

VILNIUS UNIVERSITY

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VALADKEVIČIENĖ

# The Biopsychosocial Aspects of Disability Assessment in Patients with Multiple Sclerosis

SUMMARY OF DOCTORAL DISSERTATION

Medicine and Health Sciences,  
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This dissertation was written between 2014 and 2018 at Vilnius University.

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VILNIAUS UNIVERSITETAS

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Negalios vertinimo sergantiems  
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## ABBREVIATIONS

BICAMS	Brief International Cognitive Assessment for Multiple Sclerosis
BVMT R	Brief Visuospatial Memory Test Revised
CHIIS	Compulsory Health Insurance Information System “Sveidra”
CVLT II	California Verbal Learning Test II ed.
DWCAO	the Disability and Working Capacity Assessment Office under the Ministry of Social Security and Labour of the Republic of Lithuania
EDSS	Expanded Disability Status Scale
FDS	Fatigue Descriptive Scale
HADS	Hospital Anxiety and Depression Scale
ICF	the International Classification of Functioning, Disability and Health
MS	multiple sclerosis
SDMT	Symbol Digit Modalities Test
SF36	Short Form 36 Medical Outcomes Study Questionnaire
WCL	working capacity level
WHO	the World Health Organization



## INTRODUCTION

Fifteen percent of the world's population – almost 1 000 000 000 people – are disabled.<sup>1</sup> In order to meet the needs of people with disabilities and enforce their rights, health and social security agencies require holistic descriptions for assessing an individual's activity and disability. Contemporary society finds it important to ensure that people remain capable at work, independent, universally active, and taking part in all areas of their life and the life of society as long as possible; therefore, it is crucial to make use of all possibilities provided by medical care and medical and professional rehabilitation in order to overcome disease-related obstacles in an individual's life and postpone disability. When health disorders become long-term and disability is established, the question of medical and social assistance becomes even more relevant.

The World Health Organization (WHO) recommends assessing the severity of disability according to the International Classification of Functioning, Disability and Health (ICF). The basis of ICF is a biopsychosocial model, whereby an individual's health, disability, and functioning are established taking into account their interaction with the physical, social, and psychological environment. The Disability Strategy for 2017–2023 of the Council of Europe also states that

disability is the result of interaction between individual impairments and existing attitudinal and environmental barriers. Disability may hinder the full enjoyment of human rights and fundamental freedoms and prevent persons with disabilities from participating effectively and equally in the society. Persons with multiple, complex and intersecting impairments face additional barriers and are at higher

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<sup>1</sup> WHO. No Title. World Report on Disability, 2011, 1–23.

risk of institutionalisation, exclusion and poverty. Measures to prevent or remove existing barriers are necessary investments for sustainable development and improved accessibility.<sup>2</sup>

To address the issue of the comprehensive assessment of disability, a solution is offered – using international instruments intended for the establishment of disorders of an individual's body structure and functions and of unfavorable environmental factors. WHO notes that the provision of assistance to patients should take into account not only the causes of health disorders but also the consequences of diseases, which can be reduced by adapting the environment, using technical means and attempting to affect the patients' behavior.

However, the National Program for Social Integration of the Disabled for 2013–2019, approved by the Government of the Republic of Lithuania, takes a narrower approach toward this issue.<sup>3</sup> The National Program has an objective of ensuring the satisfaction of the special needs of the disabled with different disabilities by providing social integration services (in the areas of social security, health care and education). A more complete picture, not only of medical but also of social factors of disability (following the implementation of ICF), would reduce the gap between the practice of disability assessment in Lithuania and recommended international standards, encourage relevant experts and agencies to focus on the often-disregarded biopsychosocial factors of disability and highlight the needs of a particular patient and their everyday obstacles, which could lead to concrete measures ensuring better quality of life for the disabled.

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<sup>2</sup> *Human Rights: A Reality for All*, 2017.

<sup>3</sup> Lietuvos Respublikos Vyriausybė. *Dėl nacionalinės neįgaliųjų socialinės integracijos 2013–2019 metų programos patvirtinimo nutarimas*, Vilnius, 2012.



## Relevance of the Study

Even though the biopsychosocial aspects of the life of the disabled attract researchers' attention, studies are usually fragmentary. They are not sufficiently focused on comprehensive prevention, diagnostics and disability assessment, do not always show a proper understanding of the needs of persons with chronic diseases and do not provide an adequate assessment of their possibilities to function in society.

After a change of attitude toward an individual's health, it is now being understood not as the absence of a disease but as comprehensive physical, spiritual, and social well-being, the understanding of disability has changed as well. On May 22, 2001, WHO approved the implementation of ICF into practice and the assessment of consequences of diseases and health disorders based on the following three aspects: changes in organs' functions and structure, disruptions of activity and participation, and changes in environmental and personality factors. The application of this methodology is already gaining momentum in Germany, France, Spain, Switzerland, and Italy, whereas in Lithuania, we only have isolated attempts to apply the principles of this methodology in medical rehabilitation. In his study on the biopsychosocial aspects of disability, Z. Skvarciany assessed the disability of working-age persons with malignant tumours and their health-related quality of life.<sup>4</sup>

The paper is even more relevant due to a lack of statistical data on psychosocial disability, incidence rates, the prevalence of diseases, the establishment of working capacity, and the absence of any scientific foundation for drafting laws and regulations on the establishment of disability. Currently, the working capacity level is established only on the basis of the degree of severity of the

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<sup>4</sup> Skvarciany Z. *The Disability and Health-Related Quality of Life of Working Age Persons Suffering From Malignant Cancer Tumors*, 2012, 1–17.

consequences of a disease established by the patient's doctor, the so-called basic working capacity level, and an assessment of the questionnaire which is common to all the disabled irrespective of the nature of their disability, activity, and participation.

Neurodegenerative and inflammatory diseases of the nervous system are one of the most important global and national challenges; the prevalence of these diseases and their burden on society are continually on the increase.

Multiple sclerosis (MS) is a frequent and critical autoimmune inflammatory demyelinating neurodegenerative disease of the central nervous system prevalent in Lithuania. Previous studies conducted in Lithuania (by R. Kizlaitienė, N. Giedraitienė, L. Malcienė, R. Balnytė, R. Leonavičius, B. Daškevičienė) have been focused on various aspects of MS's development, its clinical manifestation and diagnostics; however, the aspects of MS's incidence rates and disability assessment have not been examined so far. It is noteworthy that MS is generally diagnosed to young people. Even though treatment modifying MS development has advanced considerably in the 21<sup>st</sup> century in terms of controlling the course of the disease, MS is known to usually progress over time and cause long-term consequences that are treated as disabilities. The most frequent final consequence of MS is an established disability that brings long-term social and financial consequences on a national scale. Besides, certain data suggest that the recent MS incidence rate has been growing in other countries; however, we did not have the data on MS incidence trends in Lithuania before.

The working capacity level for MS patients is established using the Kurtzke Expanded Disability Status Scale and the said questionnaire, which is common to all and assesses educational background, profession, work experience, age, adaptation of the work environment and a brief activity and participation questionnaire. However, account is not taken of any specific changes in the cognitive functions of MS patients, their fatigue, anxiety, and depression, which significantly aggravate the functioning of these people and disturb

their activity and participation in the life of society. Physical disability shows itself in more advanced stages of the disease; therefore, the usual establishment of disability is delayed and should be deemed discriminatory.

The results of this dissertation are also important to practitioners. A comprehensive personal disability assessment based on ICF would let them know an individual's needs and obstacles in everyday life, which would enable a targeted planning of social and health promotion services, rehabilitation means required by the individual, and the assessment of treatment and rehabilitation efficiency. And if, from the point of view of the final consumer, meeting individual needs would determine their higher satisfaction with the received services and quality of life, then, on a macro-level, such a change would contribute to the optimization of the state's financial expenditure and rational distribution of human resources.

### Aim of the Study

To analyze the biopsychosocial aspects of disability assessments in people with multiple sclerosis.

### Objectives of the Study

1. To analyze the dynamics of the incidence of MS in the Lithuanian population.
2. To analyze the dynamics of the working capacity level of MS patients in relation with sociodemographic data, employment status, and life expectancy.
3. To analyze the relationship between the working capacity level and the different parameters of physical and mental health (memory, fatigue, anxiety, depression, cognitive functions, physical and mental quality of life, the results of Brief ICF Core Set for Multiple Sclerosis).

## Statements to be Defended

1. The incidence of MS is constantly increasing; therefore, it is necessary to strengthen the early diagnosis of this disease and provide the patients with the needed assistance during its initial stages.
2. A longitudinal connection between MS's severity and an individual's working capacity is not linear: in the early stages of the disease, the working capacity level significantly decreases, whereas later on, it stabilizes.
3. Psychosocial factors predict the working capacity level of MS patients; thus, their inclusion into the disability establishment procedure would ensure a more objective assessment of disability.

## Scientific Novelty

This paper takes a comprehensive approach toward MS, a frequent neurological disease causing significant disability. For the first time in Lithuania, country-wide MS incidence data for the last 15 years have been provided and changes in the incidence rate have been calculated, which makes it possible to predict MS's incidence trends.

The use of ten-years worth of data on a country-wide level, provided by the Disability and Working Capacity Assessment Office under the Ministry of Social Security and Labour of the Republic of Lithuania (hereinafter referred to as DWCAO), made it possible to conduct the first ever analysis of the changing trends in the working capacity level of MS patients during repeat assessments of disability; employment and life expectancy predictions have also been evaluated.

Based on modern diagnostic tests, fatigue, anxiety, and depression experienced by 184 MS patients were thoroughly examined; their cognitive functions and quality of life were assessed as well. In addition, it was the first time that a disability assessment used an ICF questionnaire for MS, including such factors as changes in body functions and structure, restrictions of activity and participation, and the impact of environmental factors. The results of this comprehensive

study made it possible to record links between psychosocial factors and not only the assessment of the initial working capacity level but also the annual change in this assessment.

There had been no comprehensive MS disability studies such as this in Lithuania before. It is our hope that the results of the study will help with a timely and more objective establishment of disability of MS patients, while the ICF, used for the assessment of biopsychosocial factors, will open new possibilities in assessing the working capacity level.

### Structure of the Paper

According to the complexity of the materials of the analyzed phenomenon, the results are presented in three different levels (Figure 1): epidemiological, the working capacity level, and the employability of patients and the psychosocial factors of MS.

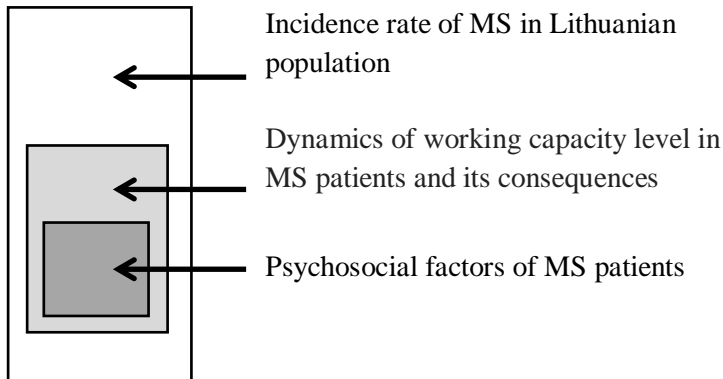


Figure 1. Levels of analysis and research stages

## METHODS

In different stages of research, different data were gathered, and different analysis procedures were applied. Thus, we introduce each research stage separately.

### Research Stage 1: Incidence Rate of Multiple Sclerosis in Lithuania

With the help of the Compulsory Health Insurance Information System “Sveidra” (CHIIS) held by the National Health Insurance Fund, the data about patients who were diagnosed with code G35 (Multiple Sclerosis) of ICD-10-CM during ambulatory check-ups and stationary visits from 2001 to 2015 were analyzed. CHIIS data provide a possibility to analyze information on an individual level, eliminate duplicate diagnoses and calculate health indicators according to a patient’s residency.

The residents’ number in sex and age group categories was obtained from Statistics Lithuania (a national agency that develops, produces, and disseminates official statistics). The crude incidence rates (CIR – ratio between individuals with newly diagnosed MS in ambulatory service) were calculated.

In order to evaluate the influence of resident structure changes on the incidence of MS during the last 15 years, the direct method of standardization using the European standard was applied, and standardized incidence rates (SIR) were calculated. Ninety-five percent confidence intervals were estimated for the averages. The data were processed using the Minitab set to estimate a linear trend model for the temporal changes of 16 parameters. For the prediction of incidence, a simple trend extrapolation method was used from the linear regression line.

