

Socioeconomic Status of MS Patients in the Podkarpackie Voivodship — a Pilot Study

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Abstract

Multiple Sclerosis (MS) is a chronic disease of the nervous system. There are approximately 2 million people suffering from MS worldwide. Poland belongs to the countries with high MS incidence and presently the estimated number is 60 000. The neurologic deficiencies occurring in result of the disease have a negative impact on many aspects of life, including professional life. The aim of the study was to evaluate the socioeconomic status of the MS patients in the Podkarpackie Voivodship. The study covered 25 MS cases from the Podkarpackie Voivodship. In all cases, MS was diagnosed by a specialist. A survey consisting of 40 single-choice questions was designed for the purposes of the study. The analysis of the data obtained from the survey indicated that the majority of the MS patients are professionally inactive which has a negative impact on their economic status. The ability to work and perform ADLs decreases in patients aged 40 or more. The self-service functions and the abilities to perform housework also deteriorate with time. The patients require assistance and care from others.

Keywords: multiple sclerosis (MS), professional activity, socioeconomic status

Introduction

Multiple Sclerosis (MS) is a chronic disease of the nervous system occurring mainly in adults. The disease slightly prevails in women. There are approximately 2 million people suffering from MS worldwide. Poland is among the countries with a high MS rate presently estimated number at 60 000 patients. Although the course of the disease differs from patient to patient, a number of common features can be distinguished. MS is an incurable disease, and therefore the available treatment may only help reduce disease activity and progression (Belniak and Bartosik-Psujek 2010, 7–30).

The symptoms, severity, and course of MS vary widely among different patients. Some symptoms may diminish, yet new ones may occur. The disease most frequently is manifested by: paresthesia, numbness, walking and balance disorders, loss of sight, eye pain, double vision, optic neuritis, weakened muscle strength, disturbed sensation, pain, cerebellar disorders, fatigue syndrome,

urinary and fecal dysfunction, sexual dysfunction, cognitive and psychopathological disorders, ataxic dysarthria, lack of abdominal reflexes, or spastic paraparesis of the lower limbs (Kozubski and Liberski 2014, 503–507). In the majority of cases the disease leads to severe disability and the additional problems occurring in MS include low self-esteem, fear, depression, cognitive dysfunctions, concentration problems, stress and a lack of ability to deal with these symptoms. These all significantly influence both professional and personal life (Woszczak 2005) for the patient.

MS is an incurable disease and that is why the available treatment may only help to reduce its severity. Some pharmaceuticals modify the course of the disease so that the progress is slowed down. Other medications shorten the length and the severity of the episodes. Patients may additionally improve the quality of life through physical activity, physiotherapy, massage, stress-reducing techniques, and diet. The ability to remain professionally active is also highly beneficial (Groetzinger 2009, 14).

From the patient's perspective, this ability of great significance, yet in 40% of cases, it becomes impossible to work during the first 5 years after the appearance of the disease. Nevertheless, there are cases of patients who still remain professionally active after 20 years. The patients who do not work should be 100% included in activities of daily living (ADLs). The family should be instructed to let the patients perform their duties by themselves which will aid them in remaining active. The ability to participate in family and social life along with the support and the participation in self-help groups constitute an important part of treatment. Patients should be introduced to new, but manageable ways of spending their free time. New interests can include music, politics, films or books. Feelings of stress, pressure and chaos have a negative influence on the progress of the disease (Ugniewska 1998, 355–356).

The available literature does not sufficiently explore the problems of the socioeconomic status of the MS patients.

1 The aim of study

The aim of the study was to evaluate the socioeconomic status of MS patients in the Podkarpackie Voivodship.

2 Material and method

The study included 25 Multiple Sclerosis (MS) patients from the Podkarpackie Voivodship. In all 25 cases of MS were diagnosed by a specialist. The study included 16 women and 9 men with the average age of 43,6; the women averaged age 47 and the men 37. Statistical analysis indicated that the women from the study group were significantly older than the men ($p = 0,02$). Nevertheless, the study group did not significantly differ in respect to education, place of residence or the degree of disability (respectively $p = 0,58$; $p = 0,09$, and $p = 0,82$).

