WHAT IS THE LEVEL OF SELF-REPORTED PHYSICAL ACTIVITY IN PEOPLE WITH MULTIPLE SCLEROSIS IN THE CZECH REPUBLIC?

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Abstract

Background: Information about the level of physical activities in people with multiple sclerosis (MS) is available from a number of countries, but not from Central European countries. No data has been published from the Czech Republic so far. The aim of our study was to investigate the type and level of physical activities/exercise in people with MS in the Czech Republic, along with the clinical factors that may influence these physical activities. This information can assist nurses in advising on complex patient care.

Methods: The clinical assessment included: the Godin–Shephard Leisure Time Physical Activity Questionnaire (GLTEQ), the 25-foot walk test (T25FW), the 2 Minute Walk Test (2MWT), the Fatigue Severity Scale (FSS), and a study-specific questionnaire that reports experience with sports and sport activities or rehabilitation exercises.

Results: In our sample of 308 people with MS, 63% reported engaging in some form of physical activity. Men exercise more regularly, while irregular exercise predominates among women. Cycling and swimming are the most popular forms of physical activity for both genders. Only one third of participants exercise several times a week – as per medical recommendations. When comparing the mean values, men are classified as active and women as moderately active (according to the GLTEQ questionnaire scores). In our sample, no strong correlations were found between physical activity level and the clinical characteristics of the patients. Weak correlations were found only for fatigue (r = -0.32), neurological disability (r = -0.22), and walking ability (r = 0.25).

Conclusion: Since regular physical activity is considered an integral part of the complex treatment of MS patients, this information can help nurses in counselling patients.

Keywords: Exercise; Motivation; Multiple sclerosis; Physical activity

INTRODUCTION

Multiple sclerosis (MS) is a chronic neurodegenerative disease that affects the central nervous system and has various symptoms. Its prevalence is relatively high in the Czech Republic. The latest available Czech data suggest a prevalence in the Czech Republic of 160/100,000 (Vachova, 2012). However, we have no available information on the level of physical activity and lifestyle of people with MS in the Czech Republic. Many studies have shown that physical activity should be a comprehensive part of the healthy lifestyle of people with MS. Given its benefits for MS symptoms, physical activity should therefore be an integral part of disease management to complement pharmacotherapy with disease modifying drugs (DMD) (Giovannoni et al., 2016). In addition to the positive effect on overall fitness and the positive impact on symptoms (Motl and Pilluti, 2012; Motl et al., 2017), the neuroprotective effect of exercise also plays a role (Diechmann et al., 2021). Some authors talking about the possible effect of regular physical activity of sufficient frequency and intensity on disease course, as a form of anti-inflammatory therapy (Dalgas et al., 2019). Therefore, an appropriate exercise regime should begin as soon as possible after the diagnosis of the disease, rather than waiting for some neurological difficulties to occur (Laermonth and Motl. 2021; Riemenschneider et al., 2022). Unfortunately, most exercise intervention studies involve patients nearly 5 years after diagnosis (Riemenschneider et al., 2018).

The most commonly recommended physical activities include aerobic exercise (especially to increase fitness and reduce fatigue) (Langeskov-Christensen et al., 2021; Mostert and Kesslering, 2002; Rasova et al., 2006) and strengthening exercises (to increase muscle strength, especially in the lower limbs to positively affect gait and balance) (Carling et al., 2017; Kjolhede et al., 2012). Regular stretching should be an integral part of the exercise regime to maintain range of motion and prevent muscle contractures (Hoang et al., 2014). Slower forms of exercise such as tai chi, yoga, or pilates are also an alternative. This so-called body and mind exercise (i.e., slow movements with full concentration, often connected with specific breathing) is highly

recommended, not only for influencing physical symptoms, but also for their positive effect on the psychological state of patients (Cramer et al., 2014, Sánchez-Lastra et al., 2019, Zou et al., 2017). In addition to exercise, which is defined as an organised and structured form of physical activity, everyday lifestyle physical activity, such as walking for at least 150 mins/ week is also recommended in MS patients (Kalb et al., 2020).

However, despite all these published recommendations, it seems that, compared to the healthy population, a large proportion of people with MS do not engage in sufficient physical activity (Motl et al., 2005, 2015).

Therefore, the aim of our study was to discover which physical activities and types of exercise people with MS in the Czech Republic do, in order to help rehabilitation specialists and nurses in counselling patients.

