QUALITY OF LIFE ASSESSMENT FROM PATIENTS WITH MULTIPLE SCLEROSIS

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Abstract: Multiple sclerosis is a socially significant disease leading to major cognitive and motor disorders. It affects young people in creative working age. The disability of these patients requires careful choice of treatment approaches, in order to improve their quality of life which is significantly impaired. Quality of life is an extremely important indicator of medicine and healthcare. The influence of a particular therapy and a complex healing program improves a number of lifestyle-related symptoms. Systematic observation and evaluation of patients with this disease allows us to seek opportunities for a change - to improve the social status of patients, allowing them to work and to maintain daily activities. Attention is usually paid only to motor activity and capacity. Influencing on cognitive impairment also leads to improved social adaptation, it reflects on the emotional sphere, characterized by mood swings and the development of depressive states. The long-term course of the disease, the addition of new symptoms, and the deterioration of old ones, have a very serious impact on the patients quality of life. The significant degree of disability in this category of patients while in early and active age is a great challenge to further seek and research into the causes of this disease and to expand the complex of healing methods. The special focus on neuro-rehabilitation, both on physical and cognitive disorders, is a prerequisite for improving the correspondent functions according to the extent of their disorder. The need dynamic assessment of quality of life through the use of specific methodologies could lead to the creation of active approaches for optimal treatment, recovery and support which will ensure the possible well-being of Multiple Sclerosis patients. This necessitates the study and analysis of the impact of rehabilitation on the quality of life of this disease. This necessitates the need to study and analyze the impact of rehabilitation on quality of life of patients with this disease. By using a particular set of rehabilitation techniques we can achieve positive changes as rehabilitation stimulates natural forces and capabilities of the body and personality with prosperity by addressing behavior.

Keywords: quality of life, disorders, social adaptation, rehabilitation

INTRODUCTION

Quality of life, according to the World Health Organizations health concepts, reflects every individual's idea of his position regarding his values and the cultural system in which he lives as well as the connection with his achievements, expectations, standards and beliefs. Over the past two decades, the term - quality of life has become increasingly popular in medical practice and health care. Health is a state of complete physical, mental and social well-being without the presence of disease or even hint of it. Multiple sclerosis (MS) is a socially significant disease leading to severe cognitive and motor disorders. It affects young people in creative, working age. The disability of these patients requires careful attention to treatment approaches, with the potential to improve the quality of life that is significantly impaired people with this disorder.

The purpose of this article is to study and analyze the quality of life of patients with multiple sclerosis before and after rehabilitation procedures. In order to achieve this goal we have set the following tasks:

1. Analysis of the principles included in the World Health Organization's "Quality of Life - 100" Framework.
2. Investigating the impact of pain on MS patients regarding their pleasure in life.
3. Establishing an assessment of the quality of life of the patients surveyed.
4. Investigate and analyze patients opinion on how they evaluate their lives at the two stages of the study.

Methods. In order to achieve this goal we used documentary and questionnaire methods.

Results and discussion. With the assistance of 15 centers around the world, the WHO has developed the framework of the World Health Organization - Quality of Life-100, where the WHO defines Quality of life as a perception of an individual in terms of his cultural perception, his value systems in which it lives and in terms of its goals, expectations, standards, care and problems. This is a extensive concept related to a person's physical health, mental status, degree of independence and autonomy, social relationships, and the features of the surrounding environment.
The aim of the developing of framework of the World Health Organization Quality of Life-100, is to use it in medical practice, research, audit and conduct. "These Principles provide a comprehensive and realistic guide for the national MS communities to implement plans to improve the quality of life of people affected by this disease lifelong."

The International MS federation included the World Health Organization's areas of Quality of Life in its Principles in order to influence policy and improve the lives of people affected by multiple sclerosis. These principles provide a comprehensive guideline for national Ms societies in their development and implementation of plans to improve quality of life.

The principles focus on common issues affecting the quality of life of people with MS, such as suffering, helplessness and disability caused by the variety of symptoms of the disease, the inability to live at home in some cases, the loss of work, movements and lack of coordination between medical and social care. As a result, the principles are not related to specific types or stages of MS.

The development of the principles is based on a series of interviews, a review of relevant literature, the clinical, program and research experience of the authors, and an analysis of the Working and Technical Monitoring Group, organized by the International MS Federation (MSIF).

Literature, including current articles, textbooks on clinical MS, articles in national MS societies, current publications on the Internet has been used. A list of posts is included, including proofs of each post. Definitions for the level of evidence in the development of the principles are as follows:

1a Meta analysis of randomly selected control experiments  
1b Randomly selected control experiment  
2a Control study - not randomly selected  
2b Quasi experimental study  
3 No experimentally descriptive study (eg, comparative study, correlation study, case study)  
4 Report of the expert committee, opinion and / or experience of competent authority

The principles are set out in the following thematic sections:
- Independence and legal capacity  
- Medical service  
- Prolonged (long-term and social) service  
- Maintaining health and preventing illness  
- Support for family members  
- Transport  
- Work and voluntary activities  
- Disability and financial assistance  
- Training  
- Housing and access to public buildings

During the developing of the principles, the first five areas covered by the World Health Organization's Quality of Life framework, include: physical and mental health, degree of independence, social contacts and environment. These areas are used to ensure that the principles will cover all aspects of the Quality of Life that concern people with MS. "Quality of Life Questionnaire for MS-54 Patients - Multiple Sclerosis Quality of Life-54 (MSQOL-54)". This is a specific questionnaire related to quality of life and health. Another scale for assessing the quality of life used to measure the effect of the disease on a MS patient is: Multiple Sclerosis Impact Scale-29 (MSIS-29). It includes 29 questions in two strands - 20 questions about physical condition and 9 - about psychological status, but it does not provide complete information about the patient and the development of the disease. However, according to some authors, it is quite sufficient as it is a sensitive and reliable indicator. It is developed with the participation and assistance of MS patients and is believed to cover all of the basic and specific aspects of the disease.

