



New insights into the socio-economic aspects of multiple sclerosis in a cohort of Polish patients

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Abstract

Introduction and objective. The diagnosis of multiple sclerosis (MS) affects the socio-economic aspects of patients' lives and poses new challenges. The objectives of the study were: 1) to determine selected socio-economic aspects of MS in Poland in relation to the disease type and patients' place of residence, and 2) to evaluate the profile of patients via the MS Society (MSS) and the occupational consequences of informing an employer about the diagnosis.

Materials and method. A retrospective, observational study was undertaken to assess a cohort of 375 Polish MS patients. Socio-economic data was collected based on the patients' responses to questions on a questionnaire. Clinical data was obtained from available medical records.

Results. Patients with relapsing-remitting MS had a significantly longer time of occupational activity, higher economic status, higher level of education, better relationships with life partner, less likely to benefit from disability benefits, and members of MSS, than patients with progressive types of the disease. The patients living in rural areas had a significantly shorter time of occupational activity, more often experienced a decrease in income, received disability pension, and were less educated than urban residents. Patients who informed their employer about an MS diagnosis significantly more often received support from the company, were professionally active for longer, and less likely to experience a decrease in income. Membership of the MSS were dominated by patients with progressive variants of the disease and advanced disability.

Conclusions. The disease variant and, to a lesser extent, the place of residence, affected the socio-economic aspects of MS. It might be advantageous for the patient to disclose information about MS diagnosis to the employer.

Key words

diagnosis, Poland, multiple sclerosis, socio-economic, rural, urban, inequalities

INTRODUCTION

Multiple sclerosis (MS) is the main non-traumatic cause of disability among young adults. The disease onset between 20 and 40 years of age results in the largest number of patients with MS being aged from 35–64 years. Thus, the disease has an adverse impact on the daily lives of patients during their potentially greatest time of social and professional activity [1, 2, 3]. Socio-economic position is a widely accepted predictor of physical health in many societies [4, 5]. Recent studies have confirmed that adverse socio-economic status is negatively associated with disability in MS patients, and its routine assessment may be useful in determining severity of the disease [6, 7, 8]. Compared to healthy peers, those with MS have a higher probability of deteriorating relationships with their life partner, more often experience a decrease in salary, and prematurely terminate occupational activity, compared to healthy peers [9, 10, 11, 12].

However, the economic consequences of MS differ between regions of the world and depend upon their degree of industrialization [13]. Additionally, even within the same

country, there are huge social and economic disparities between residents of rural and urban areas. In general, compared to urban residents, rural inhabitants are more likely to have a lower self-assessment of state of health conditions, less access to health services, and are more often unemployed, less educated and more likely to use social benefits [5, 14, 15, 16, 17].

There is little data on the impact of MS variants and patients' place of residence on the socio-economic aspects of MS in Poland. Furthermore, the diagnosis of MS places new challenges on patients' social and economic functioning. To date, the benefits of informing an employer about the diagnosis and the profile of patients who are members of the MS society (MSS) have not been assessed.

OBJECTIVE

The aim of this study was to determine selected socio-economic implications of MS in Poland in relation to the disease type and patients' place of residence, as well as to evaluate the profile of patients in the MS, and occupational consequences of informing an employer about the diagnosis.

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MATERIALS AND METHOD

The study was approved by the Committee of Bioethics of the Ludwik Rydygier Collegium Medicum (KB 473/2014). All patients gave their informed consent to having their data stored in the database.

Patient enrolment and clinical evaluation. A retrospective, observational study was conducted to assess a cohort of 375 Polish MS patients hospitalized at the Neurology Department in northern Poland between 30 June 2014 – 31 October 2016. Eligible patients fulfilled the diagnostic criteria of multiple sclerosis in force at the time of the diagnosis, were at least 18 years of age, and had at least 6 months of documented disease duration from the diagnosis. Socio-economic data were collected based on the patients' responses to questions on a questionnaire. The proprietary questionnaire developed for the purpose of this study contained questions concerning place of residence, size of household, marital status, impact of MS diagnosis on relationship with life partner and other family members, educational level, occupational activity, economic status, use of social benefits and participation in the MSS. With the developed set of questions asked by the researcher on each occasion, a uniform and repeatable evaluation of patients was possible. Clinical data was obtained by analysis of medical records from our database.