MATERIALS AND METHODS

Sample

We collected clinical data in a sample of 308 people with MS. The study population was chosen by accidental sampling from larger, long-term prospective observational studies conducted in the MS Center of the General University Hospital in Prague, Czech Republic. The study was approved by the local ethical committee and the grant number was: AZV NV18-04-00168.

Accidental sampling from the larger, long-term observational studies was based specifically on time-frame availability (i.e., examination planned between February and September 2019). In total, 515 MS patients from the original studies, available during the given timeframe, were asked to complete the Godin questionnaire on leisure-time physical activity over and above other clinical data. The completed answers from the 308 people with MS represent a response rate of 59.8% from original sample.

The inclusion criteria for MS patients were as follows: clinically isolated syndrome – or clinically definite MS confirmed by MRI and cerebrospinal fluid examination, and participation in a brain MRI volumetric assessment program. The exclusion criteria were: (a) signs and symptoms suggestive of a disease other than MS (b) serious psychiatric disorder, (c) other serious disease limiting physical activity (orthopaedical, internal), (d) pregnancy.

Assessment

People with MS completed the questionnaire during their planned routine visit to the MS Center (as part of a long-term prospective observational study with an annual MRI monitoring of brain and spinal cord and comprehensive clinical assessment, consisting of neurological and neuropsychological examinations). The test battery of clinical assessments included: the 25-foot walk test (T25FW) (Kaufman et al., 2020), the 2-Minute Walk Test (2MWT) (Gijbels et al., 2011), the Fatigue Severity Scale (FSS) (Krupp et al., 1989), the Godin-Shephard Leisure Time Physical Activity Questionnaire (GLTEQ) (Godin, 2011), and a study-specific questionnaire that reports experience with physical activities (including sports activities and rehabilitation exercises). It also included a neurologist's examination to determine the degree of neurological disability (as assessed by the Kurtzke EDSS scale - Expanded Disability Status Scale).

Timed 25-foot walk test (T25FW)

This test is part of Multiple Sclerosis Functional Composite Assessment and is often used in clinical studies. The advantage of this test is its simple administration and reproducibility. The patient is instructed to complete a distance of 7.62 meters as quickly and safely as possible. The average of two completed tests is reported (Kaufman et al., 2020).

2-minute walk test (2MW)

This test informs about walking ability by measuring the distance covered by a patient in two minutes. The mean score covered by people with MS with minimal disability is 173 meters and for moderate disability 104 meters, with minimal clinically detectable change 19.2 meters (Gijbels et al., 2011).

Fatigue Severity Scale

The Fatigue Severity Scale (FSS) is a self-administrated 9-item questionnaire that evaluates perceived severity of fatigue during the past week on a 1-7 Likert scale. The questionnaire was originally developed for people with MS. The lowest score is 7 and the maximum (indicating the greatest possible fatigue) is 63 points. The minimal detectable change is 1.3 points (CIT-lermont 13). A score \geq 36 points indicates severe fatigue (Krupp et al., 1989; Rooney et al., 2019).

Godin–Shephard Leisure Time Physical Activity Questionnaire

The Godin–Shephard Leisure Time Physical Activity Questionnaire (GLTQ) is widely used to evaluate physical activity level in different populations (Godin, 2011; Sikes et al., 2019). This is a short 4-item self-administrated questionnaire. A total score of less than 14 points is considered insufficiently active.

The standardized questionnaires were supplemented by a questionnaire developed by a team of authors who asked patients about their motivations and barriers to exercise, along with their experiences with physical activity (including sport activities and exercise during physiotherapy). There was also a question about experience with psychotherapy.

Statistical analysis

Statistical functions of the Microsoft Excel program were used for statistical evaluation. Specifically, descriptive statistics and Pearson's correlation coefficient were used.

RESULTS

Characteristics of participants

308 people with MS were enrolled to the study (224 women, 72%). The mean age of participants was 44.1 years (SD 8.3) with a mean disease duration of 15.3 (SD 6.1). The median neurological disability was mild, the EDSS score was 2.0 (range 0-6.5). A detailed description of characteristics is displayed in Table 1.

Of the total sample, 41.5% (128 participants) suffer from increased fatigue level (according to the FSS score). Based on the Godin–Shephard Leisure Time Physical Activity Questionnaire score, 116 (37.6%) participants are active, 76 (24.6%) engage in moderate physical activity, and 104 (33.7%) are not sufficiently active. Thus, only a weak correlation was observed between the presence of fatigue and the level of physical activity (as will be described later).