Tab. 1. Characteristics of the study group

	Total	Woman	Man	<i>p</i>
Gender	25	16	9	n/a
Age (mean±standard deviation).	43,6±10,9	47,0±10,9	37,4±8,2	0,02
Education (elementary/vocational/high school/university)	1/10/8/6	0/7/5/4	1/3/3/2	0,58
Place of residence (country/city)	14/11	11/5	3/6	0,09
Degree of disability (slight/moderate/significant)	6/15/4	4/10/2	2/5/2	0,82

Note: In the journal (in both Polish and English texts) European practice of number notation is followed—for example, 36 333,33 (European style) = 36 333.33 (Canadian style) = 36,333.33 (US and British style). Furthermore in the International System of Units (SI units), fixed spaces rather than commas are used to mark off groups of three digits, both to the left and to the right of the decimal point.—Ed.]

In order to evaluate the socioeconomic status, each patient completed a survey created for the need of the study. The survey consisted of 40 numbered, single choice questions. The statistical analysis of the results was conducted with the use of the Microsoft Excel Calculator Program whereas the Chi-squared test and the Student's t-test were exploited for the assessment of the significant differences occurring between the included features in the study group. The $\alpha = 0,05$ was adopted as the significance level.

3 Results

Among all patients from the study group originating in the Podkarpackie Voivodship, only 12% were completely unable to work and live independently. 44% of the patients were partially unable to work, and 44% were unable to work. The statistical analysis indicated the occurrence of significant correlation between the ability to work and gender ($p = 0,99$).

Statistical analysis indicated significantly more frequent professional inactivity in women than men. This inactivity resulted in a worse economic situation ($p = 0,02$). Almost 90% of the surveyed women and 44% of the surveyed men did not work. In the subgroup of the professionally inactive patients, only 10% were registered in the unemployment bureau, and willing to find a job.

Tab. 2. Patients by inability to work level and gender

Inability to work level	Woman		Man		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Inability to work and live independently	2	13	1	11	0,99
Inability to work.	7	44	4	44	
Partial inability to work	7	44	4	44	
Total	16	100	9	100	

Tab. 3. Patients by professional activity an gender

Professional activity	Woman		Man		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Inactive	14	88	4	44	0,02
Active.	2	13	5	56	
Total	16	100	9	100	

The data analysis reflected the presence of a direct correlation of the ability to work and age. Patients aged 40 and more presented a substantially worse ability to work and constituted twice the number ($p = 0, 01$) in comparison with younger patients. What is more, in the group of older patients, those unable to work constituted triple the number, and the number of those partially unable to work was 5 times as high when compared to the patients younger than 40.

The statistical analysis showed considerably more frequent professional inactivity in MS patients aged 40 and more ($p = 0,001$). None of the respondents aged more than 40 worked. In the group of respondents younger than 40, 42% were professionally inactive.

The analysis of the obtained data indicated a significantly greater need for assistance in ADLs in the patients aged 40 and over when juxtaposed with the younger respondents ($p = 0,001$). More than 90% of the patients aged less than 40 did not require assistance in ADLs. In the group of respondents aged 40 and more, the need for help was declared by almost $\frac{1}{4}$, and more than 60% asserted the need for partial assistance in ADLs.

The statistical analysis of the data signaled the occurrence of a meaningfully greater need for assistance in ADLs in patients suffering from MS for longer than 10 years ($p = 0,01$). Approximately 75% of respondents suffering from MS for less than 10 years did not require help in ADLs. In those suffering from MS for longer than 10 years, $\frac{1}{3}$ stated the need for assistance and 56% indicated the need for partial assistance in ADLs.