Clinical data. The onset of MS was the year of the onset of the first symptom. Depending on the time the diagnosis was established, the Poser's criteria, McDonald's criteria and Polman et al. revisions to the McDonald criteria were applied [18, 19, 20, 21]. The disease course was classified as relapsing–remitting (RRMS), secondary progressive (SPMS) or primary progressive (PPMS) [22, 23]. RRMS was defined as the presence of relapse followed by a partial or complete remission of symptoms, without disability progression between attacks. Relapse was defined as the occurrence of a new or deterioration of previously reported MS-related symptoms lasting over 24 hours, with the absence of fever or infection. SPMS was diagnosed after confirming the irreversible disability accrual for at least 6 months in patients with initial RRMS, regardless of the superimposed bouts [23, 24]. PPMS was defined as at least one-year irreversible deterioration of neurological deficits from the disease onset, with or without coexisting episodes of exacerbations [22, 25]. Patients' disability was assessed using the 10-point Kurtzke Expanded Disability Status Scale (EDSS) [26]. On the basis of this scale, patients with mild ($EDSS \leq 3.5$), moderate ($4.0 \leq EDSS \leq 5.5$) and severe ($EDSS \geq 6.0$) disability were distinguished.

Demographic and socio-economic parameters assessment. Concerning the patients' place of residence, a village, town (less than 50,000 inhabitants) and city (more than 50,000 inhabitants) were distinguished. The size of a household (number of members) was determined by taking into account only people who lived with patient for at least 6 months a year in the 2 years preceding the survey. The following categories were used to assess marital status: married, civil partnership, divorced, widowed and single. In the case of partnerships and marriages concluded prior to the diagnosis of MS, the impact of the disease on patient relations with a life partner was assessed. The impact of MS diagnosis on patient relationships

with the life partner and other family members was defined as improvement, worsening or no change. Patients were asked to indicate a person who was the main support in their daily life with the disease. The educational level of patients was classified as primary, vocational, secondary or higher. In the subgroup of patients with higher education, it was determined whether the diagnosis of MS was before or after graduation. Occupational status was defined as unemployed, employed before MS diagnosis, employed after MS diagnosis, never working, disability pension or retirement. Patients employed at the time of MS diagnosis were asked if they had informed their employer about the disease. In the case of subjects receiving a disability pension, the time from diagnosis to the application for this social benefit was determined. Economic status was determined based on the patients' opinion as high, average or low, without assessing the annual household income. In those who experienced a deterioration in financial situation, changed jobs or became unemployed since MS onset, the causes were established. Patients were asked about knowledge of existence as well as membership in the MSS in their area of residence. As active members were considered patients who participated in at least 50% of meetings of the MSS during the 6 months preceding the study.

Statistical analysis. The Shapiro-Wilk test was used to check the compatibility of the distribution of variables with the normal distribution. In the case of trials with a near-normal distribution, the arithmetic mean and standard deviation were calculated and the student's t-test for independent variables was used to compare the means. The homogeneity of variance was evaluated by the Levene test. When the distribution was significantly different from the normal distribution, the median was calculated, and the significance of the differences between the groups was checked using the non-parametric U Mann-Whitney test. Proportions in groups were evaluated using the chi-square test. The survival function was estimated using the Kaplan-Meier method to examine the relationship between time of patients' occupational activity and factors that may affect these relationships. A log-rank test was used to compare 2 survival curves. Statistical significance was assumed when $p=0.05$. Calculations were made using Statistica 12.1.