Parameter	N = 308 Mean (SD); Median (range)	
Age (years)	44.1 (SD 8.3); median 43 (26–64)	
Disease duration (years)	15.3 (SD 6.1); median 12 (3–40)	
Expanded Disability Status Scale (EDSS)	2.7 (SD 1.4); median 2 (0–6.5)	
Timed 25-foot walk test (sec)	5.13 (SD 2); median 4.65 (2.95–20.05)	
The 2-minute walk test (m)	176.9 (SD 44.2); median 183 (34–250)	
Nine hole peg test-right (sec)	19.8 (SD 4.7); median 18.85 (13.9–42.13)	
Nine hole peg test-left (sec)	21.1 (SD 6.5); median 19.6 (14.7–65.3)	
Symbol digit modality test (points)	59.17 (SD 11.9); median 60 (22–87)	
Fatigue Severity Scale (points)	31.28 (SD 15.3); median 30 (9–63)	
Godin leisure time physical activity (points)	25.3 (SD 22.9); median 20 (0–130)	
Gender (women/men)	224/84	
Disease modifying drugs	Interferon beta 1a Interferon beta 1b Peginterferon beta 1a Glatiramer acetate Teriflunamid Dimethyl fumarate Fingolimod Natalizumab Alemtuzumab Ocrelizumab Rituximab Siponimod Cladribine	112 (36.3%) 4 (1.2%) 3 (0.97%) 11 (3.5%) 25 (8.1%) 18 (5.8%) 65 (21.1%) 23 (7.4%) 7 (2.2%) 6 (1.9%) 1 (0.32%) 4 (1.2%)
	No treatment	28 (9%)

Table 1- Characteristics of participants

Most popular sport activities

A total of 195 people (63%) reported engagement in sport activities. However, only 72 people stated that they perform sports regularly (23%). These were persons with minimal and moderate disability, with a maximum EDSS of 6.0 (walking with one aid). The most popular sport activities (for both men and women) include cycling and swimming. Table 2 shows how individual sports are represented in both genders.

Frequency of exercise and use of rehabilitation

A total of 227 people with MS (73%) report that they engage in regular exercise. However, only 19 women (11% of exercising women) and 3 men (5% of exercising men) report performing exercise every day. A more frequent answer is 'exercise several times a week' (36% of exercising women, 53% of exercising men). Irregular exercise prevails in almost half of our sample. People with a higher level of neurological disability are mainly engaged in rehabilitation exercises (Table 3). More than half of all participants perform their exercise in the home environment (57%). Also popular is exercising at a fitness centre (16%) or visiting group exercise lessons (17%). Most participants report having enough information about the exercise recommendations for people with MS (33% have enough information and perform exercise, 19% have enough information and do not exercise, 13% do not want any information). Fewer people used psychotherapy than

Fewer people used psychotherapy than physiotherapy in complex rehabilitation. The most frequent were patients with a moderate level of disability (EDSS 3.0–6.0) (see Table 3).

Sport activity	Total (<i>n</i> = 195)	Men (<i>n</i> = 61)	Women (<i>n</i> = 134)
Cycling	64 (33%)	20 (33%)	44 (32%)
Swimming	48 (25%)	24 (39%)	24 (17.5%)
Walking	37 (19%)	5 (8%)	32 (23.5%)
Resistance training	27 (14%)	11 (18%)	16 (12%)
Running	24 (12%)	8 (13%)	16 (12%)
Skiing	23 (11.5%)	7 (11.5%)	16 (12%)
Yoga	17 (9%)	3 (5%)	14 (10.5%)
Tennis	12 (6%)	6 (9.5%)	6 (4.5%)
Skating	12 (6%)	3 (5%)	9 (6.5%)
Aerobic fitness machines	11 (5.5%)	5 (8%)	6 (4.5%)
Dancing	10 (5%)	0	10 (7.5%)
Pilates	6 (3%)	0	6 (4.5%)
Scooter	4 (2%)	1 (1.5%)	3 (2%)
Tai chi	3 (1.5%)	0	3 (2%)
Martial arts	5 (2.5%)	5 (8%)	0
Hockey	3 (1.5%)	3 (5%)	0

Table 2 -	Most	popular	sport	activities
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 Table 3 – Frequency of exercise and use of rehabilitation and psychotherapy