## Research Stage 2: Dynamics of the Working Capacity Level and Its Relationship with the Employment Status and Life Expectancy in MS Patients

This part of the study was conducted after signing a contract No. F5-39/BS-150000-1123-2015-05-12 between Vilnius University and DWCAO on April 23, 2015. The DWCAO agreed to provide personal data for the biomedical study “Biopsychosocial Aspects of Disability Assessment in People with Multiple Sclerosis,” and Vilnius University agreed to analyze depersonalized data and ensure ethical standards of research.

Enrolled in the study were 2 072 people with an MS diagnosis who visited the DWCAO during the period of 2006–2015. Of them, 1 341 were women, and 731 – men; average age during the first data collection was 42.49 years. It is important to note that for 1 182 patients, the first data collection was not during their first visit to the DWCAO.

The MS diagnosis for all patients was confirmed by a third-level neurology health care service using the McDonald criteria (2010 revision). All patients arrived at the DWCAO during remission, with stable long-term physical and mental dysfunctions that had affected their daily functioning and quality of life.

In all documents presented to the DWCAO, the main diagnosis was multiple sclerosis (code G35 in ICD-10-CM). If the diagnosis code and the main diagnosis had been changed during the next visit to the DWCAO, the person was excluded from the study. If the diagnosis code had been changed during the next visit, but the main diagnosis remained the same (multiple sclerosis; G35), the data from these patients were further analyzed.

Evaluations performed during the second stage of the study:

Working capacity level – the ability of a person to implement a professional competency he/she gained earlier, to acquire a new professional competency, or to perform jobs that require less professional competency. The working capacity level is established for people over 18 years of age until they reach the age of eligibility

for pension in a complex way, by assessing not only medical but also functional, professional, and other criteria that limit a person's capacity for work.

The working capacity level is set using 5% intervals, in accordance with legal regulations on the process of setting the working capacity level. A range of 0–25% working capacity indicates that an individual cannot work or has the ability to work only in the environment with adaptations to the nature of disability. A range of 30–55% indicates that an individual has a reduced level of working capacity, meaning that an individual is able to work in an environment with adaptations or no adaptations. A range of 60–100% indicates that a person has full working capacity. It is noteworthy that a different working capacity range is related to different monetary allowances for the patients. For the purposes of this study, the working capacity level data set was divided into 5 groups of individuals with the following intervals of working capacity: 0–10%, 15–25%, 30–40%, 45–55%, and 60–100%.

According to legal regulations, the validity of the working capacity level may last for 1 or 2 years or, if there are no indicators for possible improvement, can be permanent (until the end of life). Nevertheless, patients with a permanent validity of working capacity may arrive at the DWCAO for an additional assessment if they believe their disease condition has changed. While analyzing the data, it was assumed that if the patient was alive, and if the most recent validity of the working capacity level was permanent, the capacity level and employment status were the same until the end of the study.

Periodicity of assessment: the primary evaluation is conducted during the first visit and when the decision on the level is done. A repeat evaluation of the working capacity level is conducted at the end of the validity of the primary evaluation or due to any changes in the individual's health condition, changes of reasons for the working capacity level, or if a person or the funding institution do not accept the results of the DWCAO's evaluation. There were also inquiries about possible deaths of patients who did not return to repeat evaluations.



Sociodemographic data (gender, age during the first visit), employment status and its changes during re-evaluations: sociodemographic and employment data were collected after patient visits to the DWCAO and transferred to local research spreadsheets from the DWCAO database for further analysis.

### Research Stage 3: Psychosocial Factors of MS Patients

Research was conducted at Vilnius University Hospital Santaros Klinikos (in-patient department of neurological disorders and the MS service in an out-patient clinic) and the DWCAO during 2014–2018. The study received an approval (No.158200-14-753-271) from the Lithuanian Bioethics Committee on December 9, 2014. The State Data Protection Inspectorate approved the Vilnius University's Plan for Legal Protection of Personal Data while conducting this study (04–20–2015, No.2R-2270(2.6-1)). Each participant signed an informed consent and an agreement regarding personal data usage.

The cross-sectional study involved 184 people with MS. One hundred fifty-seven people visited the DWCAO to determine their working capacity levels (study group), and 27 people with MS did not visit the DWCAO (control group).

#### **Inclusion criteria:**

- 1) Age over 18 years;
- 2) MS diagnosis confirmed using the McDonald criteria revised in 2010;
- 3) MS remission stage and a stable neurological condition;
- 4) No other diseases related to the central or peripheral nervous system, metabolic, or other significant diseases that could affect the working capacity level;
- 5) Fluent Lithuanian language;
- 6) Voluntary consent to take part in the study or voluntary consent to take part in the study and the signature of an informed consent form including an agreement regarding personal data usage.

### **Exclusion criteria:**

For people with MS, those were any findings contradicting the inclusion criteria.

One person was excluded from the study due to an insufficient fluency of Lithuanian language, and one study participant refused to continue the participation in the study after failure in conducting the California verbal learning test. For the control group, the data about the disease were not collected.

### **Assessment instruments and data collection**

- 1. Expanded Disability Status Scale, EDSS.** The EDSS scale ranges from 0 to 10 in 0.5 unit increments that represent higher levels of disability. 0 – normal neurologic exam, 10 – Death due to MS.
- 2. Working capacity level** – assessment using 5% intervals, as described in Research Stage 2.
- 3. Fatigue self-assessment** – 10-point Likert type scale measuring fatigue during the study; 0 – no fatigue, 10 – very high fatigue.
- 4. Fatigue Descriptive Scale, FDS,** including subscales of Initiative, Modality, Frequency, Severity and the Uhthoff's effect. Total score range is 0-17; 0 – no fatigue, 17 – strong fatigue.
- 5. Hospital Anxiety and Depression Scale, HADS.** Fourteen item scale with scores between 0 and 21; 0 – no symptoms of anxiety or depression, 21 – heavy symptoms of anxiety or depression.
- 6. Memory self-assessment** – 10-point Likert type scale measuring one's own memory; 0 – very bad, 10 – very good.
- 7. Brief International Cognitive Assessment for Multiple Sclerosis, BICAMS,** which consists of:
  - Symbol Digit Modalities Test, SDMT; Performance is defined by total number of correct pairings within 90 seconds.
  - Brief Visuospatial Memory Test-Revised, BVMT-R (3 sets); Score range for each set is 0-12.
  - California verbal learning test II ed., CVLT-II, Lithuanian version (5 attempts). Total score is range is 0-80; 0 – no recall of words, 80 – full recall of words.

- 8. Short Form 36 Medical Outcomes Study Questionnaire**, with subscales of Physical functioning, Role limitations due to physical health, Pain, General health, Physical component summary, Energy/fatigue, Social functioning, Role limitations due to emotional problems, Emotional well-being, Mental component summary; SF-36. Each subscale score range is 0-100; 0 – worst health, 100 – best health.
- 9. Brief ICF Core Set for Multiple Sclerosis** including data about: b130 – Energy and drive functions, b152 – Emotional functions, b164 – Higher-level cognitive functions, b210 – Seeing functions, b280 – Sensation of pain, b620 – Urination functions, b730 – Muscle power functions, b770 – Gait pattern functions, s110 – Structure of the brain, s120 – Spinal cord and related structures, d175 – Solving problems, d230 – Carrying out one’s daily routine, d450 – Walking, d455 – Moving around, d760 – Family relationships, d850 – Remunerative employment, e310 – Immediate family, e355 – Health professionals, e410 – Individual attitudes of immediate family members, e580 – Health services, systems and policies. The level of impairment or restriction qualified for all components by a qualifier scale (0 = no impairment/restriction to 4 = complete impairment/restriction). For ‘Environmental factors’ a comparable 0–4 scale is applied, where categories can be either a facilitator or a barrier.
- 10. Disease data** – MS type, time from the first MS symptoms in calendar years, time from MS diagnosis in calendar years.
- 11. Sociodemographic data** – gender, age in years, education, employment status, possession of profession.

The working capacity level and EDSS information were collected twice: at the beginning of the study and after 1 year. All other variables were measured only at the beginning of the study.

Statistical analysis was performed using the statistical software package SPSS 17.0 (version for MS Windows). Descriptive statistics for quantitative variables are presented using mean (M) and standard

deviations (SD), and for qualitative (discrete) variables – using the absolute value and percentage of the analyzed sample group (%). The Student t test was used to compare the means of two independent groups of quantitative variables. The normality of variables was assessed using a Kolmogorov-Smirnov test. If a given comparison consisted of more than 2 groups, an analysis of variance ANOVA was conducted (if there were no equal variances, Welch's ANOVA was applied). Group comparisons were made using a Tukey HSD Post Hoc test. To compare discrete (qualitative) variables, a Chi-square ( $\chi^2$ ) independence criterion was used and, due to the small sample size, the exact Fisher test was conducted. The Pearson correlation coefficient was used to determine the relationship between variables. A logistic regression analysis (Forward Wald) was used to predict the worsening of health state in one year. A stepwise selection of independent variables was conducted. A variable was included in the model if  $p < 0.05$  and was excluded from the model if  $p > 0.1$ . An ROC analysis was conducted to get the critical values for predicting change in employment status, the worsening of health condition's or death. The level of significance was  $\alpha = 0.05$ .

## RESULTS

### **I. The incidence of MS in Lithuanian population in 2001–2015**

The first objective of this study was to analyze the dynamics of the incidence of MS in Lithuanian population. This was done in 3 steps:

- 1) The crude incidence rates of MS and incidence rates standardized by age were calculated;
- 2) A prediction of the incidence of MS in the entire population was conducted;
- 3) A prediction of the incidence of MS according to gender was performed.

The data from CHIIS showed that the number of newly diagnosed MS cases was increasing in Lithuania every year. In 2001, MS was diagnosed to 162 new individuals (61 males and 101 females), whereas 343 new cases of MS (101 males and 242 females) were diagnosed in 2015. The CIR and SIR of MS are presented in Table 1. During 2001–2015, the incidence of MS was on average 6.5 (95% CI 5.7–7.3) cases per 100 000 residents, 4.9 (95% CI 4.5–5.3) and 8.1 (95% CI 6.9–9.3) for 100 000 males and females, respectively. These rates had been fluctuating over the past 15 years – the difference between the highest and the lowest incidence rates was 5.7 times. The incidence difference among males was 2.9 times, and among females – 8.9 times.

In 2015, 2 526 persons had the diagnosis of MS, so the prevalence was 87 cases per 100 000 residents of Lithuania.

In Lithuania, the overall incidence rate tended to increase during the period of 2001–2015 (Fig. 2). However, an increase in the incidence rate of MS in 2011 and 2013 could be related to changes of the disease registration system.

During the period of 2001 to 2015, the overall incidence rate was increasing on average by 3.5 cases per 100 000 persons yearly. If the tendencies prevail, the overall incidence rate of MS is estimated to reach 13 cases per 100 000 persons in 2020.

The incidence of MS among males showed only a slight increase until 2012 and a sharp increase beginning with 2013 (Fig. 3). The incidence rate in males was increasing by 3.1 cases per 100 000 yearly. If the tendencies remain, incidence is estimated to reach 9 cases per 100 000 males in 2020. During 2001–2015, incidence increased by 3.8 cases per 100 000 females yearly. If the tendencies remain, the MS incidence among females in Lithuania is estimated to reach 16 new cases per 100 000 females in 2020 (Fig. 4).

