Ethical difficulties in Medical Rehabilitation in Romania – Case study

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Abstract:
In the field of medical rehabilitation, our patients are often in a vulnerable state and are unable to process the real dimension of their illness, so the way that disability is discussed with the patient and his/her family is crucial in the process of understanding their condition and the realistic rehabilitation outcomes. In Romania, these aspects developed later after the ending of the communist period, after we became part of different groupings such as EU and we started to establish good social networks. After a traumatic condition that changes the patient’s and his family’s life the medical decision concerns not only the short-term outcome, but also long-term disability management for daily-life activities.

CASE PRESENTATION
In disabilities which include hemiplegia and paraplegia, there is a certain dramatic moment, “the moment of truth”, when patients realize that they are not going to be able to lead the same life as before the accident. This is precisely the moment when the Medical Rehabilitation team must intervene, in order to help the patients recover as much as possible from the negative effects that have an impact on several levels (psychological, physical, social, economic), simultaneously. In order to support this, I will tell you the success story of E.F., an outstanding woman who has been continuously fighting for her freedom to choose, ever since her life suddenly changed after an accident. A physically fit, vibrant young woman in her prime was injured in an instant after falling down from a tree. “I have started to prepare for life when I was hardly 19 years old. That unexpected fall from the tree meant a lot of suffering but has “opened” new ways to a different career than the one I was dreaming about. We realize the importance of things and the power that we have inside us only when we lose them. And this is when we really start to fight and struggle. I believe that all the power of human beings resides in their minds, which have to be trained so as to successfully face any kind of obstacle. Finally, all those years of hard training made me become an optimist, happy with the person that I have become, and very determined to go on in my life that I consider to be the typical life. After the accident I graduated from the School of Management and this helped me prepare for the job that I have now: Deputy Manager of the Motivation Romania Foundation. Also, I am married to a great man and we have a gorgeous child. My “career” means that every day, I say to myself and to those around me: ‘YOU CAN DO IT!’” After a few failed surgeries, she and her family faced the hard truth: she was facing a lifetime in a wheelchair with no chance to ever walk again. E.’s story is extremely familiar for many physicians around the world. Facing this case, we needed to state clearly the outcome and her further options.

Commentary
The incidence of traumatic pathologies leading to disability increasingly involves more and more young people. The prevalence of spinal-cord injuries (SCI) remains the highest in the United States of America, but the incidence is increasing in Europe as well. In 2007, the global incidence of traumatic SCI was estimated at 23 million, meaning approximately 179,300 new cases per year [9]. According to the World Health Organization [10], every year between 250,000 and 500,000 people suffer a spinal cord injury caused mostly by preventable causes such as road accidents, falls or violence. A significant proportion of traumatic spinal-cord injury is due to work or sports-related injuries. In traditional countries, such as those in the Middle East, but also in our country, the debate about knowledge and consent with respect to illness and health-care revolves around family norms, based on the Koran and the Bible. In the communist era, these were hidden, somehow omitted from the conversation between doctor and patient. After 1990, we started to develop and to take into consideration ethical principles and some personal values and expectations of the patient. Thus, the family unit is responsible for any decision about the treatment and care. These beliefs value an important ethical principle, non-malfeasance (“first do no harm”). This attempts to protect patients from any emotional and physical harm caused by facing illness and disability directly.

Physician-patient relationship
Disability in young people usually appears suddenly. Patients and their families face serious and life-conditioning decisions that will affect them immediately. The doctor–patient relationship is critical for vulnerable patients who experience a heightened reliance on the physician’s competence, skills, and good will. Common decisions taken by patients with disabilities and their rehabilitation doctor can deeply affect the quality of life for the patients. It is extremely difficult to establish a protocol in making clear, indisputable decisions in the face of complex, unexpected tragedies [5]. Physicians will sometimes encounter a patient whose needs, or demands, strain the therapeutic alliance. Many studies show that people often change their minds about what is tolerable when the condition changes [6]. It is important for the physician to have a tolerable attitude towards the patient and to expect them to change their mind. The doctor–patient relationship has been and remains a keystone of care: the medium in which data are gathered, diagnoses and plans are made,
compliance is accomplished, and healing, patient activation, and support are provided. The relationship therefore directly
determines the quality and completeness of information elicited and understood. It is the major influence on practitioner and
patient satisfaction and hence contributes to practice, maintenance and prevention of practitioner burnout and turnover. It is the
major determinant of compliance. [12] Models of medical decision-making usually focus on cognitive, situational, and
socio-cultural variables in accounting for human performance. However, these models rarely address the emotional
component. As Emanuel & Emanuel (1992) state, four relation patterns relate to medical decision-making [3]:
1. The paternalistic model, in which the physician takes the responsibility of deciding which interventions are best for the
patient’s health and well-being.
2. The informative model, in which the physician only provides information and the patient, makes an informed
decision.
3. The interpretive model, in which the doctor elicits information about the patients and their values and helps them to
make a medical decision.
4. The deliberative model, in which the physician helps the patient to form or choose health-related values.
Halpern J. tries to deconstruct many errors that will affect judgment and challenge clinicians and their patients who make serious
decisions. He describes three mechanisms which seem to underline forecasting errors [5]:
1. Focalism: one tends to emphasize factors that will change over those who will remain the same;
2. Immune neglect: the person fails to take into account that defense mechanisms, such as denial, will aid in adapting and
coping;
3. Inability to predict genuine adaptation.

