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The role of an occupational therapist in working with people with MS in the opinion of patients

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Original article

Abstract

Introduction: A person suffering from multiple sclerosis needs the care of numerous specialists, starting with the care of a doctor and a physiotherapist, and ending with an occupational therapist. Therefore, the purpose of the study was to assess the role of an occupational therapist in working with people with MS in the opinion of patients.

Material and methods: 108 persons with multiple sclerosis aged 24 to 71 (average age 41.8 ±11.1) participated in the study. The research tool was the author's questionnaire consisting of 28 questions regarding the disease and the cooperation with an occupational therapist. The results were developed using descriptive statistics, which included the arithmetic mean, standard deviation, minimum value and maximum value. For statistical analysis, the R software was used, and all analyses were performed with the Chi-squared test and the Fisher's exact test with the Monte Carlo simulation method.

Results and conclusions: During the exacerbation of the disease, the respondents had the greatest difficulty in getting dressed and getting out of bed or chair. The least problematic issue for the respondents was the continuation of their favourite activities, hobbies. Among the respondents, most of persons who regularly attended rehabilitation cooperated with an occupational therapist. Most of the respondents participated in occupational therapy held in a rehabilitation centre and indicated modifications of daily performed activities as a therapeutic intervention. In the group under study, most persons would like to cooperate with an occupational therapist individually at home. Among these persons, most would expect to develop alternative methods of performing important but difficult activities and to introduce auxiliary equipment during the exacerbation of the disease.

Keywords

- occupational therapist
- multiple sclerosis

Contribution

A – the preparation of the research project
B – the assembly of data for the research undertaken
C – the conducting of statistical analysis
D – interpretation of results
E – manuscript preparation
F – literature review
G – revising the manuscript

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Introduction

Multiple sclerosis (MS) is the most common inflammatory and demyelinating disease of the central nervous system. A characteristic feature is its progressive course, with periods of remission and exacerbations, leading to multifocal damage to the central nervous system.[1–3] Although this disease occurs in numerous forms and has very diverse symptoms, their common feature is the constantly deteriorating patient's general condition as well as numerous motor problems significantly reducing the level of functioning in everyday life and the quality of life of the patient. Multiple sclerosis is associated with the occurrence of pain and leads to reduced physical activity, associated not only with moving outside or within the home, but also with self-care activities. The illness also has a negative impact on family and social relations, often limiting the possibility of paid employment. In its course, a limitation of the patient's independence takes place quite quickly; also, often the sexual problems occur, which lead to intimate interference and may deepen the low self-esteem of such person.[4–8] Patients are affected by the impairment of cognitive functions, the pace of transfer of the information and completion of the given task, abstract reasoning, as well as fatigue occurring even after a minor effort, often coexisting with depression.[9–12]

A person suffering from multiple sclerosis needs the care of numerous specialists, starting with the care of a doctor and a physiotherapist, and ending with an occupational therapist. Occupational therapy, as one of the medical branches, is a significant part of the rehabilitation of patients with multiple sclerosis, and its task is to provide the patient with the opportunity to achieve independence, both in terms of self-care activities and in functioning in the family and social environment.[13–15] The role of occupational therapy for people suffering from multiple sclerosis focuses on intervention in the field of everyday activities related to self-care activities and social life. Occupational therapist can help in dealing with fatigue, cognitive symptoms, as well as he / she have an impact on issues related to leisure activities and spending free time. Therapeutic intervention often focuses on educating the patient and his/her family about the disease, the possibilities of institutional and technological support (e.g. use of available auxiliary equipment), or modifications of activities that are important for the patient. Occupational therapist motivates to work effectively and to overcome environmental barriers, he/she accompanies the patient, but does not relieve him / her.[16]

Occupational therapy should also consist an addition to physiotherapy. Occupational therapist can try to improve the coordination, mental state of the patient, reduce muscle tension and counteract contractures and motor limitations. Occupational therapist can also support the development of substitute activities when irreversible changes occur, as well as strengthen proper movement patterns.[17–19]

The role of occupational therapy for patients with multiple sclerosis can be considered in physical and mental terms. Occupational therapist improves the quality of life, enhancing the independence of patients suffering from multiple sclerosis.[13,16,17]

Therefore, the purpose of the study was to assess the role of an occupational therapist in working with people with MS in the opinion of patients.

