/caregiver's refusal or marginal involvement in the rehabilitation plan;
7. Issues related to advance directives and DNR orders;
8. Quality of life issues raised by refusal of team's recommendations regarding dysphagia management;
9. Are there limits to patient's/surrogate autonomy?
10. Responsibilities of team members when they have knowledge about potentially criminal or dangerous behaviors of patients;
11. Questionable practical competency of the family/caregivers;
12. Truth-telling regarding prognosis.

For example, when dealing with ethical issues which arise during the treatment of spinal cord injured patients (SCIPs), there are four major levels of discussion:

1. Is society really doing the utmost of its abilities to prevent SCI? (societal aspects)
2. Are the acutely injured patients receiving the best available comprehensive –integrative medical/surgical treatments? (professional issues)
3. In the face of different levels of insurance and different levels of care/treatment/follow-up, are the chronic SCIPs receiving the best available comprehensive care and exposure to the knowledge about prevention of secondary and tertiary complications? (business and economic factors)
4. Is societal legal/social/educational/vocational infrastructure doing the utmost of its possibilities and duties to fully re-integrate these patients to the main stream of life (patient's rights and welfare)?

Many other ethical issues arise: life and death questions concerning ventilated SCIPs, for how long will the initial rehabilitation period take? How should the team find the “golden path” between different “interests/pressure” of the insurer, the hospital directors, patient/family wishes, and the team itself? To whom should the team be loyal? (Why do only physicians take the Oath at the end of their studies? Often there is a gap (conflicts) between patient's autonomy/self-governance abilities and team's efforts for beneficence /non-maleficence and efforts towards patient's independence in ADL, and the reality of injustice (various insurance levels). Patients' selection is done in some countries according to: insurance policy, availability of beds, age, SCIPs with other past diseases (chronic conditions, i.e. psychiatric, oncologic, etc') or recent complications (pressure sores, depression), admittance according to “rehab potential”, or social/vocational background.

Frankel (7) described the main ethical principles which he found to be important while treating SCIPs:

1. Hippocratic Oath,
2. Declaration of Geneva from 1948,
3. Declaration of Helsinki (principles in research) from 1964,
4. The Medical Research Council guidance from 1964.

These issues are important (especially in the US) given the following facts:

- There are limited resources for RM.
- Plurality of moral/ethical perspectives.
- There is an increased emphasis on self –management, self-treatment, autonomy to decide.
- Absence of universal coverage. Huge portion of uninsured people (not in countries with full socialized/nationalized medical care).
- An increasing competition among various health care providers (13-17, 21).

## GENERAL CONSIDERATIONS

In Wickler's view (22), bioethics has grown as a discipline through four stages:

1. Bioethics (medical ethics, medical deontology) was a code of professional conduct.

2. Bioethical debate was carried out during the 1960's by physicians in dialogue with the society.
3. Bioethics stems from the arising dialogue between doctor and patient: euthanasia, truth telling, confidentiality etc. Doctors and patients made decisions from a spectrum of alternatives. All are subjected to elements as financing, and regulation of the health care professions and institutions. There is an interaction between health economics and management in order to deliver the proper treatment.
4. The last phase is dealing with population's bioethics. It “transcends health care to include the full range of determinants of health status: the link between social stratification and health status, the fact that bioethics has never adequately addressed the ethical issues in public health policy and practice ... a merger between the field of bioethics and health policy and human rights ... bioethics is going to contribute to the renewal process and the equity-oriented planning which will result from it, it must indeed attain this fourth stage of its developments” (22).

## Literatura

1. Sapere aude. Dostopno na: [https://en.wikipedia.org/wiki/Sapere\\_aude](https://en.wikipedia.org/wiki/Sapere_aude)
2. Ohry A, Keren O. The premature aging process and new functional losses among people with chronic disabilities. *Crit Rev Phys Rehab Med.* 2008; 20 (1): 77-88.
3. Keren O, Ohry A, Meyer S. Restorogenesis - reflections about recovery. *Crit Rev Phys Rehab Med.* 2008; 20 (1): 55-63
4. Veatch RM. The medical model: its nature and problems. *Stud Hastings Cent.* 1973; 1 (3): 59-76.
5. Blumen N, Bar-On Z, Azaria M, Ohry A. Ethical issues in rehabilitation medicine. *Harefuah.* 1994; 126 (5): 286-91.
6. Ohry A. Ethical questions in the treatment of spinal cord injured patients. *Paraplegia.* 1987; 25 (3): 293-5.
7. Frankel HL. Ethical considerations in treatment and research in spinal injuries. *Paraplegia.* 1975;12 (4): 242-5.
8. Ohry A, Ohry-Kossoy K. Ethical considerations in rehabilitation medicine. *Tel Aviv University Studies in Law.* 1997; 13 (5): 263-9.
9. Ohry A. Clinical and ethical aspects of patients in chronic vegetative state. *Harefuah.* 1993; 125 (11): 426-8.
10. Black D. POM + EBM = CPD. *J Med Ethics.* 2000; 26 (4): 229-30.
11. Gellman W. Attitudes toward rehabilitation of the disabled. *Am J Occup Ther.* 1960; 14: 188-90.
12. Whitehouse FA: The utilization of human resources: a philosophic approach to rehabilitation. *Dis Chest.* 1956; 30 (6): 606-27.



13. Caplan AL. Informed consent and provider-patient relationship in rehabilitation medicine. V: *If I were a rich man could I buy a pancreas?* Bloomington: Indiana University Press; cop. 1992: 240-55.
14. Haas JF. Ethical issues in rehabilitation medicine. V: DeLisa JA, Gans BM, eds. *Rehabilitation medicine: principles and practice*. 3rd ed. Philadelphia: Lippincott-Raven; cop. 1998: pp. 1086-97.
15. Weber LJ, Wayland MT, Holton B. Health care professionals and industry: reducing conflicts of interest and established best practices. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S20-4.
16. Kirschner KL, Stocking C, Wagner LB, Foye SJ, Siegler M. Ethical issues identified by rehabilitation clinicians. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S2-8.
17. Macciocchi SN, Stringer AY. Assessing risk and harm: the convergence of ethical and empirical considerations. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S15- 9.
18. Blackmer J, Ethical issues in rehabilitation medicine. *Scand J Rehab Med*. 2000; 32 (2): 51-5.
19. Stineman MG, Musick DW. Protection of human subjects with disability: guidelines for research. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S9-14.
20. Kirschner KL, Stocking C, Wagner LB, Foye SJ, Siegler M. Ethical issues identified by rehabilitation clinicians. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S2-8.
21. Batavia AI. The ethics of PAS: morally relevant relationships between personal assistance and physician-assisted suicide. *Arch Phys Med Rehabil*. 2001; 82 (12 Suppl 2): S25-31.
22. Wickler D. Bioethics, human rights and the renewal of health for all: an overview. V: Bankowski Z, Bryant JH, Gallagher J, eds. *Ethics, equity and renewal of WHO's health for all strategy: proceedings of the 29th CIOMS conference*, Geneva, Switzerland, March 12-14 1997. Geneva: Council for International Organizations of Medical Sciences (CIOMS); 1997: P21-35.