Tab. 4. Patients by inability to work level and age (in years)

Inability to work level	< 40		> 40		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Inability to work and live independently	1	8	2	15	0,01
Inability to work	2	17	9	69	
Partial inability to work	9	75	2	15	
Total	12	100	13	100	

Tab. 5. Patients by professional activity an age (in years)

Professional activity	< 40		> 40		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Inactive	5	42	13	100	0,001
Active	7	58	0	0	
Total	12	100	13	100	

Tab. 6. Patients by the need for assistance in ADLs and age (in years)

The need of assistance	< 40		> 40		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Yes	1	8	3	23	0,001
Partial	0	0	8	62	
No	11	92	2	15	
Total	12	100	13	100	

Tab. 7. Patients by the need of assistance in ADLs and duration of the disease (in years)

The need of assistance	< 10		> 10		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Yes	1	6	3	33	0,01
Partial	3	19	5	56	
No	12	75	1	11	
Total	16	100	9	100	

4 Discussion

According to the Polish MS Association, in Poland there are approximately 60 000 patients diagnosed with MS. Annually, from 400 to 450 new cases are diagnosed, mainly in young, professionally active people or those still getting their education. Some MS patients decide to leave work by themselves, but in the majority of cases they are dismissed. The reason for this situation is their worsening condition, tendency to become fatigued and lack of motivation in fulfilling their duties. MS patients are not recommended to perform activities requiring much strength, exposure to extreme temperatures or much responsibility (Cendrowski 1986, 240). It is noteworthy, however, that staying professionally active for as long as possible is of advantage and is a necessary treatment recommendation. Professional activity occupies the patients, restores the feeling of independence and increases their income (Forsythe 1986, 81). Employers should consider transferring them to different and suitable positions. Unfortunately, this mainly applies to younger patients with rare relapses. In the case of student patients, a medical certificate may facilitate the participation in extramural courses (Cendrowski 1986, 240).

Very frequently, after the diagnosis has been stated the patients question the need to remain professionally active. Nevertheless, it must be remembered that from the point of view of personal and not financial satisfaction, it is very important to stay professionally active. It increases the feelings of self-esteem and belonging to society, thus the quality of life is perceived as better (Miller 2006). What is regrettable is that the research conducted by our team indicates that the MS patients in the Podkarpackie Voivodship are mainly professionally inactive which is even more strongly apparent among patients aged 40 or more. Our data also shows that the professional activity decreases as the duration of the disease increases.

An MS patient should remember that the fact that the disease has been diagnosed does cause a deterioration of his/her qualities as an employee and none of the previously acquired skills are being lost. Employers often find it difficult to deal with the information that an employee suffers from MS. Typically, this is caused by insufficient information and misconceptions concerning MS among society at-large. Employers usually fear the costs related to the employment of a person suffering from MS. In reality, an MS employee does not require any particular conveniences. An employee—employer discussion concerning fears and needs is of great value.

In addition to professional activity, participation in ADLs is extremely important. MS may significantly affect the performance of housework requiring more strength than the MS patient is able to demonstrate. In the case of relapses and prolonged disability, activities may become limited to planning and coordination of housework. In situations like these, relatives and friends may be very supportive (Benz 2004, 47–51).

The data acquired indicated that the self-service functions and the ability to perform housework deteriorate together with the duration of the disease. The social aspect relates to interpersonal relations, that is—relations within the family, friends and people from other social groups. The occurrence of MS does not cause exclusion from society yet the majority of MS patients experience a deterioration in the quality of social life. The main reason for such a situation is not the physical condition or the motoric dysfunctions but the lack of long term planning concerning life itself and the performance of ADLs. The adjustment to the new situation is very challenging for MS patients, especially when the disease mainly affects young and active people who have had plans and expectations concerning their future family and professional lives (Szafraniec and Czernicki 1998).

MS is typically diagnosed in patients aged between 20 and 40. For every individual, this is the period to enter life in full. The patients still study, start a family, or begin to work. In the cases of proper MS treatment life-span is not affected. Nevertheless, both the life of the patient and the family is influenced by the symptoms and the necessity to struggle with them. The unpredictability of the course of the disease makes some plans impossible (Ochojska 2000).

The loss of physical fitness significantly decreases self-esteem. Consequently, the patient does not feel like an equal member of the family or company. Focusing on self-honesty and abilities, and not the unknown of the future, facilitate the battle with MS (Czarnecka 2007).

Further research will take into account a larger study group in respect of the degree of disability and the duration of the disease.

Conclusions

The majority of the examined MS patients are professionally inactive which has a negative impact on their economic status. In the studied population of MS patients aged 40 and more, the ability to work and perform ADLs deteriorates. The duration of the disease affects the self-service functions and the abilities to perform housework. Patients suffering from MS for a longer period are more likely to require assistance and care from others.

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