Materials and methodology

Respondents characteristics

108 persons with MS participated in the study, including 60 women (56%) and 48 men (44%). The oldest respondent was 71 years old, the youngest 24 years old (Table 1).

Table 1. Age distribution of the persons surveyed

Characteristics	Women			
	$\bar{x}$	SD	Min	Max
Age (years)	40.9	10.8	24	64
	Men			
Age (years)	42.9	11.4	26	71
	Whole group			
Age (years)	41.8	11.1	24	71

The largest number of respondents (43 persons, 40%) indicated their place of residence as a city over 500 thousand residents, while the least (12 persons, 11%) indicated the city from 50 thousand up to 150 thousand residents. Other respondents live in the village (22 persons, 20%), towns up to 50 thousand residents (13 persons, 12%,) and cities from 150 to 500 thousand residents (18 persons, 17%).

The collected data on the of time since the diagnosis of the disease were as follows: the largest number of respondents, as many as 43 persons (40%) indicated that the diagnosis took place from 5 to 10 years ago,

42 respondents (39%) was diagnosed over 10 years ago. The least, 23 respondents (21%) stated that the diagnosis took place up to 5 years ago.

The largest percentage of respondents – 72 persons (67%) indicated that they suffer the relapsing-remitting form of the disease, 22 respondents (20%) answered that they suffer from the originally progressive form of multiple sclerosis, while 14 persons (13%) indicated that it is a secondary progressive form.

Research method

The research method was a diagnostic survey, and the selected technique was a survey. The research tool was an author's questionnaire consisting of 28 questions, including: personal information, which included basic social and demographic data (3 questions), 18 closed questions, 3 half-open questions and 4 filtering questions. The research was carried out using an online form questionnaire.

The results were developed using descriptive statistics, which included the arithmetic mean, standard deviation, minimum value and maximum value. For statistical analysis, the R software was used, and all analyses were performed with the Chi-squared test and the Fisher's exact test with the Monte Carlo simulation method. The level of significance of $p \leq 0.05$ was assumed.

Results

Descriptive statistics

The respondents were asked which activities of everyday life make it difficult for them at the time when the disease is in exacerbation phase (the respondents could choose more than one answer). Majority, i.e. 66 persons, indicated that the most problematic activity is getting out of bed / chair and getting dressed (Table 2).

Table 2. Activities which cause difficulties for the respondents during exacerbation of the disease

Activity	Answers	
	N	%
Preparation of food	52	9.2
Personal hygiene	47	8.3
Dressing	65	11.5
Moving to your place of residence	53	9.3
Getting out of bed/chair	66	11.6
Maintaining a household	49	8.6
Using public transport	46	8.1
Leaving the house	57	10.1
Shopping	46	8.1
Paid employment	45	7.9
Favourite leisure activities/hobbies	37	6.5
Other	4	0.7

The respondents also answered questions concerning their rehabilitation. The vast majority of respondents (75 persons, 69%) participated in rehabilitation, and 33 persons (31%) declared that they had not undertaken rehabilitation yet.

Another group of questions was addressed to people who participated in rehabilitation (75 persons), and the questions concerned the potential cooperation with an occupational therapist. Among the persons under rehabilitation 44 (59%) persons indicated that the occupational therapist participated in the rehabilitation process, the remaining 31 persons (41%) had no contact with such a specialist. The respondents who had contact with the occupational therapist answered additional multiple choice questions regarding the place in which they worked with the occupational therapist and the type of cooperation (Table 3).

The next question concerned the whole group of respondents (108 persons). The respondents were asked to indicate what, in their opinion, the cooperation with the occupational therapist looks like now and what they

Table 3. Cooperation with an occupational therapist

Question	Answers		
		N	%
Where was cooperation with an occupational therapist established?	Foundation	10	13
	Rehabilitation centre	34	45
	The clinic where the rehabilitation is carried out	3	4
	Patient home	7	9

Question	Answers		
		N	%
What cooperation with an occupational therapist consisted of?	Modification of daily activities	25	33
	Advice on institutional assistance	11	14
	Assistance in adapting the place of residence	5	6
	Selection of auxiliary equipment	17	22
	Art therapy activities	21	28

think it should look like. The majority, 58 respondents (54%) stated that currently it is work in a group of patients, but hardly less, 50 persons (46%), indicated individual work with a patient. In the case of opinions on what such cooperation should look like, the vast majority, as many as 84 respondents (78%) stated that it should be individual work with the patient, and only 24 persons (22%) considered that it could be group work.