RESULTS

Clinical characteristics. The study group consisted of 260 women (69.3%) and 115 men (30.7%), mean age – 43.1 ± 12.5 years; mean age at disease onset – 32.3 ± 10.9 years; median disease duration – 9.0 years. Mean EDSS score at the time of the study – 3.7 ± 1.7 . Subgroups with mild, moderate and severe disability included 188 (50.1%), 120 (32.0%) and 67 (17.9%) subjects, respectively. The 214 (57.1%) patients were distributed into RRMS, 104 (27.7%) into SPMS and 57 (15.2%) into PPMS with respect to the disease course. In the study cohort, 125 patients (33.3%) used immunomodulatory drugs (IMDs): interferon-beta 1a, interferon-beta 1b, glatiramer acetate, and peginterferon. The median time from MS diagnosis to initiation of the IMDs was 1.0 year. Median duration of treatment – 3.0 years. Detailed clinical characteristics and disability outcomes of the study cohort have been presented in an earlier study [27].

Socio-economic assessment. Response rate to the questionnaire was 100%. The socio-economic data of the study cohort in relation to MS variant and patients' place of residence are presented in Tables 1 and 2. 119 (31.7%) respondents were rural inhabitants, 97 (25.9%) and 159 (42.4%) were urban inhabitants of towns and cities. The median number of family members in the patients' households was 3. At the time of the study, 322 patients were in a relationship with a life partner (mean duration – 18.7 ±12.5 years), 39 were single and 14 widowed. 277 (73.9%) patients were married and 45 (12%) were in a civil partnership. The duration of marriages and partnerships was 20.8 ±2.0 years and 5.5 ±5.9 years, respectively ($p < 0.0001$). In the majority of the assessed relationships (64.3%), the relations between patients and life partner did not change after the diagnosis of MS, an improvement was noted in 17.4% and deterioration in 18.3% of patients. Of the assessed parameters, only the duration of the disease significantly affected the patient's relationship with a life partner (Tab. 3). The variant of MS on a level of statistical tendency influenced the patient's relationship with a partner, and the impact of patients' residence on these relationships was not statistically significant (Tab. 1 and 2). Among the relationships of patients with a life partner concluded before the diagnosis of MS, the disease was reason for 25 (9%) breakdowns in marriage and 8 (17.8%) breakdowns in civil partnerships ($p = 0.0726$). In the study cohort, 32 marriages and 15 civil partnerships were concluded after the diagnosis of MS. Of these, 4 (12.5%) marriages and 3 (20.0%) partnerships broke down due to the disease. The median time from diagnosis to breakdown of these relationships was 2 years (marriages – 3 years, civil partnerships – 1 year) ($p < 0.0001$). In the majority of patients, relationships with other family members after diagnosis of MS did not change (70.7%); improvement was reported by 24.5% and deterioration by 4.8% of respondents. The sex

life of patients ($p = 0.3511$), MS variant ($p = 0.1885$) and place of residence ($p = 0.6061$) did not affect the relationships with family members other than the partner. Among the people indicated by patients as the main support in their daily life with MS were mentioned: life partner (46.7%), parents (21.9%), children (13.6%), no one (9.3%), friends (4.3%), siblings (3.7%) and a doctor (0.5%).

The educational level of respondents was significantly affected by their place of residence and MS variant. The highest percentage of subjects with higher education was recorded among urban dwellers and patients with RRMS (Tab. 1 and 2). 32 (23.9%) patients with higher education graduated from university after diagnosis of MS with the median time of 2 years.

In the study group, 169 (45.1%) patients had knowledge about the existence of an MSS in their areas of residence. Significantly more often they were inhabitants of urban rather than rural areas, as well as patients with progressive variants of MS (Tab. 1 and 2). Membership of an MSS was declared by 66 (17.6%) patients – 32 (27.8%) men and 34 (13.1%) women ($p = 0.0005$), as well as 17 (9.0%) respondents with mild, 28 (23.3%) with moderate and 21 (31.3%) with severe disability ($p < 0.0001$). The place of residence did not significantly affect a patients' membership of the MSS (Tab. 2).