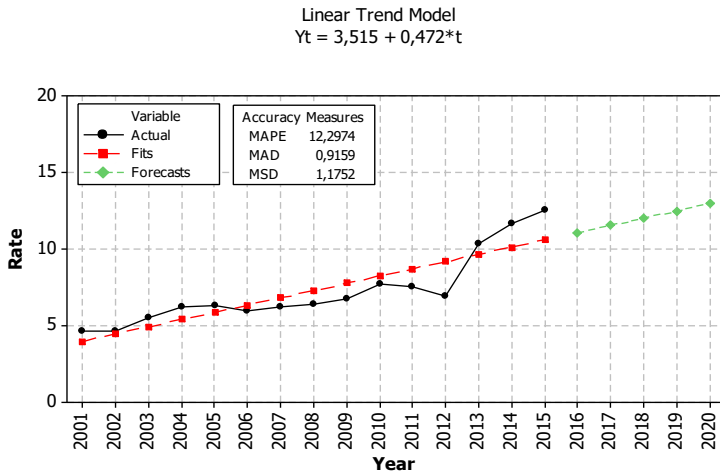


Figure 2. The incidence of MS in the Lithuanian population per 100 000 residents from 2001 to 2015, and estimated results in 2020

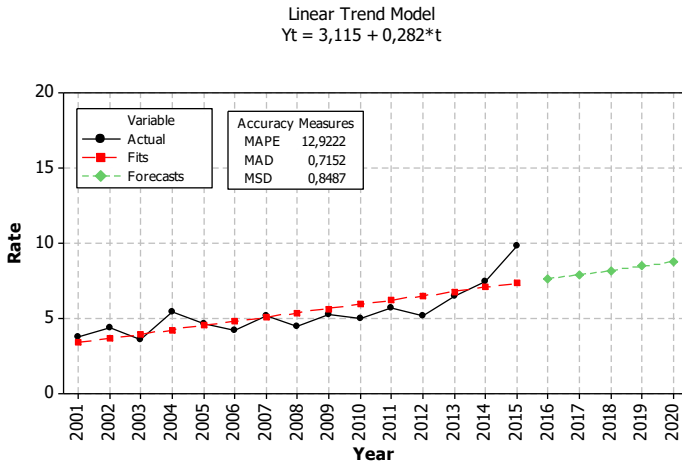


Figure 3. The incidence of MS in males in Lithuania per 100 000 males from 2001 to 2015, and estimated results in 2020

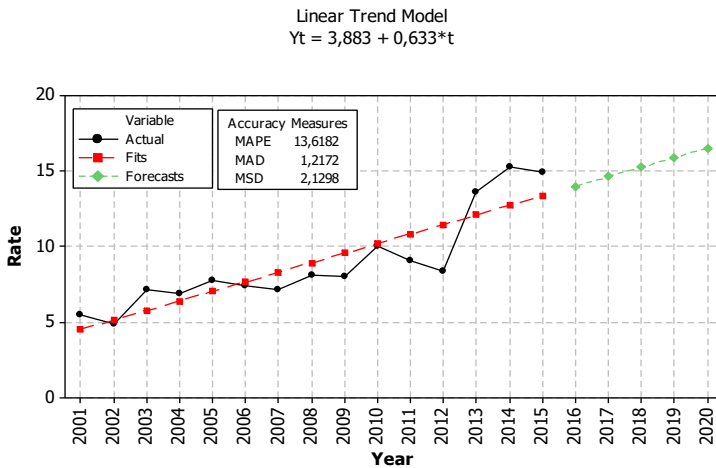


Figure 4. The incidence of MS in females in Lithuania per 100 000 females from 2001 to 2015, and estimated results in 2020

The female-to-male sex ratio in the incidence rate in MS in Lithuania showed a tendency to increase over the period of 2001 to 2015. Currently, females are affected from 1.5 to 2 times more often

than males. If this tendency remains, in 2020, females are expected to be diagnosed with MS two times more often than males.

## **II. Dynamics of the Working Capacity Level of MS until a Repeated Visit to the DWCAO**

The second objective of the study was to analyze the dynamics of the working capacity level of MS patients in relation with sociodemographic data, employment status and life expectancy. This was done in 4 steps:

- 1) The evaluation of the dynamics of the working capacity level until a repeat visit to the DWCAO;
- 2) The analysis of the structure of the working capacity level depending on age and gender of the patients;
- 3) The dynamics of employment status among the patients;
- 4) The relationship between the death of patients, their working capacity level, and age.

As mentioned before, the working capacity level is usually set for a limited period of time (6 months, 1 year, 2 years) unless a change in health state or vocational or functional factors is permanent; then, the working capacity level is set until reaching pension. During the period of 2006–2015, 2 072 people visited the DWCAO in order to have their working capacity level estimated. Of these patients, 451 (21.7%) visited the DWCAO twice, 291 (13.9%) – three times, 323 (15.4%) – four times, 256 (12.2%) – five times, and 170 (8.1%) patients – six times and more. While comparing the working capacity level during the first and second visits, it was noted that the result was the same among 52.5% of patients, with the working capacity increasing among 8.3% of patients and decreasing among 39.2% of patients (average time until the second visit was 1.5 years). The dynamics of MS did not depend on the gender of patients ( $p = .882$ ).

Similar proportions of the working capacity level are seen when analyzing the data from the second and the third visits (11.9%, 54.7%, and 33.4%), and there is no difference between genders either ( $p =$



.540) (average time from the second to the third visit was 1.8 years). However, there are changes seen when we analyze the proportions of the third and fourth visits: the working capacity level had increased among 12.2% of patients, remained the same among 31.3%, and decreased among 56.5% (the average time from the second to the third visits was 3.0 years or on average 6.3 years since the first visit). While comparing the results of the fourth visit between genders, there were no differences found ( $p = .454$ ). It proves that visiting the DWCAO repeatedly is related not only to the validity of the working capacity level but to the worsening condition of the patients as well.

Additionally, we have analyzed how many patients had MS diagnosis each year and what was their working capacity level. The data sample was  $N = 14\,291$ . As it was mentioned before, the validity of the working capacity level may differ from 1 or 2 years to an untermiated duration. Thus, the gaps between repeated visits were filled with data from previous visits. The results are presented in Figure 5. It is seen that during the analyzed period, the proportion of lower working capacity level (15–25) patients present in the sample had been increasing each year (linear regression  $R^2 = .67$ ). The same could be said for the proportion of the highest working capacity level ( $\geq 60$ ) group in the sample (linear regression  $R^2 = .86$ ).

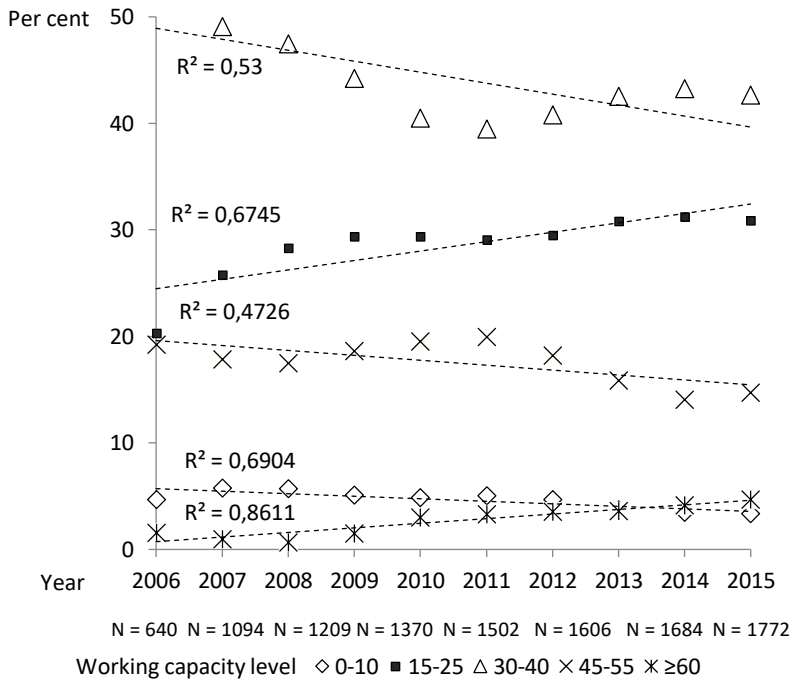
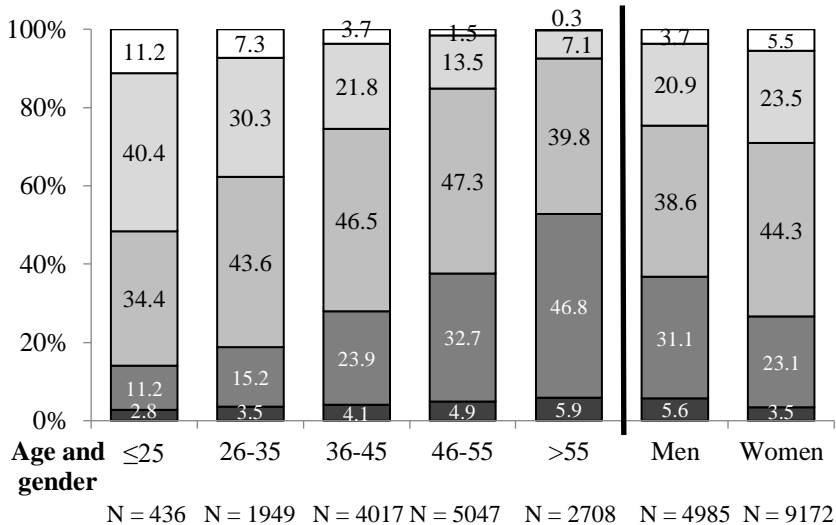


Figure 5. The proportion of different working capacity levels established by the DWCAO among MS patients in 2006–2015

Notes: Data are taken on the last day of each year. If the patient had not visited the DWCAO during the analyzed year and their working capacity level was valid, it was assumed it was the same as during the previous visit.

Knowing that the incidence rate between men and women is different and that MS progresses with time, it was important to compare the working capacity level among different age and gender groups. The study population was divided into five groups: 25 years of age and younger, 26–35, 36–45, 46–55, and over 55. The data presented in Figure 6 show that the older the patient becomes, the lower is their working capacity level. The Pearson correlation coefficient between age and the working capacity level is  $r = -0.313$ ,  $p < .001$ . No statistically significant difference was found between gender groups (Chi-square = 2.785,  $p = .733$ ).



Working capacity level    ■ 0-10   ■ 15-25   □ 30-40   □ 45-55   □ ≥60

Figure 6. The proportion of different working capacity levels established by the DWCAO among MS patients of different age and gender groups

Note: During the study, data on some MS patients were taken ten times, while on others just once, but it is rational to include all the data into the study because the patients were getting older (they changed their age groups), and their working capacity levels were changing as well.

The next step of our study was to analyze how the employment statuses of patients were related with their working capacities and age. A comparison of the results of patients who visited the DWCAO at least twice (N = 1 491) revealed that out of 688 (46.1%) patients who were working at the beginning of the study, 212 (30.8%) did not work during the second visit, compared to 52 (6.5%) patients who changed their employment status in the non-working group (N = 803) (p < .001). The total sample of working patients during the second visit was 528 (35.4%).

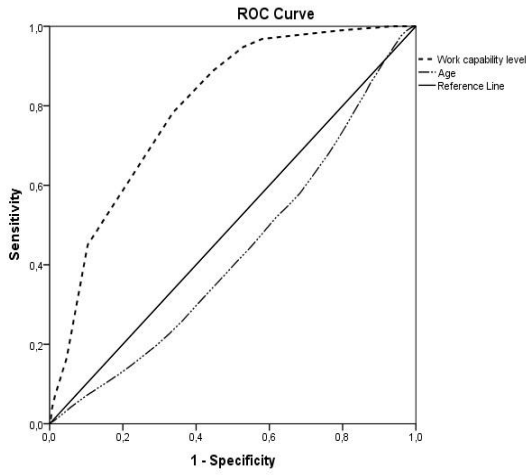
In order to determine the critical value of the working capacity level when patients change their employment status from working to non-working, we conducted an ROC curve analysis (Figure 4). It was established that when sensitivity was .783, specificity was .663, and the area under the curve (AUC) (95% CI) was .797 (.789 - .804),  $p < .001$ , whereas the critical value of the working capacity level was 37.5.

While analyzing what is the critical value of age for the change of an employment status from working to non-working, AUC (95% CI) was .433 (.423 - .443),  $p < .001$  and did not fit the minimal requirements for further analysis.

To conclude, it could be stated that a change of employment status in patients with MS is more related with the severity of the disease than with the age of a patient.

Finally, we analyzed the relationship between patient deaths, their working capacity levels and age. During the study, 198 (9.6%) patients died because of various reasons (the exact death cause was not analyzed). In order to determine the critical value of the working capacity level when patients die, we conducted an ROC curve analysis (Figure 5). The data sample was  $N = 2\ 072$ ; that is the final status of each patient at the end of the study. It was established that when sensitivity was .696, specificity was .838, and the area under the curve (AUC) (95% CI) was .803 (.769 - .836),  $p < .001$ , while the critical value of the working capacity level was 22.5. While analyzing what is the critical value of age for the prediction of death, AUC (95% CI) was .495 (.453 - .537),  $p = .806$ , which shows no relationship between these two variables. Thus, the deaths of MS patients should be more related with the disease rather than age parameters.

a)



b)

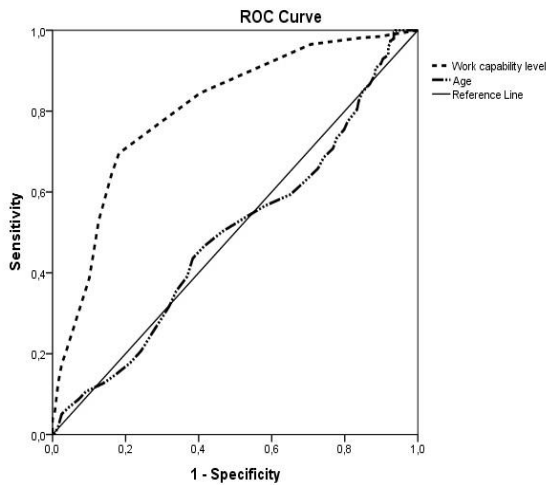


Figure 7. ROC curve in predicting (a) change in employment status and (b) death by working capacity level and age

## Psychosocial factors of MS patients

The third objective of the study was to analyze the relationship between the working capacity level and different parameters of physical and mental health. This was done in 8 steps:

- 1) The relationship between the working capacity level, sociodemographic and clinical characteristics was assessed;
- 2) The relationship between the working capacity level and quality of life was evaluated;
- 3) The relationship between the working capacity level and cognitive functions was calculated;
- 4) A comparison of fatigue between different working capacity groups was conducted;
- 5) A comparison of anxiety and depression between different working capacity groups was done;
- 6) The results of ICF between different working capacity groups were analyzed;
- 7) Correlations of EDSS with all variables of the study were calculated;
- 8) Factors predicting a worsening of the working capacity level were identified.