Neurological disability level EDSS (n = 308)	Engage in sport activities	Performing exercise	Have attended or are attending rehabilitation	Have used or are using psychotherapy
EDSS 0 (<i>n</i> = 4)	3 (75%)	4 (100%)	1 (25%)	1 (25%)
EDSS 1–1.5 (<i>n</i> = 98)	69 (71%)	75 (77%)	21 (22%)	25 (26%)
EDSS 2–2.5 (<i>n</i> = 86)	61 (71%)	67 (78%)	32 (38%)	19 (22%)
EDSS 3–3.5 (<i>n</i> = 46)	30 (66%)	33 (73%)	21 (47%)	19 (42%)
EDSS 4–4.5 (<i>n</i> = 42)	24 (57%)	37 (88%)	25 (60%)	17 (40%)
EDSS 5–5.5 (<i>n</i> = 16)	5 (31%)	10 (62%)	9 (56%)	5 (31%)
EDSS 6.0 (<i>n</i> = 9)	2 (22%)	9 (100%)	7 (78%)	4 (44%)
EDSS 6.5 (<i>n</i> = 7)	0 (0%)	6 (85%)	6 (86%)	1 (14%)

Exercise motivation and barriers

Patients in both genders (men and women) report the main motivation for exercise: do something positive for their health conditions). Other important motivators include improving fitness and having fun (see Table 4).

124 participants (4%, 93 women and 31 men) do not perform any exercise or sport activity. The main reported barrier to exercise is lack of time, followed by a subjectively perceived insufficient physical condition, deterioration in physical condition after physical activity, or lack of information about appropriate exercise (Table 4).

Physical activity correlations

Correlation analysis comparing the level of physical activity (GLTQ) with other variables (age, disability-EDSS, fatigue-FSS level, and walking ability – 2MW) revealed only a weak correlation between the level of physical activity and fatigue (r = -0.32), walking ability (r = 0.25), and neurological disability (r = -0.22). All correlations are displayed in Table 5.

Exercise motivation (<i>n</i> = 308)	Exercise barrier (<i>n</i> = 124)
Do something good for yourself (34%)	Lack of time (26%)
Fitness improvement (25%)	Physical restrictions (6%)
Fondness for exercising (17%)	Worsening after exercise (3.5%)
Symptom improvement (12%)	Lack of information (3%)
Fears of deterioration (6%)	Laziness (1%)
Family and friends' recommendations (3%)	Lack of equipment (0.5%)
Medical recommendations (2%)	Did not respond (64%)
Others (1%)	

Table 4 - Exercise motivation and barriers

Table 5 - Physical activity correlations

Pearson correlation	Godin leisure time physical activity questionnaire
Neurological disability (EDSS)	-0.22
Age	-0.04
Disease duration	-0.09
Fatigue Severity Scale	-0.32
Timed 25-foot walk test	-0.18
The 2-minute walk test	0.25

Interpretation: 0.0-0.19 = very weak correlation; 0.2-0.39 = weak correlation; 0.4-0.59 = moderate correlation; 0.6-0.79 = strong correlation; 0.8-1.0 = very strong correlation.

DISCUSSION

This study provides new information on attitudes towards exercise and physical activity among people with MS in the Czech Republic. 195 patients (63% of the total) reported some form of involvement in sports activities. More men exercise regularly, while irregular exercise predominates among women. Cycling and swimming are the most popular forms of physical activity for both genders. The third most popular activity is resistance training for men and walking for women. In a similar Canadian study, patients of both genders most often preferred walking, followed by strengthening and stretching (Asano et al., 2013). Other studies have reported a similar representation of physical activities. Studies from America (Latimer-Cheung et al., 2013) and Sweden (Anens et al., 2017) also indicate the frequent occurrence of aerobic exercise (often in the form of cycling or walking on a treadmill) and strength training. The same trend was also found in an Italian study (Contrò et al., 2017).

similar sample characteriscs). In this study, women were also less physically active (Kahraman et al., 2015). The same seems to be true for healthy adults in the Czech Republic, where men are also more active (Hamrik et al., 2014). However, if physically demanding household chores are also included in physical activities, the level of physical activity is equal for both genders (Azevedo et al., 2007). When planning a physical activity regime, nurses, physiotherapists, and other healthcare professionals should therefore be aware that many people with MS also need extra energy to cope with home and work duties, and may be more limited by their fatigue and spasticity.

In our sample, most respondents perform exercise and physical activity irregularly. Only one third of participants declare that they meet

the healthy lifestyle and exercise recommen-

dations of performing exercise several times a week (Kalb et al., 2020). The mean physical

activity level, as assessed by the Godin questionnaire, was moderately active for women

(23.5 points) and active for men (29.6 points).