Patients were also asked about their expectations concerning an occupational therapist. According to the vast majority of respondents (98 persons, 91%), an occupational therapist could help in the process of rehabilitation of patients with MS; only 10 persons (9%) holds that an occupational therapist could not help in this regard. Also, the vast majority of respondents (88 persons, 96%) considered that an occupational therapist could help in achieving greater independence in performing everyday activities during the time of exacerbation phase of the disease. Only 20 persons (4%) considered that they would not receive such support from an occupational therapist.

Respondents also commented on the people with whom the occupational therapist should cooperate. In this question, the respondents could choose more than one answer (Table 4).

Table 4. Cooperation of the occupational therapist with other people and specialists

Question	Answers		
		N	%
Who should the occupational therapist cooperate with when being involved in the rehabilitation of a person suffering from MS?	With the patient	92	34.1
	With the attending physician	60	22.2
	With a physiotherapist	69	25.5
	With the patient's family and friends	49	18.1

Table 5. The scope and place of cooperation of the occupational therapist with the patient

Question	Answers		
		N	%
To what extent could an occupational therapist help persons suffering from MS?	Sociotherapy	14	17
	Art therapy activities	22	27
	Advice on institutional assistance	32	39
	Education of the patient's family	*50*	*61*
	Assistance in adapting the apartment	*34*	*41*
	Development of alternative ways of performing important yet difficult activities	*62*	*76*
	Selection of auxiliary equipment	60	74

Question	Answers		
		N	%
Where could cooperation with an occupational therapist take place?	In Occupational Therapy Workshop	10	12
	In the foundation with which the patient is associated	12	14
	In a rehabilitation centre	38	46
	In the clinic where the rehabilitation is carried out	23	28
	Individually at home	77	95

The next question concerned the willingness to cooperate with an occupational therapist. As many as 81 respondents (75%) replied that they would like to cooperate, while 27 persons (25%) replied "no". Respondents who answered "yes" were asked to indicate to what extent they would expect to get help from an occupational therapist and also to indicate the place where, in their opinion, cooperation with an occupational therapist should take place (Table 5).

Statistical analysis

The dependencies between the selected variables were examined. The willingness to cooperate with an occupational therapist was analysed, as well as the expected scope of assistance from an occupational therapist and the gender of the respondents. In both cases, the significance level was higher than assumed, i.e. there was no relationship between the studied variables and the gender of the respondents (Table 6).

Another analysis concerned the relationship between the time of the disease and the participation of the occupational therapist in the rehabilitation process, the relationship between the type of activity causing difficulty and the willingness to cooperate with the occupational therapist, as well as between the place of cooperation with the occupational therapist and the type of this cooperation. Only in the case of the last pair of variables, a statistically significant relationship was obtained (Table 6).

Table 6. Relationships between various aspects of cooperation between patients with MS and occupational therapist

Variables		*p*
Gender	Willingness to cooperate with an occupational therapist	0.8231
	Expected scope of assistance from an occupational therapist	0.9631
Time of disease	Participation of an occupational therapist in the rehabilitation process	0.08481
Activities that make difficulties	Willingness to cooperate with an occupational therapist	0.997
Place of cooperation with an occupational therapist	Type of cooperation with an occupational therapist	**0.02999**

Discussion

Multiple sclerosis is a progressive, chronic central nervous system disease. It is estimated that in Poland, the incidence of the disease is 37–91 cases per 100,000 inhabitants.[20] It affects people of the so-called working age, 20–40 years old, women suffer from this disease more often.[7,21] In the study by Brole et al., the ratio of women to men is 68% to 32%.[22] This is confirmed by the results of our own research, in which 56% were women and their average age was about 40 years. Similar results in their research on the assessment of the quality of life of patients with multiple sclerosis were noted by Stachowska et al.,[7] in which the largest group consisted of women between 21 and 65 years of age, with the average age of women being 41 years.

MS is a disease whose clinical picture is heterogeneous. It has various courses, with the most commonly diagnosed form being the relapsing-remitting.[22] In our own research, the majority (67%) had such a form. Similar results were obtained by Stachowska et al.,[7] in which out of 75 respondents, 48% of respondents described the form of multiple sclerosis as relapsing-remitting.