### **Relationship between the Working Capacity Level, Sociodemographic and Clinical Characteristics**

The cross-sectional study involved 184 people with MS that had different working capacity levels and visited the DWCAO a different number of times. During the first research stage, it was proved that the incidence rate in women was higher; thus, it was important to ensure that the results of that study stage could be analyzed in the whole sample. We conducted a comparison of sociodemographic and clinical characteristics between gender groups (Table 1).

Table 1. Comparison of sociodemographic and clinical characteristics between gender groups.

		Men N = 65	Women N = 119	P
Age		4.5 ± 11.7	41.4 ± 1.9	.604
Time from symptoms		11.0 ± 7.8	9.6 ± 8.3	.266
Time from diagnosis		3.6 ± 4.9	3.2 ± 5.2	.869
Starting level of EDSS		3.9 ± 1.4	3.7 ± 1.3	.182
Education	Basic	1 (1.5%)	3 (2.5%)	.569
	Secondary	19 (29.2%)	22 (18.5%)	
	Vocational	10 (15.4%)	20 (16.8%)	
	College	9 (13.8%)	18 (15.1%)	
	Higher	26 (40.0%)	56 (47.1%)	
Profession	(has)	50 (76.9%)	103 (86.6%)	.073
Participation in labour market	(yes)	42 (66.7%)	79 (66.4%)	.553
Type of disease	SPMS	8 (12.3%)	11 (9.2%)	.713
	PPMS	2 (3.1%)	2 (1.7%)	
	PRMS	0 (.0%)	1 (.8%)	
	RRMS	55 (84.6%)	105 (88.2%)	

SPMS – secondary-progressive multiple sclerosis, PPMS – primary-progressive multiple sclerosis, PRMS – progressive-relapsing multiple sclerosis, RRMS – relapsing-remitting multiple sclerosis.

The analysis of the data presented in Table 1 shows that both men and women were of similar age and educational background and had a similar EDSS starting level, that the duration from symptoms and disease diagnosis in both groups does not differ either, and that there were no differences between the type of disease. Thus, a further analysis of the data in the entire group is correct.

Knowing that the working capacity level is divided into 4 groups, which differ by the severity of disease, it was reasonable to analyze all these groups without joining them into some larger units.

Table 2 presents data about the relationship between the working capacity level and sociodemographic and clinical characteristics.

Their analysis reveals that a lower working capacity is related to older age and longer tenure of the disease. Those with the lowest working capacity level had higher EDSS scores and were employed more seldom. However, we should see the positive side of the data as well: 9 out of 30 patients with working capacity of 0–25% were working. Thus, it could not be said that the most severe form of MS eliminates these people from active participation in the labor market.



Table 2. Relationship between the working capacity level, sociodemographic and clinical characteristics.

		WCL 0-25 N = 30	WCL 30-40 N = 100	WCL 45-55 N = 21	WCL 60-100 N = 6	WCL unknown N = 27	p
Age		48.3 ± 1.3	42.8 ± 1.6	35.3 ± 8.0	36.0 ± 8.3	32.3 ± 9.3	<.001 ab
Time from symptoms		14.7 ± 1.2	1.1 ± 8.1	9.2 ± 4.8	9.3 ± 8.3	6.1 ± 5.2	.002 cd
Time from diagnosis		4.7 ± 7.5	3.1 ± 4.5	3.6 ± 4.8	4.5 ± 4.5	2.0 ± 3.4	.316
Starting EDSS level		5.7 ± .8	4.1 ± .8	2.7 ± .7	2.1 ± .5	2.1 ± .7	<.001 ef
Gender	Men	14 (46.7%)	33 (33.0%)	4 (19.0%)	1 (16.7%)	13 (48.1%)	.125
Education	Basic	2 (6.7%)	1 (1.0%)	0 (0%)	1 (16.7%)	0 (.0%)	.149
	Secondary	8 (26.7%)	18 (18.0%)	4 (19.0%)	2 (33.3%)	9 (33.3%)	
	Vocational	7 (23.3%)	17 (17.0%)	4 (19.0%)	1 (16.7%)	1 (3.7%)	
	College	4 (13.3%)	16 (16.0%)	4 (19.0%)	1 (16.7%)	2 (7.4%)	
	Higher	9 (3.0%)	48 (48.0%)	9 (42.9%)	1 (16.7%)	15 (55.6%)	
Profession	(has)	23 (76.7%)	86 (86.0%)	19 (9.5%)	3 (5.0%)	22 (81.5%)	.134
Participation in labor market	(yes)	9 (3.0%)	67 (68.4%)	14 (66.7%)	5 (83.3%)	26 (96.3%)	<.001 ag
Type of disease	SPMS	10 (33.3%)	9 (9.0%)	0 (0%)	0 (0%)	0 (0%)	.009
	PPMS	1 (3.3%)	3 (3.0%)	0 (0%)	0 (0%)	0 (0%)	
	PRMS	0 (.0%)	1 (1.0%)	0 (0%)	0 (0%)	0 (0%)	
	RRMS	19 (63.3%)	87 (87.0%)	21 (100%)	6 (100%)	27 (100%)	

SPMS – secondary-progressive multiple sclerosis, PPMS – primary-progressive multiple sclerosis, PRMS – progressive-relapsing multiple sclerosis, RRMS – relapsing-remitting multiple sclerosis.

Post hoc: a - 1<2,3,4,5, b - 2>3,5, c - 1>2,3,5, d - 2>5, e - 3>5, f - 1>2>3,4,5, g - 2,3<4,5

## Relationship between the Working Capacity Level and Quality of Life

In the second step of analysis, we compared the results of the Short Form 36 Medical Outcomes Study Questionnaire in different working capacity groups (Table 3).

Table 3. Relationship between the working capacity level and health-related life quality (SF-36).

	WCL 0–25 N = 30	WCL 30–40 N = 100	WCL 45–55 N = 21	WCL 60–100 N = 6	WCL unknown N = 27	p
Physical functioning	16.5 ± 18.7	37.0 ± 21.0	46.7 ± 28.5	53.3 ± 17.5	85.4 ± 14.4	<.001 <sup>a</sup>
Role limitations due to physical health	3.3 ± 8.6	18.3 ± 28.4	27.4 ± 35.3	20.8 ± 18.8	72.2 ± 32.8	<.001 <sup>d</sup>
Pain	45.9 ± 28.6	50.1 ± 27.3	55.6 ± 21.4	59.3 ± 32.7	71.6 ± 26.0	.003 <sup>b</sup>
General health	22.7 ± 12.2	27.1 ± 14.4	30.2 ± 17.5	27.5 ± 27.0	49.8 ± 17.7	<.001 <sup>c</sup>
Physical component summary	88.4 ± 42.1	132.4 ± 64.5	159.8 ± 77.1	160.9 ± 68.0	279.0 ± 71.6	<.001 <sup>a</sup>
Energy/fatigue	32.3 ± 17.7	36.5 ± 17.2	39.3 ± 16.7	42.5 ± 23.6	64.1 ± 16.2	<.001 <sup>c</sup>
Social functioning	25.9 ± 19.7	39.4 ± 18.6	38.6 ± 20.7	40.7 ± 23.0	63.0 ± 21.8	<.001 <sup>d</sup>
Role limitations due to emotional problems	15.6 ± 32.4	37.0 ± 42.1	42.9 ± 41.0	22.2 ± 17.2	80.3 ± 33.7	<.001 <sup>d</sup>
Emotional well-being	45.6 ± 20.9	53.6 ± 19.6	48.8 ± 20.7	47.3 ± 26.5	71.7 ± 14.1	<.001 <sup>c</sup>
Mental component summary	119.4 ± 68.8	166.5 ± 77.0	169.5 ± 82.3	152.8 ± 79.5	279.0 ± 71.5	<.001 <sup>d</sup>

Post hoc: a - 1<2,3,4<5, b - 1,2,3<5, c - 1,2,3,4<5, d - 1<2,3<5 and 4<5.

The data presented in Table 3 show that people with an unknown working capacity level had higher scores of SF-36 in all subscales comparing to those who already know their working capacity level. The analysis only of those 157 with known working capacity level demonstrates that:

- Patients with a working capacity of 0–25% had lower results in Physical functioning, Role limitations due to physical health, Physical component summary; Social functioning, Role limitations due to emotional problems and Mental component summary

subscales comparing to those with working capacities of 30–40% or 45–55%.

- There is no difference between 0–25%, 30–40% and 45–55% working capacity groups in the subscales of Pain, General health, Energy/fatigue and Emotional well-being.

### **Relationship between the Working Capacity Level and Cognitive Functions**

In the third step of analysis, we compared cognitive functions between groups (Table 4).

Table 4. Relationship between the working capacity level and cognitive functions.

	WCL 0–25 N = 30	WCL 30–40 N = 100	WCL 45–55 N = 21	WCL 60–100 N = 6	WCL unknown N = 27	p
Memory self-assessed	5.9 ± 2.5	5.9 ± 2.0	6.7 ± 2.4	7.0 ± 1.8	8.3 ± 1.3	<b>&lt;.001</b> b
SDMT	30.9 ± 16.2	40.5 ± 11.7	45.4 ± 13.3	51.0 ± 15.0	50.3 ± 12.2	<b>&lt;.001</b> ac
CVLT-II 1 attempt	5.4 ± 2.8	6.2 ± 2.0	6.5 ± 2.1	6.5 ± 2.2	6.3 ± 2.0	.390
CVLT-II 2 attempt	7.1 ± 2.9	8.5 ± 2.4	8.5 ± 2.7	9.3 ± 2.2	9.1 ± 2.5	<b>.038</b> f
CVLT-II 3 attempt	8.1 ± 3.0	9.6 ± 2.5	10.4 ± 2.5	10.7 ± 1.6	10.8 ± 2.6	<b>.001</b> ac
CVLT-II 4 attempt	8.3 ± 3.3	9.9 ± 2.4	10.4 ± 2.5	12.0 ± 2.4	11.5 ± 2.3	<b>&lt;.001</b> ac
CVLT-II 5 attempt	9.0 ± 4.0	10.4 ± 2.8	11.0 ± 2.9	11.2 ± 2.0	12.4 ± 2.7	<b>.001</b> bc
CVLT-II sum	38.0 ± 15.2	44.6 ± 10.5	46.7 ± 11.3	49.7 ± 5.1	50.0 ± 10.3	<b>.002</b> ac
BVMT-R 1 set	3.2 ± 2.2	3.9 ± 2.0	3.9 ± 2.2	5.2 ± 2.0	4.9 ± 2.6	<b>.039</b> hc
BVMT-R 2 set	4.5 ± 2.7	5.9 ± 2.5	6.4 ± 2.8	8.2 ± 1.7	7.9 ± 2.9	<b>&lt;.001</b> ade
BVMT-R 3 set	4.7 ± 2.8	6.9 ± 2.7	7.1 ± 2.8	9.0 ± 2.5	9.0 ± 2.5	<b>&lt;.001</b> ag
BVMT-R sum	12.4 ± 7.3	16.7 ± 6.4	17.2 ± 7.2	22.3 ± 6.0	21.7 ± 7.0	<b>&lt;.001</b> ade

Post hoc: a - 1<2,3,4,5, b - 1,2,3<5, c- 2<5, d - 2<4,5, e - 3<5, f - 1<2,5, g - 2,3<5, h - 1<4,5

The data presented in Table 4 show that people with unknown working capacity levels had higher scores in all subscales, with the exception of CVLT-II 1 attempt. The analysis only of those with known working capacity levels demonstrates that:

- Patients with a working capacity of 0–25% had lower results in SDMT, CVLT-II 3, 4 and 5 attempts and CVTL-II sum, BVMT-R 2 and 3 sets and BVMT-R sum comparing to those with working capacities of 30–40%, 45–55% or 60–100%.