RESULTS FROM EMPIRICAL QUALITY OF LIFE RESEARCH ON MS PATIENTS

We conducted a study of patients with multiple sclerosis diagnosis in Nervous Disease Clinics of University Hospitals in the country. The main document used to collect primary information is Patient Questionnaire - MSQOL - 54, which consists of 52 elements, grouped in 12 scales, as well as two separate points. The survey was conducted in two stages - before /2013 / and in /2015 / - two years after the rehabilitation of patients with MS.
During the first stage of the study, 336 patients with MS were informed that they would be called again in two years to assess the impact of rehabilitation procedures on their quality of life. All patients have a clinical diagnosis of multiple sclerosis confirmed by MRT of the main brain and spinal cord brain, corresponding to the relevant criteria for this disease.

During the second stage of the study, a response of 297 patients from 336 respondents was received via a postal questionnaire. A survey card from the first stage of the study was used, with additional five questions specifying the type, number and quality / effectiveness / of the rehabilitation procedures carried out for the period of 2 years.

By using one of the questions in the survey we attempted to present a comparative assessment of the quality of life for patients diagnosed with MS before and after rehabilitation procedures. The results show that pain interferes with the enjoyment of life in varying degrees for more than half (54.2% in the first stage and 53.2% in the second stage) of the patients surveyed, while 7.1% in the first stage and only 2.3% of the second stage stated that pain affects too much on the pleasure of life. 8.4% of the respondents in the first stage and 4.1% in the second stage, stated that this impact is very pronounced. / Figure 1. /

Figure 1. Comparative presentation of pain impact on MS patients regarding the pleasure of life during the two stages of the study

Using the scale from zero to 10 in our survey, we tried to assess the quality of life of patients according to their judgment, as zero is the worst possible quality of life and 10 being the best quality of life. The results are presented in Table 1. In the first stage of the study, the majority of respondents 19.6% rated their quality of life by 6, followed by 17.3%, according to which it was 8, and the respondents 16.7%, who give an assessment 7. At the second stage of the survey, 23.2% of the surveyed respondents assessed their quality of life by 8, followed by 19.2% for which it is 7, and finally the respondents 17.2%, who give an assessment 6. We see an increase in the quality of life assessment of patients after rehabilitation procedures.

Table 1. Comparison of the quality of life assessment of the respondents at the two stages of the study

<table>
<thead>
<tr>
<th>Quality of life scale</th>
<th>Number</th>
<th>Relative share in%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>First stage</td>
<td>Second stage</td>
</tr>
<tr>
<td>Worst quality of life - 0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>17</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>20</td>
<td>38</td>
</tr>
<tr>
<td>6</td>
<td>33</td>
<td>51</td>
</tr>
</tbody>
</table>
Almost one-third of the respondents (29.1% in the first stage and 33.9% in the second stage) felt their live as generally pleasant, and 15.5% in the first stage and 26.3% in the second stage were mostly satisfied with it. With mixed feelings, approximately the same level of satisfaction and disparity were the largest part of the respondents, 39.3% in the first stage of the study and 27.6% of the patients in the second stage. / Figure 2. / Figure 2. Comparative representation of patients perceptions of how they see their lives as a whole at the two stages of the study.

<table>
<thead>
<tr>
<th></th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>Best quality of life - 10</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>28</td>
<td>57</td>
<td>16.7</td>
<td>19.2</td>
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<tr>
<td></td>
<td>29</td>
<td>69</td>
<td>17.3</td>
<td>23.2</td>
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<td></td>
<td>14</td>
<td>39</td>
<td>8.3</td>
<td>13.1</td>
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<td>15</td>
<td>32</td>
<td>8.9</td>
<td>10.8</td>
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<tr>
<td></td>
<td>336</td>
<td>297</td>
<td>100</td>
<td>100</td>
<td></td>
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</tbody>
</table>

The comparative analysis of the results of the two stages of the survey showed that the relative share of the mostly dissatisfied form life patients declined by 3.8% in the second stage as well as the unfortunate patients by 2%.

Conclusions and recommendations
From the presented results we can draw the following conclusions:
1. Pain hinders the enjoyment of life in varying degrees for more than half (54.2% in the first stage and 53.2% in the second stage) of the patients surveyed in the two stages of the study.
2. With mixed feelings, approximately the same level of satisfaction and disparity were the largest part of the respondents, 39.3% in the first stage of the study and 27.6% of the patients in the second stage.
3. The majority of respondents from the first stage of the survey (75.6%) assess their quality of life between 4 and 8 on the scale from zero to ten, and in the second stage 85.5% of the respondents assess their quality of life life between 5 and 9.

As a result of the study, the following recommendations can be made:
1. To the NATIONAL HEALTH INSURANCE CASH DESK AND NATIONAL INSURANCE INSTITUTE:
   - to increase the number of hospitalizations of patients diagnosed with multiple sclerosis on a clinical pathway and on the program for prevention and rehabilitation of NIH according to the needs of patients with multiple sclerosis.
   - to create an opportunity for these patients to execute rehabilitation in ambulatory conditions without the need of (Medical direction number 3) from General practitioner (GP).
   - to improving the quality of the rehabilitation procedures.
2. TO THE MINISTRY OF HEALTH - to develop policies based on good European practices in this field to ensure equal access to rehabilitation for patients with multiple sclerosis.
3. To MS SOCIETY - BULGARIA - to conduct periodic anonymous questionnaires among the patients with multiple sclerosis to evaluate their specific needs of rehabilitation.

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