The analysis of the research conducted by Jeżuchowska[23] indicates that persons suffering from multiple sclerosis have a worse assessment of their quality of life, especially physical and emotional functioning. Przychodzka et al.,[4] conducted a study in which the

respondents suffering from multiple sclerosis assessed the efficiency related to self-service, family life and professional work. The results showed that 32% of respondents indicated minimum limitations in the area of personal hygiene and dressing, while hardly less, 31% replied that they have no limitations. When assessing food and drink, more than half of the respondents indicated no limitations in performing this activity, while the preparation of meals by 23 persons was not difficult; however, 16 respondents indicated significant limitations in this activity. In moving outside the place of residence, 41% of the respondents indicated significant limitations. Similarly, in own research, where 11.5% of respondents indicated difficulties in dressing, and 8.3% of respondents reported a problem with activities connected with personal hygiene. Also, the preparation of food was difficult for 9.2% of the respondents. In the case of own research (namely urban transport), 8.1% of respondents indicated the difficulty in moving outside home. In their research, Karakiewicz et al.,[24] showed the dependency that the older the age, the worse the quality of life of patients with multiple sclerosis. With age, there are more limitations in the physical sphere; therefore the self-care as well as the emotional state deteriorates. It can be assumed that the limitations of persons suffering from multiple sclerosis result from the progressive nature of the disease, and thus, the deepening of disability. They are also related to relapses, i.e. exacerbations of the disease, during which the patient's capabilities are even more limited. Deepening disability, which creates difficulties in the field of self-care, in social life or the issue of paid employment, also leads to deterioration of mental state.[24,25] Therefore, in the case of MS patients, comprehensive rehabilitation is so significant, which includes cooperation with a doctor, physiotherapist, psychologist, speech therapist and occupational therapist. According to the research conducted by Finlayson et al. in the United States,[16] more than half of the respondents suffering from multiple sclerosis did not use the services of an occupational therapist. On the other hand, it was noted in own research, where 59% of respondents regularly attending rehabilitation cooperated with an occupational therapist. Finlayson et al.[16] also show that people who used the services of an occupational therapist were satisfied with the results of the therapy. They used the opportunity to help in everyday activities, social life, as well as adaptation of the place pf residence. In their own research, 33% of the respondents who cooperated with an occupational therapist indicated that they used assistance in modifying everyday activities, which were important yet difficult to perform. Likewise, numerous respondents in this group benefited from the advantages of auxiliary equipment. Fewest number of the respondents had the opportunity to use the adaptation of the apartment.

The role of occupational therapy in the rehabilitation of people suffering from multiple sclerosis focuses on intervention in the area of daily activities related to self-care, social life, as well as leisure activities and spending free time. During the therapeutic process, an occupational therapist improves the quality of life of patients, supports their return to independence.[16]

Occupational therapists also introduce psychosocial and professional interventions to improve the sense of self-efficacy as well as help to reduce the sense of loneliness of people suffering from disease.[26,27] Cognitive interventions based on improving concentration of attention and memory take place in order to maintain daily tasks,[28] meal preparation and financial management.[29] These therapies also improve the quality of life of patients with multiple sclerosis.[28,29,30]

The therapist can also educate the patient and his/her family in the matters concerning the possibility of institutional assistance, the use of available auxiliary equipment. The task of an occupational therapist is also to motivate the patient to overcome barriers and work effectively during therapy.[16]

Conclusions

Results and conclusions: During the exacerbation of the disease, the respondents had the greatest difficulty in getting dressed and getting out of bed or chair. The least problematic issue for the respondents was the continuation of their favourite activities, hobbies.

Among the respondents, most of persons who regularly attended rehabilitation cooperated with an occupational therapist. Most of the respondents participated in occupational therapy held in a rehabilitation centre and indicated modifications of daily performed activities as a therapeutic intervention.

In the group of respondents, the majority of respondents believed that nowadays the occupational therapy takes the form of group classes. The vast majority of respondents believed that the therapeutic process should take place individually.

In the group under study, most persons would like to cooperate with an occupational therapist individually at home. Among these persons, most would expect to develop alternative methods of performing important but difficult activities and to introduce auxiliary equipment during the exacerbation of the disease.

The place of cooperation of the occupational therapist with patients with MS definitely affects the type of this cooperation.

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