- Patients with a working capacity of 30–40% had statistically lower results in BVMT-R 2 set and in BVMT-R sum comparing to those with working capacity of 60–100%.
- There were no differences between groups in memory self-assessment and CVLT-II 1 attempt.

### Relationship between the Working Capacity Level and Fatigue

In the fourth step of analysis, we compared fatigue results between groups (Table 5).

Table 5. Relationship between the working capacity level and fatigue

	WCL 0–25 N = 30	WCL 30–40 N = 100	WCL 45–55 N = 21	WCL 60–100 N = 6	WCL unknown N = 27	p
Fatigue self-assessed	6.6 ± 2.1	6.1 ± 2.0	5.6 ± 2.4	5.8 ± 2.7	3.8 ± 2.7	<.001 a
FDS-Initiative	1.7 ± 0.5	1.6 ± 0.5	1.7 ± 0.6	1.5 ± 0.6	1.2 ± 0.7	.007 b
FDS-Modality	1.6 ± 0.6	1.0 ± 0.8	1.1 ± 0.8	0.8 ± 1.0	0.4 ± 0.8	<.001 ce
FDS-Frequency	2.1 ± 0.7	1.9 ± 0.7	1.5 ± 0.9	1.8 ± 1.0	1.1 ± 1.0	<.001 fg
FDS-Severity	2.4 ± 0.8	2.0 ± 0.8	1.6 ± 0.9	1.8 ± 0.8	0.6 ± 0.8	<.001 hjk
FDS-Uhthoff's effect	0.9 ± 0.3	0.9 ± 0.2	0.9 ± 0.4	1.0 ± 0.0	0.3 ± 0.5	<.001 a
FDS sum	11.4 ± 4.3	8.8 ± 3.9	8.8 ± 4.4	7.5 ± 2.4	3.7 ± 4.3	<.001 d

Post hoc: a - 1,2,3,4>5, b - 1,2,3>5, c - 1>2,3,4,5, d - 1>2,3,4>5, e - 2,3>5, f - 1>3,5, g - 2,4>5, h - 1>2,3,5, j - 2>3,5, k - 3,4>5

The data presented in Table 5 show that people with unknown working capacity feel less fatigue. The analysis only of those with known working capacity levels demonstrates that:

- Patients with working capacity of 0–25% had higher results in fatigue modality, severity and FDS sum comparing to those with working capacities of 30–40% and 45–55%.

- The comparison of the groups by frequency of fatigue shows that those with a working capacity of 30–40% seldom feel fatigue comparing to those with a working capacity of 0–25%.
- The groups do not differ by fatigue self-assessment, FDS initiative and FDS Uhthoff's score.

### **Relationship between the Working Capacity Level, Anxiety and Depression**

In the fifth step of analysis, we compared the levels of anxiety and depression in different working capacity groups (Table 6).

Table 6. Relationship between the working capacity level, anxiety and depression.

		WCL 0-25 N = 30	WCL 30-40 N = 100	WCL 45-55 N = 21	WCL 60-100 N = 6	WCL unknown N = 27	p
HAD Anxiety		8.4 ± 4.9	7.2 ± 3.7	7.3 ± 4.2	6.3 ± 4.8	3.3 ± 4.3	<.001 <sup>a</sup>
HAD Depression		11.0 ± 5.3	9.1 ± 3.8	1.4 ± 4.1	12.2 ± 6.2	6.2 ± 4.1	<.001 <sup>b</sup>
HAD Anxiety	1	13 (43.3%)	51 (51.0%)	9 (42.9%)	4 (66.7%)	26 (96.3%)	.019
	2	9 (3.0%)	31 (31.0%)	8 (38.1%)	1 (16.7%)	1 (3.7%)	
	3	6 (2.0%)	15 (15.0%)	3 (14.3%)	1 (16.7%)	0 (0%)	
	4	2 (6.7%)	3 (3.0%)	1 (4.8%)	0 (0%)	0 (0%)	
HAD Depression	1	7 (23.3%)	37 (37.0%)	5 (23.8%)	2 (33.3%)	17 (63.0%)	<.001
	2	4 (13.3%)	23 (23.0%)	8 (38.1%)	0 (0%)	7 (25.9%)	
	3	11 (36.7%)	34 (34.0%)	3 (14.3%)	1 (16.7%)	2 (7.4%)	
	4	8 (26.7%)	6 (6.0%)	5 (23.8%)	3 (5.0%)	1 (3.7%)	

1 – normal, 2 – mild, 3 – moderate, 4 – severe level of depression or anxiety.

Post hoc: a - 1,2,3>5, b - 1,2,3,4>5 and 1>2

The analysis of the data presented in Table 6 shows that those with an unknown working capacity had fewer anxiety and depression symptoms. Comparing the groups with known working capacities, it is seen that those with a working capacity of -25% have more severe depression than those with working capacity of 30–40%. There were no other differences between groups.

### **Relationship between the Working Capacity Level and the Results of the Brief ICF Core Set for Multiple Sclerosis**

In the sixth step of analysis, the results of the results of the Brief ICF Core Set for Multiple Sclerosis were compared between groups. First of all, we analyzed the distribution of different parameters in our sample (Figure 8 and Figure 9). The data revealed that 66% of the study's participants indicated that d455 – Moving around was a complete difficulty. The second biggest difficulty is d850 – Remunerative employment; this was indicated by 32% of the study's participants.

On the other hand, as many as 81% of the respondents said that b164 – Higher-level cognitive functions were not impaired. For 63% of the study's participants, there were no problems with d230 – Carrying out daily routine, and 57% had no issues with d175 – Solving problems.

The analysis of the environmental factors (Figure 9) shows that only 7–10% of the study's participants experience negative attitudes from e310 – Immediate family or e355 – Health professionals and that it is a barrier for them. But most often, immediate family is the strongest facilitator helping to manage difficulties related to the disease.



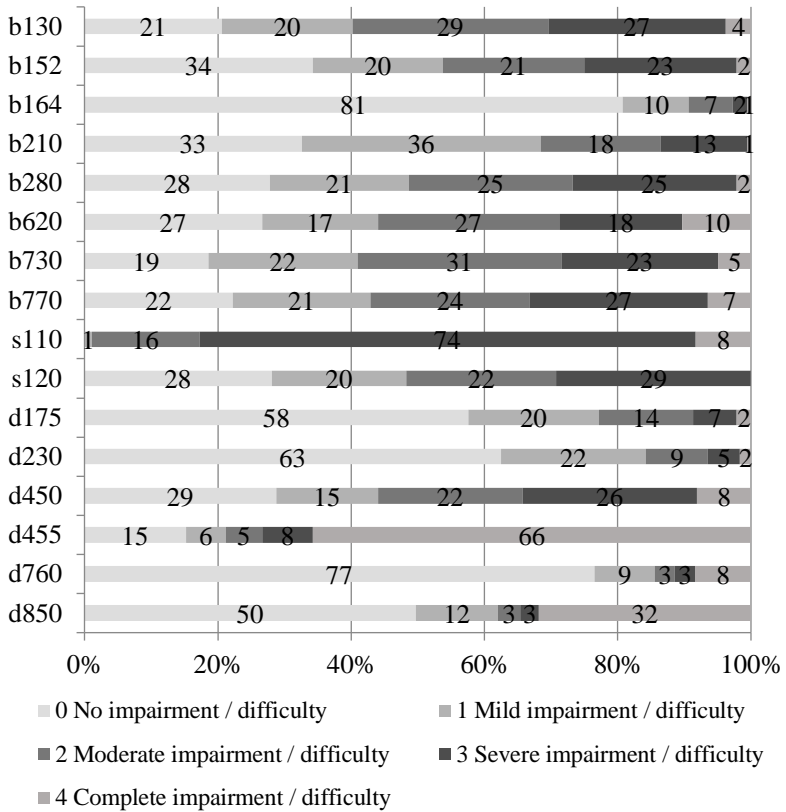


Figure 8. An evaluation of ICF body functions, body structure and activity & participation in percent

Note: b130 – Energy and drive functions, b152 – Emotional functions, b164 – Higher-level cognitive functions, b210 – Seeing functions, b280 – Sensation of pain, b620 – Urination functions, b730 – Muscle power functions, b770 – Gait pattern functions, s110 – Structure of brain, s120 – Spinal cord and related structures, d175 – Solving problems, d230 – Carrying out daily routine, d450 – Walking, d455 – Moving around, d760 – Family relationships, d850 – Remunerative employment.

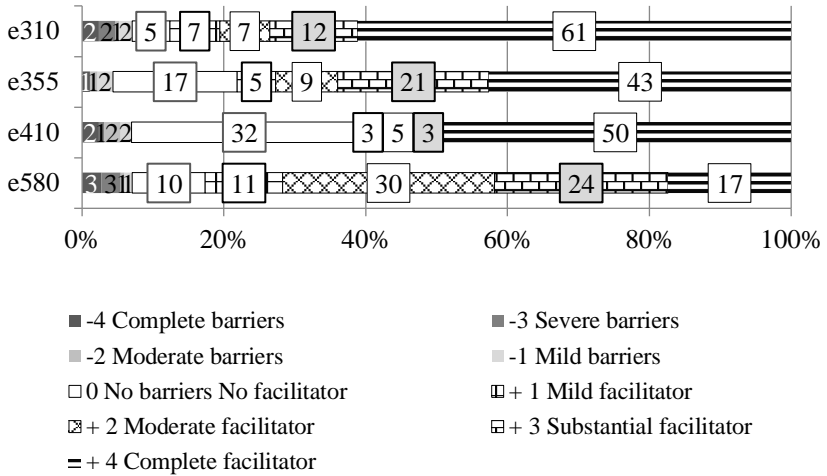


Figure 9. An evaluation of ICF environmental factors in percent

Note: e310 – Immediate family, e355 – Health professionals, e410 – Individual attitudes of immediate family members, e580 – Health services, systems and policies.

There was an assumption that patients with different working capacities faced different difficulties and barriers. Thus, the results were compared between groups (Table 7).

This time, as in previous steps of analysis, the results of those with unknown working capacities were better than in other groups. The analysis only of the groups with known working capacities demonstrates that:

- The groups do not differ by their results of b152 – Emotional functions, b164 – Higher-level cognitive functions, b280 – Sensation of pain, s120 – Spinal cord and related structures, d760 – Family relationships, e310 – Immediate family, e355 – Health professionals, e410 – Individual attitudes of immediate family members, e580 – Health services, systems and policies.

Table 7. The scores of ICF between different working capacity groups.

	WCL 0-25 N = 30	WCL 30-40 N = 100	WCL 45-55 N = 21	WCL 60-100 N = 6	WCL unknown N = 27	P	Post hoc
b130	2.2 ± 1.0	1.9 ± 1.1	1.9 ± 1.3	1.2 ± 1.2	0.5 ± 0.7	<.001	1,2,3>5 1>4
b152	1.9 ± 1.3	1.5 ± 1.2	1.3 ± 1.3	1.7 ± 1.6	0.3 ± 0.5	<.001	1,2,3,4>5
b164	0.5 ± 1.0	0.3 ± 0.7	0.2 ± 0.5	0.8 ± 1.6	0.0 ± 0.2	.063	
b210	1.5 ± 1.1	1.3 ± 1.0	0.7 ± 0.7	0.7 ± 0.5	0.6 ± 0.9	<.001	12,>3,5
b280	1.7 ± 1.3	1.8 ± 1.2	1.4 ± 0.9	1.3 ± 1.2	0.6 ± 0.8	<.001	1,2,3>5
b620	2.9 ± 1.0	1.8 ± 1.2	1.2 ± 1.2	1.5 ± 1.1	0.3 ± 0.6	<.001	1>2,3,4,5 2>3,5 3,4>5 1>2,3,4,5
b730	2.8 ± 0.9	2.0 ± 1.0	1.1 ± 1.0	1.3 ± 0.8	0.3 ± 0.5	<.001	2>3,5 3,4>5
b770	2.8 ± 1.0	2.0 ± 1.0	1.2 ± 1.0	1.0 ± 0.6	0.1 ± 0.3	<.001	1>2,3,4,5 2>4,5 3,4>5
s110	3.1 ± 0.6	2.9 ± 0.5	2.8 ± 0.4	2.5 ± 0.6	2.7 ± 0.5	.002	1>3,4,5 2>4,5
*(17/53/8/3/9) s120	1.6 ± 1.3	1.5 ± 1.2	1.5 ± 1.1	1.0 ± 1.7	1.8 ± 1.2	.891	
d175	1.3 ± 1.4	0.8 ± 1.0	0.9 ± 1.1	0.3 ± 0.5	0.0 ± 0.2	<.001	1>2,4,5 2,3>5
d230	1.0 ± 1.1	0.7 ± 1.0	0.5 ± 0.8	0.8 ± 1.0	0.0 ± 0.2	.002	1>2,5 2>5

d450	3.2 ± 0.7	1.9 ± 1.2	1.1 ± 1.1	1.2 ± 0.8	0.0 ± 0.2	<.001	1>2,3,4,5 2>3,5; 3>5
d455	3.8 ± 0.8	3.6 ± 1.0	3.0 ± 1.4	2.8 ± 1.3	0.2 ± 0.5	<.001	1>3,45 2>3,5 3,4>5
*(27/89/18/5/27) d760	0.6 ± 1.2	0.7 ± 1.4	0.4 ± 1.0	1.0 ± 1.7	0.0 ± 0.2	.111	
d850	2.8 ± 1.7	1.6 ± 1.8	1.4 ± 1.9	1.5 ± 2.0	0.0 ± 0.2	<.001	1>3,5 2,3,4>5
*(28/91/18/6/27) e310	7.5 ± 1.6	6.9 ± 2.0	7.1 ± 1.9	7.0 ± 1.6	5.7 ± 2.0	.019	1,2,3>5
e355	6.5 ± 2.1	6.6 ± 1.8	6.6 ± 1.7	6.7 ± 1.8	6.1 ± 1.6	.832	
*(21/64/13/5/26) e410	7.0 ± 1.9	6.6 ± 2.2	5.8 ± 2.5	5.8 ± 2.7	4.0 ± 0.5	<.001	1,2,3>5
e580	6.1 ± 1.0	6.4 ± 1.3	6.1 ± 1.7	5.8 ± 3.1	3.7 ± 2.5	<.001	1,2,3>5