Our findings are similar as the Turkish (with

On the contrary, a US study that used objective measurement of physical activity showed no difference between men and women's physical activity. Both genders were deficient in exercise compared to people from healthy populations (Klaren et al., 2013). In contrast, a Swedish study in older MS patients (over 50 years of age) describes lower physical activity in men. In their study, men showed less physical activity and had lower levels of self-efficacy. Women, on the other hand, showed higher levels of fatigue than men. The study attributes this result to the greater musculoskeletal impairment in men in their sample. The study also showed less social support from family members for physical activity in men than women (Anens et al., 2014).

In our sample, no strong correlations were found between physical activity level and the clinical characteristics of the patients. Weak correlations were found only for fatigue severity, neurological disability, and walking ability. Our data and experience from clinical practice show that even people with very limited walking ability (EDSS ≥ 5.0) can engage in regular physical activity (in modified version), such as arm ergometer, pilates, or stretching exercise. It seems that more important is choose for each patient individually suitable type of physical acitivity (e.g. in accessible sport facilities, with available exercise equipment). When choosing this individually tailored activity we should take the preferences and patient's motivation into consideration. There is therefore space for expert consultation from a physiotherapist on individually suitable (and available) physical activities (Mulligan et al., 2013). Doctors, rehabilitation staff, and nurses can therefore provide patients with basic information and, if a more detailed consultation is needed, advise the patient to contact a specialised MS physiotherapist.

Our findings are also consistent with a study by Streber et al. (2016) in that neither age nor gender of MS patients is related to the level of physical activity, as in healthy population.

In contrast, in the healthy population in the Czech Republic, the physical activity level is decreasing with age (Hamrik et al., 2014). In our sample of people with MS more limiting may be the degree of fatigue, although here no strong correlation with fatigue was found. For those with lower fatigue levels, 72% of people (178 persons) engage in physical activity, of whom 32% exercise regularly. In 129 persons with excessive fatigue (more than 36 FSS points), 45% do not perform any leisure-time physical activity. 40% of patients exercise irregularly and only 12% of patients exercise regularly. The negative impact of fatigue has also been described in other studies (Asano et al., 2013). However, a well-chosen exercise programme (often combined with education or psychotherapy) can help to limit fatigue (Thomas et al., 2013).

The individuals in our cohort were well informed about the recommended physical activities, they also frequently mention experience with physiotherapy and psychotherapy (see Table 3). With increasing disability, leisure-time physical activities are decreasing and the proportion of rehabilitation exercises increasing. The most common reported motivator is intrinsic motivation to exercise (a desire to do something for themselves, to increase fitness, or a liking for exercise). Similar findings were reported in a survey of people with MS in the USA, where the most common motivation for exercise was to maintain fitness and quality of life, feel good, and to keep one's ability to manage activities (Dlugonski et al., 2012).

Interestingly, the people with MS in our sample seem to be quite active, considering that up to 60% of the Czech population has a rather sedentary lifestyle (Hamrik et al., 2014).

For comparison, a US study found that patients often complain to health professionals about a lack of information about exercise. They reported a lack of information about the benefits of exercise, the form of exercise, or appropriate exercise equipment (Laermonth et al., 2017).

The results may be influenced to some extent by the organisation of care for people with MS in the Czech Republic. In the Czech Republic, care for people with MS is organised in the form of specialised MS centres (with specialised MS neurologist and MS nurses), where they receive special immunotherapy treatment and have access to specialised physiotherapy and psychotherapy. This may also be the reason for the high percentage of rehabilitation and psychotherapy use in our sample.

The main limitation of the study is that the reporting of the level of physical activity is subjective. Thus, it can be assumed that even those who reported no exercise have some level of physical activity as part of their daily activities.

CONCLUSION

Our work provides new information about physical activity among people with MS in the Czech Republic. The most popular sport activities were cycling, swimming, walking, and resistance training. Participants most often mentioned intrinsic motivation to exercise and the desire to do something for themselves. The most common subjectively reported barriers to exercise include poor fitness, deterioration in physical condition after physical activity, or lack of information. These findings may help nurses in counselling and rehabilitation specialists to better plan rehabilitation and exercise activities for people with MS (not only) in the Czech Republic.

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Ethical aspects and conflict of interest

The authors have no conflict of interest to declare.

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