

mgr Jan Sznajder

**Fizjoterapia w stwardnieniu bocznym zanikowym
– ograniczenia kwalifikacji i monitorowania**

Physiotherapy in amyotrophic lateral sclerosis
– limitations of qualification and monitoring

Rozprawa doktorska na stopień doktora
w dziedzinie nauk medycznych i nauk o zdrowiu
w dyscyplinie nauki o zdrowiu
przedkładana Radzie Dyscypliny Nauk o Zdrowiu
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Promotor: **prof. dr hab. n. med. Magdalena Kuźma-Kozakiewicz**

Katedra i Klinika Neurologii WUM

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Abstract

Amyotrophic lateral sclerosis (ALS), which peaks at the age of 50-60, is characterized by a progressive muscle weakness and a gradual loss of motor functions. Decreased gross and fine motor abilities, as well as respiratory insufficiency, lead to a sedentary followed by a recumbent lifestyle supported by mechanical ventilation. Despite scientific studies on beneficial impact of physical exercise on the patients' functioning and quality of life, no detailed recommendations regarding physiotherapy in this group of patients have been developed to date. A series of publications presented in the doctoral dissertation concerns the analysis of factors that may increase participation of ALS patients in clinical trials in physiotherapy what may translate into the development of recommendations for the rehabilitation of ALS patients.

The aim of the work was:

1. the assessment of factors affecting the participation of ALS patients in a low-intensity physiotherapy program,
2. the correlation of physical activity after diagnosis with the functional status of patients with ALS at various stages of the disease.

In the first study, we analyzed factors influencing the enrollment and retention of ALS patients in low-intensity physiotherapy program. The study involved 104 patients hospitalized at the Department of Neurology, University Clinical Center of the Medical University of Warsaw, and the out-patient clinic. Beside an analysis of demographic (age, sex) and clinical factors (location of disease onset, time from symptom onset to the diagnosis, disease duration), at quarterly follow-up visits we assessed the body mass index (BMI), the muscle strength using Medical Research Council scale (MRC) and hand-held dynamometer (HHD), the functional status using the Amyotrophic Lateral Sclerosis Functional Scale-revised (ALSFRS-R) and functional tests: a Two-Minute Walk Test (2MWT), a Trunk Control Test (TCT), a Frenchay Arm Test (FAT), a Time Up and Go (TUG) and a Five Stand Up Test from a chair (5 Five Sit to Stand, 5STS). Based on research conducted in a group of patients clinically and demographically representative of the general population of ALS patients, we found that the main factors that affected the decision to participate or resign from participation in studies on physiotherapy in ALS included a long commute to the clinical center, a rapid disease progression and a lack of interest. The ALSFRS-R scale and the assessment of muscle strength using the MRC scale and a hand dynamometer have been shown to be effective tools for monitoring changes in the functional status of patients over time. The study showed that the factors influencing the enrollment of patients in the study were the male gender, younger age and a better functional status, while the factors

influencing the retention of patients in the prospective study – the male gender, better functional status and a greater muscle strength during qualification.

The second study concerned the analysis of the frequency and pattern of physical activity among patients with ALS (n=96), their attitude to activity and the impact of regularly performed exercises at home on functional status. On the basis of the physical activity survey and the assessment of the functional status using the ALSFRS-R and the assessment of muscle strength (MRC and HHD), we obtained information on the patients' daily physical activity. Patients were assessed at three-month intervals. During the initial visit, we showed that over 70% of patients undertook regular physical activity after the diagnosis, of whom 2/3 exercised daily. The predominant position of patients during the day was related to muscle strength and functional status, but did not determine the frequency of exercise. In fact, the results of the survey at the initial visit showed a higher proportion of patients engaging in exercise among those who were more likely to take horizontal position during the day as compared to those who were sedentary or in motion. Regular physical exercise was perceived by patients as having a positive effect on the functional status (74%) and mood (79%). Interestingly, the long-term results of the study showed that the bulbar onset of the disease was a negative prognostic factor for undertaking physical activity by patients in subsequent periods of the disease. There was a correlation between the exercise duration and the functional status and muscle strength. Based on the analysis of the results during three consecutive visits, we have shown that regular physical activity is associated with a slower disease progression in the respiratory subscale of the ALSFRS-R.

Based on the conducted research, the following conclusions were drawn:

1. Younger age, male sex and a better functional status determine the participation of ALS patients in the study on the impact of low-intensity physiotherapy. Male sex, a better functional status and a greater muscle strength determine the patients' retention in the study.
2. The majority of patients with ALS declare regular physical activity regardless of their functional status. The bulbar disease onset is an unfavorable prognostic factor for undertaking physical activity in the course of the disease. The amount of time devoted to physical exercise correlates with functional status and muscle strength. A positively perceived physical activity is associated in a long term with a better respiratory efficiency, but not with general functional status and higher muscle strength.