\* during the study, information was not gathered from all patients; thus, the sample size of each group is presented.

b130 –Energy and drive functions, b152 – Emotional functions, b164 – Higher-level cognitive functions, b210 – Seeing functions, b280 – Sensation of pain, b620 – Urination functions, b730 – Muscle power functions, b770 – Gait pattern functions, s110 – Structure of brain, s120 – Spinal cord and related structures, d175 – Solving problems, d230 – Carrying out daily routine, d450 – Walking, d455 – Moving around, d760 – Family relationships, d850 – Remunerative employment, e310 – Immediate family, e355 – Health professionals, e410 – Individual attitudes of immediate family members, e580 – Health services, systems and policies.

- Those with a working capacity of 0–25% have more problems in b620 – Urination functions, b730 – Muscle power functions and b770 – Gait pattern functions comparing to those with working capacity of 30–40%, 45–55% or 60–100%.
- Those with working capacity of 0–25% have more severe impairments in s110 – Structure of brain and more difficulties in d455 – Moving around comparing to those with working capacity of 45–55% or 60–100%.
- Those with working capacity of 0–25% have more difficulties in d230 – Carrying out daily routine or d175 – Solving problems comparing to those with working capacity of 30–40%; they have more difficulties related to 850 - Remunerative employment and their b210 – Seeing functions are more impaired comparing to those with working capacity of 45–55%; they also have more difficulties related to b130 – Energy and drive functions comparing to those with working capacity of 60–100%.
- Those with working capacity of 30–40% have more difficulties related with b210 – Seeing functions, b620 – Urination functions, b730 – Muscle power functions and d455 – Moving around comparing to those with working capacity of 45–55%.
- Those with working capacity of 30–40% have impaired s110 – Structure of brain and have more problems related to b770 – Gait pattern functions comparing to those with working capacity of 60–100%.

The analysis of the dynamics of different categories during the worsening of working capacity demonstrates that people in the 0–25% category could be in a lower position by more than 1 row score comparing to those with higher working capacity. For example, those with a working capacity of 0–25% indicated that d450 – Walking function was a severe difficulty, while those with the working capacity of 30–40% indicated that it was a moderate difficulty ( $M = 3.2$  and  $M = 1.9$  respectively). The same tendency is seen with b620 – Urination functions ( $M = 2.9$  in the 0–25% working capacity group and  $M = 1.8$

in the 30–40% working capacity group) or with d850 – Remunerative employment ( $M = 2.8$  and  $M = 1.6$ , respectively).

Additionally, a bigger difference than by 1 row score is seen between those with the working capacity of 60–100% and those with an unknown working capacity. That is seen in b152 – Emotional functions ( $M = 1.7$  and  $M = 0.3$ , respectively), b620 – Urination functions ( $M = 1.5$  and  $M = 0.3$ , respectively), d450 – Walking ( $M = 1.2$  and  $M = 0.04$ , respectively), d455 – Moving around ( $M = 2.8$  and  $M = 0.2$ , respectively) and d850 – Remunerative employment ( $M = 1.5$  and  $M = 0.04$ , respectively).

To conclude, the cascaded worsening of different functions could be related with the working capacity level.

### **Relationship of EDSS with Life Quality, Cognitive Functions, Fatigue, Anxiety, Depression and Results of ICF**

Currently, EDSS is the main instrument for the evaluation of a person's functionality in primary care. Thus, it was important to know which parameters it was related to the most. Correlations are presented in Table 8.

Table 8 shows that the strongest EDSS correlation is  $r = .692$ ,  $p < .01$  with d450 – Walking: the greater the EDSS score, the more this function is impaired. High correlations were found with b770 – Gait pattern functions ( $r = .672$ ,  $p < .001$ ) and b730 – Muscle power functions ( $r = .648$ ,  $p < 0.001$ ). As for SF-36, the highest correlation was with Physical functioning ( $r = -.628$ ,  $p < .001$ ): the higher the EDSS score, the lower Physical functioning was.

Interestingly enough, there were no statistically significant correlations only with the 1<sup>st</sup> attempt of CVLT-II 1, the HAD depression scale, b164 – Higher-level cognitive functions, s110 – Structure of brain and e355 – Attitudes of health professionals.

Table 8. Correlations of EDSS with research variables.

Variable	r	Variable	r	Variable	r	Variable	r
Physical functioning	-.628**	CVLT-II 1 attempt	-.061	Memory self-assessed	-.227**	b130	.285**
Role limitations due to physical health	-.445**	CVLT-II 2 attempt	-.195**	SDMT	-.361**	b152	.229**
Pain	-.244**	CVLT-II 3 attempt	-.257**	Fatigue self-assessed	.346**	b164	.016
General health	-.331**	CVLT-II 4 attempt	-.342**	FDS- initiative	.165*	b210	.233**
Physical component summary	-.538**	CVLT-II 5 attempt	-.298**	FDS- modality	.353**	b280	.229**
Energy/fatigue	-.372**	CVLT-II sum	-.272**	FDS- frequency	.370**	b620	.551**
Social functioning	-.368**	BVMT-R 1 set	-.167*	FDS- severity	.490**	b730	.648**
Role limitations due to emotional problems	-.292**	BVMT-R 2 set	-.322**	FDS- Uhthoff's effect	.361**	b770	.672**
Emotional well-being	-.162*	BVMT-R 3 set	-.368**	FDS sum	.428**	s110	.012
Mental component summary	-.357**	BVMT-R sum	-.319**	HAD Anxiety	.281**	s120	-.353**
				HAD Depression	.122		

\* p < 0,05, \*\* p < 0,01

EDSS – Expanded Disability Status Scale, CVLT – California verbal learning test II ed, BVMT-R – Brief Visuospatial Memory Test-Revised, SDMT – Symbol/Digit Modalities Test, FDS – Fatigue Descriptive Scale, HAD – Hospital Anxiety and Depression Scale, b130 – Energy and drive functions, b152 – Emotional functions, b164 – Higher-level cognitive functions, b210 – Seeing functions, b280 – Sensation of pain, b620 – Urination functions, b730 – Muscle power functions, b770 – Gait pattern functions, s110 – Structure of brain, s120 – Spinal cord and related structures, d175 – Solving problems, d230 - Carrying out daily routine, d450 – Walking, d455 – Moving around, d760 – Family relationships, d850 – Remunerative employment, e310 – Immediate family, e355 – Health professionals, e410 – Individual attitudes of immediate family members, e580 – Health services, systems and policies.

## **Relationship between a Worsening Working Capacity and Life Quality, Cognitive Functions, Fatigue, Anxiety, Depression and the Results of ICF**

The last step in this analysis was to assess a worsening working capacity (or EDSS) in relation with different parameters of physical and mental health. The analysis was conducted only among those study participants whose diagnoses had been made during the last five years, because scientific literature indicated that after such a period the disease becomes stabilized.<sup>5</sup>

There were 72 study participants who fit this criterion. The change of their condition was analyzed one year after initial assessment. A worsening of the condition was indicated if the participant had a higher EDSS score comparing to the starting one at the end of a study year – in total, 21 study participants fell within that category. Another group included those whose conditions had not change or had improved; it consisted of 51 study participants. Improvement was noted among 9 study participants, but usually that was improvement in the EDSS scale by 0.5 point.

In order to ensure that differences between groups are not affected by the initial characteristics of different group participants, the first step in analysis was group comparison based on sociodemographic and clinical parameters. Results are presented in Table 9.

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<sup>5</sup> Confavreux C, Vukusic S, Moreau T, Adeleine P. “Relapses and Progression of Disability in Multiple Sclerosis.” *N Engl J Med*. 2000 Nov 16;343(20):1430–8.



Table 9. A comparison of patients whose conditions had worsened in one year and whose conditions had not change/had improved.

		Condition worsened N = 21	Condition had not changed/ had improved N = 51	p
Age		43.5 ± 9.6	38.6 ± 12.45	.110
Time from symptoms		5.3 ± 4.0	5.3 ± 5.6	.947
Time from diagnosis		3.7 ± 4.0	3.3 ± 5.6	.733
Starting EDSS level		3.6 ± 1.1	3.3 ± 1.2	.321
Starting working capacity level		39.0 ± 9.7	39.6 ± 14.5	.858
Gender	Men	5 (23.8%)	19 (37.3%)	.206
Education	Basic	0 (.0%)	1 (2.0%)	.975
	Secondary	5 (23.8%)	13 (25.5%)	
	Vocational	4 (19.0%)	9 (17.6%)	
	College	4 (19.0%)	10 (19.6%)	
	Higher	8 (38.1%)	18 (35.3%)	
Profession	(has)	17 (81.0%)	41 (7.7%)	.617
Participation in the labor market	(yes)	14 (66.7%)	40 (8.0%)	.184
Type of disease	SPMS	2 (9.5%)	2 (3.9%)	.284
	PPMS	0 (.0%)	1 (2.0%)	
	PRMS	1 (4.8%)	0 (.0%)	
	RRMS	18 (85.7%)	48 (94.1%)	

SPMS – secondary-progressive multiple sclerosis, PPMS – primary-progressive multiple sclerosis, PRMS – progressive-relapsing multiple sclerosis, RRMS – relapsing-remitting multiple sclerosis.

The data presented in Table 9 show that groups do not differ by initial parameters, with the exception of rehabilitation. Thus, the further analysis, discovering the variables related with a worsening of the condition, was correct.

The comparison of SF-36 results between these two groups revealed that those whose condition had worsened had lower results in Physical functioning ( $33.6 \pm 21.2$  vs  $53.0 \pm 28.0$ ,  $p = .006$ ), Physical component summary ( $122.4 \pm 69,8$  vs  $171.444 \pm 89.6$ ,  $p = .016$ ) and Mental component summary ( $145.6 \pm 88.1$  vs.  $193.7 \pm 81.0$ ,  $p = .039$ ) comparing to those whose condition had not changed or had improved.

The analysis of cognitive functions related with the change in condition found that Visuospatial Memory results were statistically different between groups: for those whose conditions had worsened, the sum of BVMT-R was 14.8, while for those whose conditions had not changed or had improved, this sum was 19.0 ( $p = .016$ )

The comparison of fatigue results between groups also revealed differences. Both using self-assessment and the FDS scale, it was discovered that those whose conditions had worsened felt more intense fatigue ( $6.3 \pm 1.9$  vs.  $4.9 \pm 2.2$ ,  $p = .007$ ), it was felt more frequently ( $1.9 \pm 0.7$  vs.  $1.5 \pm 0.8$ ,  $p = .032$ ), the fatigue limited their functioning in different areas of life ( $2.2 \pm 0.8$  vs.  $1.4 \pm 1.0$ ,  $p = .002$ ), and it was more often related with Uhthoff's effect ( $1.0 \pm 0$  vs.  $.7 \pm .5$ ,  $p = .005$ ) comparing to those whose conditions had not changed or had improved.

There were no differences found between groups while analyzing their emotional states (anxiety and depression).