Ethical principles applied in medical rehabilitation
The American Board of Internal Medicine and the European Federation of Internal Medicine have jointly proposed
that the medical professionalism should emphasize three fundamental principles [2]:
1. Primacy of patient welfare
2. Patient autonomy
3. Social justice

According to the first principle, the physician should be altruistic and provide a moral compass not influenced by
economic, bureaucratic and political changes and challenges. However, nowadays, there are certain concerns about the
physician’s commitment to the patient’s care and about how it is influenced by the conditions of the medical practice and the
external sources. In comparison to this basic ethical principle comes the second of the principles listed above: the patient’s
autonomy. According to this principle, patients should be able to take their own decisions, and take into consideration their own
personal wishes, values and expectations. These two principles, even if they seem contradictory, have a common denominator:
the need to protect the patients from any harm. In order to best approach a difficult case such as this, we must focus on the best
decision-making model. For this, we chose the model developed by the Hastings Center that involves eight steps [13]:
1. Professional commitment
2. Systematic evaluation of the case
3. Communication among all involved
4. Consideration of ethical principles
5. Decision-making
6. Documentation of the decision
7. Implementation of the decision and a change if necessary
8. Response to the objections and changes

Professional commitment is based on the three fundamental principles stated by the American Board of Internal
Medicine and the European Federation of Internal Medicine. It also involves an honest and appropriate relationship between the
patients and their physician, and also the need for constant improvement of health-care, access to care and a just distribution of
financial resources. The doctor is permanently in search for the best approach, constantly improving his knowledge. Probably
the most important step in the medical decision-making is the second: a systematic and thorough evaluation of the patient.
When a complicated case requires a complex moral analysis, it is the responsibility of the care provider to gather all relevant
information. Probably the most suitable model in this case is that developed by the American Academy of Hospice and
Palliative Medicine, based on four topics: a) Medical indications; b) Patient preferences; c) Quality of life; d) Contextual features.
This model is a “four-box model”.

Table 1 – The “four-box model” developed by the American Academy of Hospice and Palliative Medicine

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<tr>
<th>A. CLINICAL FACTS</th>
<th>B. BIOGRAPHICAL FACTS</th>
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<td>C. QUALITY OF LIFE</td>
<td>D. CULTURAL FACTS</td>
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A. CLINICAL FACTS
   a. What are the diagnosis and the outcome?
   b. What are the symptoms and how was the patient’s condition changed?
   c. What are the proposed treatment and its intention?
   d. What are the potential benefits of each treatment and their possible burdens?

B. BIOGRAPHICAL FACTS
   a. Who is the patient?
   b. What are the patient’s wishes and values?
   c. How do the patients describe their quality of life?
   d. Does the patient have enough capacity to make decisions about potential treatment?
   e. Who is involved in making the decision?

C. QUALITY OF LIFE
   a. How does the patient describe his/her quality of life?
   b. What types of treatment would provide the best outcome for the patient?
   c. What is achievable with regard to the patient’s preferences?

D. CULTURAL FACTS
   a. What is the patient’s relationship with family, friends and society?
   b. What are the patient’s cultural, religious and spiritual values?
   c. What are the potential benefits of each treatment and their possible burdens for patients and their family – emotionally and financially? What are the possible alternatives?
   d. What are the legal considerations?

Conclusions
When facing ethical decisions about emotionally charged issues, the model of shared decision-making can ensure communication and respect between physicians, patients and their family members. Disability and, most importantly, the intersections between social support, employment, technology, institutions, the built environment, and social practices, will necessarily be associated with the moral dimensions of life. Given that environmental and social arrangements are not accidental or neutral, but rather the result of factors including policy choices, institutional and socioeconomic structures, and social values (including prejudice), there are frequent linkages between experiences of disability and moral experience. Moral experience can provide a conceptual framework within which to design and implement studies related to living with a disability. Ethical issues are very common in the care of individuals living with impairments, activity limitations and participation restrictions. They can be encountered in all stages of medical rehabilitation: acute, sub-acute and chronic outpatient rehabilitation. Questions about the limitations of principle-based medical ethics have contributed to renewed interest in alternative frameworks such as virtue-based ethics, the ethic of caring and a system of ethics based on respect for people. Many doctors believe that the ethical principles should be respected, unless there are strong reasons to overrule them. However, some difficulties may arise when someone tries to apply these principles to clinical situations. Physical-therapy researchers, and other researchers in the field of rehabilitation, have a range of methodological and theoretical approaches they can bring to the analysis of the experience of disability.

References
2. Charter of the ABIM Foundation, ACP-ASIM Foundation and European Foundation of Internal Medicine