Finally, the results of ICF were compared between those whose conditions had worsened and those whose conditions had not changed or had improved. In the group with worsened conditions, the following functions and structures were more impaired or caused more difficulties:

- Energy and drive functions ( $2.0 \pm 1.0$  vs.  $1.4 \pm 1.1$ ,  $p = .040$ );
- Emotional functions ( $1.8 \pm 1.2$  vs.  $1.1 \pm 1.1$ ,  $p = .047$ );
- Higher-level cognitive functions ( $.6 \pm .8$  vs.  $.1 \pm .3$ ,  $p = .001$ );
- Walking ( $1.8 \pm 1.2$  vs.  $1.1 \pm 1.3$ ,  $p = .048$ );
- Moving around ( $3.3 \pm 1.4$  vs.  $2.2 \pm 1.8$ ,  $p = .018$ );
- Family relationships ( $1.0 \pm 1.7$  vs.  $.3 \pm .9$ ,  $p = .048$ );
- Remunerative employment ( $2.2 \pm 1.8$  vs.  $1.0 \pm 1.6$ ,  $p = .006$ ).

In order to analyze the factors having the greatest predicting value for condition worsening (coded 1) comparing to the stability or improvement of the condition (coded 0), a logistic predictive analysis (Forward Wald) was conducted. To avoid multicollinearity, the

following regressors were included into the analysis: Physical functioning, Physical component summary, Mental component summary, BVMT-R sum, FDS sum, b130 – Energy and drive functions, b152 – Emotional functions, b164 – Higher-level cognitive functions, d450 – Walking, d455 – Moving around and d850 – Remunerative employment.

The results showed that only 2 regressors – FDS sum and b164 – Higher-level cognitive functions – predicted a worsening of the condition (Model Fit  $\chi^2 = 18.7$   $p < .001$ ; Hosmer and Lemeshow  $\chi^2 = 11,369$   $p = .123$ ). With their help, 74.3% of the data can be classified correctly and the 33.2% of result dispersion could be explained (the determinant coefficient of Negelkerke).

Table 10. Regressors predicting a worsening of the condition in patients with MS in 1 year.

Regressors	Regression coefficient (B) (standard error)	Wald statistics	p	Exp (B)
FDS sum	.20 (.08)	6.17	.013	1.22
b164 – Higher-level cognitive functions	1.39 (.55)	6.45	.011	4.00
Constant	-2.98 (.83)	13.00	<.001	.05

Knowing that the FDS sum dispersion was equal from 0 to 17, it was reasonable to establish its critical value for predicting a condition worsening after 1 year. An ROC analysis was conducted. Its results

are presented in Figure 10. The area under the curve is .728 (95% CI 0.614–0.843),  $p = .002$ . With sensitivity of .762 and specificity of .627, the critical value is 8.5; when it is exceeded, the chances of worsening increase.

The dispersion of b164 – Higher-level cognitive functions was too small; thus, an ROC analysis was not performed.

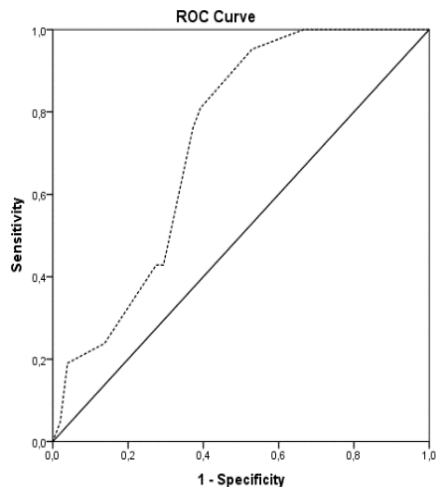


Figure 10. An ROC analysis predicting worsening of MS condition in 1 year by results of FDS sum

## CONCLUSIONS

1. In 2000–2015, the incidence rate of Multiple Sclerosis in Lithuania was increasing (3.5 cases per 100 000 people), among women in particular. Females are affected on average 1.7 times more frequently than males, and this ratio was growing in 15 years. Should such a tendency remain, women are expected to be diagnosed with MS two times more often than men in Lithuania in 2020.
2. In time, advancing MS has impact on a person's working capacity. Before their repeat visit to the DWCAO, the MS patients' health conditions worsen and their working capacity levels decrease; however, the actual course of the disease gradually stabilizes. The critical value of working capacity predicting the individual's participation in the labor market is equal to 37.5 percent. The working capacity level decreases with increasing age; no difference between genders was identified.
3. For less than five years, a worsening of the condition of MS patients in one year is best predicted by fatigue and impairment of higher-level cognitive functions. The higher the working capacity level of the individual, the fewer the impairment specified by patients in the assessment by ICF categories. For MS patients, Moving Around and Remunerative Employment causes the largest difficulty in activity and participation, and the brain is most damaged compared with other body structures. Inclusion of the ICF category sets into the criteria for the establishment of the working capacity level would ensure a disability assessment that is individual and comprehensive, i.e., biopsychosocial.

## PRACTICAL PROPOSALS AND RECOMMENDATIONS

1. Considering that MS causes irreversible disability early on, it is crucial that medical doctors provide a timely referral to MS patients for the establishment of their working capacity levels, following a prior clinical assessment of all their impaired functions focusing on cognitive functions and fatigue, because these are the best predictors of decreasing working capacity. Poor indicators of the latter functions are the first to hinder the patients from remaining in employment.
2. We recommend using the ICF category sets in health care institutions, rehabilitation units, where teams of professionals would provide a detailed multidisciplinary description of impaired functions as well as conduct the assessment of functioning that a person with a disability can achieve with the help of auxiliary means. Such a thorough examination of patients would also enable an objective establishment of disability.
3. We recommend integrating ICF provisions into the disability establishment criteria and ensuring more objective comprehensive procedures for an individual's evaluation, including not only medical factors but also individual social factors limiting the person's activity and participation, such as social relationships and circumstances.
4. The ICF should become a widely-used practical instrument encompassing the spectrum of disease symptoms as well as functionality restrictions, taking into consideration the factors of the environment where people live; such factors influence physical and social exclusion as well as the attitude toward the disabled. For this purpose, we recommend continuing with research, since the ICF is a comprehensive classification based on a universal language understood by health professionals, investigators, policy

developers, patients, and organizations of the disabled around the world.

6. We recommend adopting the universal ICF system in Lithuania; this system is applied globally by various professionals based on various parameters and for various assessments.

## PUBLICATIONS

1. Valadkevičienė D, Kavaliūnas A, Kizlaitienė R, Jocys M, Jatuzis D. Incidence rate and sex ratio in multiple sclerosis in Lithuania. *Brain and Behavior*. 2018:e01150. DOI: 10.1002/brb3.1150.
2. D. Valadkevičienė, D. Jatuzis, I. Žukauskaitė. Sergančiųjų išsėtinė skleroze biopsichosocialinis vertinimas, taikant Tarptautinės funkcionavimo, neįgalumo ir sveikatos klasifikacijos trumpąjį kategorijų rinkinį, ir jo sąsajos su darbingumo lygiu. *Neurologijos seminarai*. 2018; 23(77):201-212. DOI: 10.29014/ns.2018.25.

## PRESENTATIONS

1. Valadkevičienė D, Jatuzis D, Būtėnaitė L, Gulbinas R. “Assessment of the brief ICF Core Set reliability for the evaluation of working capacity in the case of multiple sclerosis.” The 21<sup>st</sup> European Congress of Physical and Rehabilitation Medicine, May 1–6, 2018, Vilnius.
2. Valadkevičienė D, Kavaliūnas A, Kizlaitienė R, Jocys M, Jatuzis D. “Changes in the incidence of multiple sclerosis in Lithuania from 2001 to 2015.” The Fourth International Conference “Evolutionary Medicine: Health and Diseases in Changing Environment,” June 5–8, 2018, Vilnius.
3. Valadkevičienė D, Jatuzis, D Kizlaitienė R. “Work capability level of patients with multiple sclerosis in Lithuania: it’s dynamics and relationship with employment status and letal outcomes.” The 9<sup>th</sup> Baltic Congress of Neurology, September 6–8, 2018, Kaunas.
4. D. Valadkevičienė. “Sergančių išsėtinė skleroze biopsichosocialinių galimybių vertinimas naudojant tarptautinius instrumentus.” The 15<sup>th</sup> Summer School of Neurologists, June 16–18, 2017, Klaipėda.
5. D. Valadkevičienė. “Išsėtinė sklerozė, fizinė ir kognityvinė negalia.” The 16<sup>th</sup> Summer School of Neurologists, June 8–10, 2018, Marijampolė.



## THESES

D. Valadkeviciene. "Disability of patients with multiple sclerosis in Lithuania." International Scientific-Practical Conference on Medical Examinations and Rehabilitation, September 14, 2018, Minsk, Belarus.

## BRIEF INFORMATION ABOUT THE AUTHOR

### EDUCATION

- 2014–2018            PhD studies at Vilnius University.  
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- 2005 – current        Head of Vilnius’s 2<sup>nd</sup> territorial department at  
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Responsibilities include decision-making in  
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## SUMMARY IN LITHUANIAN

15 procentų pasaulio gyventojų – beveik 1 000 000 000 žmonių, – yra neįgalūs. Siekiant patenkinti žmonių su negalia poreikius ir teises sveikatos ir socialinės apsaugos tarnyboms reikalingi holistiniai žmogaus veiklos ir negalios vertinimo aprašai. Šiuolaikinei visuomenei svarbu, kad asmenys kuo ilgiau išliktų darbingi, savarankiški, visapusiškai aktyvūs, dalyvaujantys visose savo gyvenimo ir visuomenės srityse, todėl būtina išnaudoti visas medicininės priežiūros ir medicininės bei profesinės reabilitacijos galimybes įveikti ligos sukeltas kliūtis asmens gyvenime ir atitolinti negalią. Kai sveikatos sutrikimai tampa ilgalaikiai ir nustatoma negalia, medicininės ir socialinės paramos klausimas tampa dar aktualesnis.

Pasaulio sveikatos organizacija (PSO) rekomenduoja negalios sunkumą vertinti remiantis Tarptautine funkcionavimo, negalios ir sveikatos klasifikacija (TFK). TFK pagrindas yra biopsichosocialinis modelis, kuriame žmogaus sveikata, negalia ir funkcionavimas nustatomas atsižvelgiant į asmens sąveiką su fizine, socialine ir psichologine aplinka. Kad negalia nėra tik asmens sveikatos problema konstatuojama ir Europos Tarybos 2017–2023 m. strategijoje dėl negalios. Joje minima, kad „negalia yra atskirų sutrikimų ir egzistuojančio neigiamo požiūrio bei aplinkos kliūčių sąveikos rezultatas. Negalia gali trukdyti neįgaliesiems naudotis visomis žmogaus teisėmis pagrindinėmis laisvėmis ir neleisti jiems veiksmingai ir lygiai su kitais dalyvauti visuomenės gyvenime. Asmenys, turintys daugybinių, sudėtingų ir kompleksinių sutrikimų, susiduria su papildomomis kliūtimis, taip pat gresia didesnis nepalankių įpročių visuomenėje įsitvirtinimas, atskirties ir skurdo rizika“. Todėl kaip sprendimas siūlomas tarptautinių instrumentų, skirtų asmens kūno sandaros ir funkcijų sutrikimams bei nepalankių aplinkos veiksnių nustatymui, naudojimas. PSO atkreipia dėmesį, kad teikiant pagalbą ligoniams turi būti vertinamos ne tik sveikatos

sutrikimų priežastys, bet ir ligų pasekmės, kurias galima sumažinti pritaikant aplinką, naudojant technines priemones, stengiantis paveikti ligonių elgseną.

Visgi, Lietuvos Respublikos Vyriausybės patvirtintoje Nacionalinėje neįgaliųjų socialinės integracijos 2013–2019 metų programoje į šią problemą žvelgiama šiek tiek siauriau. Joje keliamas tikslas – užtikrinti skirtingas negalias turinčių neįgaliųjų specialiųjų poreikių tenkinimą socialinės integracijos paslaugomis (socialinės apsaugos, sveikatos priežiūros, švietimo srityse). Pilnesnis vaizdas (įdiegus TFK) apie ne tik medicininius, bet ir socialinius negalios veiksnius priartintų mūsų šalyje taikomą negalios vertinimo praktiką prie rekomenduojamų tarptautinių standartų, skatintų atkreipti didesnę atsakingų specialistų ir tarnybų dėmesį į iki šiol neretai ignoruojamus negalios biopsichosocialinius veiksnius, išryškintų konkretaus paciento poreikius ir kliūtis kasdieniniame gyvenime, o tuomet jau galima tikėtis ir konkrečių priemonių, padedančių geresnei neįgaliųjų gyvenimo kokybei.

Nors biopsichosocialiniai neįgaliųjų gyvenimo aspektai sulaukia tyrėjų dėmesio, dažniausiai tyrimai yra fragmentiški. Juose skiriamas nepakankamas dėmesys kompleksinei prevencijai, diagnostikai ir negalios vertinimui, ne visada tinkamai suprantami lėtiniais susirgimais sergančių asmenų poreikiai, netinkamai įvertinamos jų galimybės funkcionuoti visuomenėje.

Pasikeitus požiūriui į asmens sveikatą ir suprantant ją ne kaip ligos nebuvimą, o kaip visavertę fizinę, dvasinę ir socialinę gerovę, pakito ir negalios samprata. Dar 2001 m. gegužės 22 d. PSO pritarė nuostatai įdiegti į praktiką TFK, ir ligų sukeltas pasekmes bei sveikatos sutrikimus vertinti trimis aspektais: organų funkcijos ir struktūros pokyčiai, veiklos bei dalyvumo sutrikimai, aplinkos ir asmenybės veiksnių kaita. Šios metodikos taikymas Vokietijoje, Prancūzijoje, Ispanijoje, Šveicarijoje, Italijoje jau įgauna pagreitį, tuo tarpu Lietuvoje turime tik pavienius bandymus taikyti šios metodikos principus medicininėje reabilitacijoje. Žinomas negalios

biopsichosocialinius aspektus nagrinėjęs mokslinis tyrimas. Jame Z. Skvarciany tyrė darbingo amžiaus asmenų, sergančiųjų piktybiniais navikais, negalumą bei su sveikata susijusią gyvenimo kokybę. Jis pabrėžė, kad nustatant neįgalumą būtina atsižvelgti į biopsichosocialinį aspektą ir vertinant sveikatos būklę sergantiems piktybiniais navikais naudoti gyvenimo kokybės klausimyną (EQ–5D–SL) bei TFK, kadangi ji atspindi pagrindines gyvenimo veiklos funkcijas ir sritis.

Darbo aktualumą didina ir tai, kad trūksta statistinių duomenų apie psichosocialinę negalią, sergamumą, ligų paplitimą, darbingumo nustatymą, nėra mokslinio pagrindimo rengiant negalios nustatymo teisės aktus. Šiandien darbingumo lygis nustatomas, vadovaujantis tik gydančio gydytojo nustatytu ligos padarinių sunkumo laipsniu, taip vadinamu baziniu darbingumo lygiu, ir bendru visiems neįgaliesiems, nepriklausomai nuo negalios pobūdžio, veiklos ir dalyvumo klausimyno įvertinimu.

Neurodegeneracinės ir uždegiminės nervų sistemos ligos – vienas reikšmingiausių ir nacionalinių iššūkių, šių ligų paplitimo mastas ir našta visuomenei nuolat auga. Išsėtinė sklerozė – dažna ir labai svarbi autoimuninė uždegiminė demielinizuojanti neurodegeneracinė nervų sistemos liga, paplitusi Lietuvoje. Ankstesniuose Lietuvoje atliktuose moksliniuose darbuose (R. Kizlaitienė, N. Giedraitienė, L. Malcienė, R. Balnytė, R. Leonavičius, B. Daškevičienė) buvo tiriami įvairūs IS eigos, klinikinio pasireiškimo, diagnostikos aspektai, tačiau iki šiol nenagrinėti IS sergamumo ir negalios vertinimo aspektai. Verta pabrėžti, kad išsėtine skleroze (IS) dažniausiai suserga jauno amžiaus žmonės. Nors IS eigą modifikuojantis gydymas XXI amžiuje padarė didelę pažangą kontroliuojant ligos eigą, visgi bėgant laikui IS paprastai progresuoja bei sukelia ilgalaikius padarinius, kurie traktuojami kaip negalia. Dažniausia galutinė IS pasekmė yra nustatoma negalia, kuri valstybės mastu turi ilgalaikius socialinius ir finansinius padarinius. Be to, yra duomenų, kad IS sergamumas

pastaruoju metu kitose šalyse dažnėja, tačiau duomenų apie IS sergamumo tendencijas Lietuvoje iki šiol neturėjome.

Sergantiems išsėtine skleroze darbingumo lygis nustatomas Kurtzke išplėstinės neįgalumo būklės įvertinimo skale bei aukščiau minėtu visiems bendru klausimynu, vertinančiu išsilavinimą, profesiją, darbo patirtį, amžių, darbinės aplinkos pritaikymą bei trumpą veiklos ir dalyvavimo klausimyną. Tačiau nėra atsižvelgiama į išsėtine skleroze sergančių specifinius pažintinių funkcijų pokyčius, jų patiriamą nuovargį, nerimą, depresiją, kas ženkliai apsunkina šių žmonių funkcionavimą, trikdo asmens veiklą ir dalyvavimą visuomeniniame gyvenime. Fizinė negalia išryškėja jau ligai progresuojant, todėl įprastinis negalios nustatymas tampa pavėluotu ir laikytinas diskriminaciniu.

Šios disertacijos rezultatai yra svarbūs ir praktikams. Atlikus asmens kompleksinį negalios vertinimą naudojant TFK, būtų žinomi asmens poreikiai ir kliūtys kasdieniniame gyvenime, kas leistų tikslingai planuoti jam reikalingas socialines ir sveikatinimo paslaugas, reabilitacijos priemones, vertinti gydymo ir reabilitacijos efektyvumą. Ir jei, žvelgiant iš galutinio vartotojo perspektyvos, individualių poreikių atliepimas lemtų didesnę asmens pasitenkinimą gaunamomis paslaugomis ir gyvenimo kokybe, tai makro lygiu šis pokytis prisidėtų prie valstybės finansinių išlaidų optimizavimo ir racionalaus žmoniškųjų išteklių paskirstymo.

### Darbo tikslas

Išanalizuoti negalios vertinimo sergantiems išsėtine skleroze biopsichosocialinius aspektus.

### Darbo uždaviniai

1. Įvertinti Lietuvos populiacijos sergamumo IS dinamiką.
2. Įvertinti sergančių IS darbingumo lygio dinamikos sąsajas su sociodemografiniais rodikliais, užimtumo statusu ir gyvenimo trukme.

3. Įvertinti, kokios yra asmens darbingumo lygio sąsajos su skirtingais asmens fizinės ir psichinės sveikatos rodikliais (atmintimi, nuovargiu, nerimu, depresija, pažinimo funkcijomis, fizine ir psichine sveikata, Tarptautinės funkcionavimo, negalumo ir sveikatos klasifikacijos kategorijų rinkinio rezultatais).

#### Ginamieji teiginiai

1. Sergamumas IS nuolat didėja, todėl būtina stiprinti šia liga sergančių ankstyvą diagnostiką ir pagalbos teikimą pradinėse ligos stadijose.
2. IS ligos sunkumo ir asmens darbingumo longitudinalinė sąsaja nėra linijinė: pradiniam ligos etape darbingumo lygis ženkliai mažėja, o vėliau stabilizuojasi.
3. Psichosocialiniai veiksniai prognozuoja sergančiųjų IS darbingumo lygį, todėl jų įtraukimas į neįgalumo nustatymo procedūrą užtikrintų objektyvesnę negalios vertinimą.

#### Darbo naujumas

Šiame darbe kompleksiskai pažvelgta į dažną ir reikšmingą negalią sukeliančią neurologinę ligą – išsėtinę sklerozę. Pirmą kartą šalyje populiaciniame lygmenyje pateikiami paskutiniųjų penkiolikos metų IS sergamumo duomenys ir apskaičiuotas sergamumo kitimas, kas leidžia prognozuoti IS sergančiųjų paplitimo tendencijas.

Panaudojant visos Lietuvos NDNT dešimties metų duomenis, pirmą kartą išanalizuotas sergančiųjų IS darbingumo lygio kitimo tendencijos pakartotinių DL vertinimų metu, įvertintos užimtumo ir gyvenimo trukmės prognozės.

Remiantis šiuolaikiniais diagnostiniais tyrimais detalai ištirtas 184 asmenų, sergančių IS, patiriamas nuovargis, nerimas bei depresija, įvertintos pažintinės funkcijos, gyvenimo kokybė. Be to pirmą kartą asmenų su IS kūno funkcijos ir struktūros pokyčiai, veiklos ir dalyvumo apribojimai bei aplinkos veiksnių poveikis negaliai įvertinti

panaudojus TFK klausimyną skirtą IS. Visapusiško tyrimo rezultatai leido fiksuoti psichosocialinių veiksnių sąsajas ne tik su pradiniu darbingumo lygio įvertinimu, bet ir šio įvertinimo pokyčiu per metus.

Taip visapusiškai IS šalyje nebuvo tyrinėta. Tikimės, kad tyrimo rezultatai padės laiku ir objektyviau nustatyti negalią, o biopsichosocialinių veiksnių įvertinimui panaudota TFK atvers naujas galimybes vertinant darbingumo lygį.

## IŠVADOS

1. 2000-2015 m. sergamumas išsėtine skleroze Lietuvoje didėjo (3,5 atvejo 100 000 gyventojų kasmet), labiau moterų tarpe. Moterys išsėtine skleroze serga vidutiniškai 1,7 karto dažniau už vyrus, ir šis santykis per 15 metų didėjo. Išliekant šioms tendencijoms, tikėtina, kad 2020 metais Lietuvoje moterys sirgs 2 kartus dažniau už vyrus.

2. Laikui bėgant progresuojanti IS paveikia asmens darbingumą. Asmenų, sergančių IS, iki pakartotino apsilankymo NDNT sveikatos būklė blogėja ir darbingumo lygis mažėja, tačiau ilgainiui ligos eiga stabilizuojasi. Kritinė darbingumo lygio vertė, prognozuojanti ar asmuo išliks darbo rinkoje, yra 37,5 proc. Darbingumo lygis mažėja didėjant amžiui, skirtumo tarp lyčių nenustatyta.

3. Mažiau nei penkerius metus IS sergančių pacientų būklės pablogėjimą per vienerius metus geriausiai prognozuoja nuovargis ir aukštesniosios pažinimo funkcijos sutrikimas. Kuo didesnis asmens darbingumo lygis, tuo mažiau kliuvinių TFK kategorijų vertinime nurodo sergantieji. Sergantiems IS didžiausi veiklos ir dalyvumo sunkumai buvo ėjimas kitais nei ėjimas būdais ir mokamas darbas, iš kūno struktūrų labiausiai pažeistos galvos smegenys. TFK kategorijų rinkinių įtraukimas į darbingumo lygio nustatymo kriterijus užtikrintų individualų, visapusišką, t.y. biopsichosocialinį, negalios vertinimą.



## PRAKTINIAI PASIŪLYMAI IR REKOMENDACIJOS

1. Kadangi IS anksti sukelia negrįžtamą negalia, svarbu, kad gydytojai sergančiuosius laiku nukreiptų darbingumo lygiui nustatyti, prieš tai kliniškai įvertinę visas sutrikusias funkcijas, atkreipiant dėmesį į pažinimo funkcijas ir nuovargį, nes tai geriausiai prognozuoja darbingumo mažėjimą. Pastarųjų funkcijų prasti rodikliai greičiausiai užkerta kelią dirbti.

2. Rekomenduojame TFK kategorijų rinkinius naudoti gydymo įstaigose, rehabilitacijos skyriuose, kur specialistų komanda užtikrintų išsamų daugiadisciplininį sutrikusių funkcijų aprašymą ir apibūdinimą bei funkcionavimo, kuri asmuo su negalia gali pasiekti panaudojus pagalbines priemones, įvertinimą. Toks išsamus ligonių ištyrimas leistų ir objektyviai nustatyti negalia.

3. Rekomenduojame TFK nuostatas integruoti į neįgalumo nustatymo kriterijus, užtikrinti objektyvesnes kompleksines asmens vertinimo procedūras, kurių metu įvertinami ne tik medicininiai faktoriai, bet ir individualūs asmens veiklą ir dalyvumą ribojantys socialiniai faktoriai: socialiniai ryšiai bei aplinkybės.

4. TFK turi tapti plačiai naudojamu praktiniu įrankiu, kuris apima ir ligos simptomų spektrą ir funkcionavimo apribojimus, atsižvelgiant į aplinkos, kurioje žmonės gyvena, veiksnius, kurie įtakoja fizinę, socialinę atskirtį ir požiūrį į neįgaliuosius. Šiuo tikslu rekomenduojame tęsti mokslinius tyrimus, nes TFK yra visapusiška klasifikacija, kuri pagrįsta universalia kalba, kurią supranta sveikatos specialistai, tyrėjai, politikos kūrėjai, pacientai ir neįgaliųjų organizacijos.

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