At the time of the disease onset, 330 (88%) respondents were professionally active. At the time of MS diagnosis, 324 (86.4%) patients worked and 35 (9.3%) were self-employed. Of the 289 patients employed at the time of MS diagnosis, 184 (63.7%) informed their employer about their condition. Among these patients, the vast majority (81.5%) received support from the company. At the time of the survey, the percentage of working and non-working patients was comparable (50.4% vs. 49.6%). In the study cohort, the median time from disease onset to the end of patients' occupational activity was 4 years, with no

Table 1. Clinical and socio-economic characteristics of patients according to MS variant

Type of parameter	Total	RRMS	SPMS	PPMS	p-value
Median duration of the disease (range), years	9.0 (0.5-44)	6.0 (0.5-42)	15.0 (1-44)	8.5 (1-38)	<0.0001
Mean EDSS score (median)	3.7 ±1.7 (3.5)	2.6 ±1.0 (2.5)	5.3 ±1.1 (5.0)	5.3 ±1.3 (5.5)	<0.0001
Educational level N(%)					
Primary	14 (3.7%)	8 (57,1%)	4 (28,6%)	2 (14,3%)	<0.0001
Vocational	85 (22.7%)	31 (36,5%)	36 (42,4%)	18 (21,2%)	
Secondary	142 (37.9%)	77 (54,2%)	39 (27,5%)	26 (18,3%)	
Higher	134 (35.7%)	98 (73,1%)	25 (18,7%)	11 (8,2%)	
Relationship with life partner after MS diagnosis					
Improvement	56 (17.4%)	37 (20.4%)	12 (13.0%)	7 (14.3%)	0.0555
Deterioration	59 (18.3%)	24 (13.3%)	25 (27.2%)	10 (20.4%)	
No change	207 (64.3%)	120 (66.3%)	55 (59.8%)	32 (65.3%)	
Economic status					
High	149 (39.7%)	106 (49.5%)	30 (28.8%)	13 (22.8%)	0.0002
Average	203 (54.2%)	99 (46.3%)	66 (63.5%)	38 (66.7%)	
Low	23 (6.1%)	9 (4.2%)	8 (7.7%)	6 (10.5%)	
Occupational activity N(%)					
Unemployed	164 (43.7%)	49 (22.9%)	75 (72.1%)	40 (70.2%)	0.0001
Employed before MS diagnosis	166 (44.3%)	126 (58.9%)	24 (23.1%)	16 (28.1%)	
Employed after MS diagnosis	23 (6.1%)	22 (10.3%)	1 (1,0%)	0 (0%)	
Never working	22 (5.9%)	17 (7.9%)	4 (3,8%)	1 (1.7%)	
Decrease in income due to MS	154 (41.1%)	53 (24.8%)	70 (67.3%)	31 (54.4%)	0.0001
Disability pension N(%)	155 (41.3%)	47 (22.0%)	78 (75.0%)	30 (52.6%)	0.0001
Knowledge about existence of MS Society in the place of residence N(%)	169 (45.1%)	85 (39.7%)	59 (56.7%)	25 (43,9%)	0.0336
Membership in the MS Society N (%)	66 (17.6%)	23 (11%)	28 (27%)	15 (26%)	0.0003

Table 2. Socio-economic aspects of study cohort according to patients' place of residence

Type of socio-economic parameter	Place of residence			p-value
	Rural	Town	City	
Educational level N(%)				
Primary	7 (5.9%)	1 (1.0%)	6 (3.8%)	<0.0001
Vocational	42 (35.3%)	20 (20.6%)	23 (14.5%)	
Secondary	42 (35.3%)	44 (45.4%)	56 (35.2%)	
Higher	28 (23.5%)	32 (33.0%)	74 (46.5%)	
Relationship with life partner after MS diagnosis N(%)				
Improvement	17 (17%)	16 (18.2%)	21 (15.7%)	0.6052
Deterioration	19 (19%)	13 (14.8%)	25 (18.7%)	
No change	64 (64%)	59 (67%)	88 (65.6%)	
Economic status N(%)				
High	41 (34.5%)	40 (41.2%)	68 (42.8%)	0.2553
Average	73 (61.3%)	48 (49.5%)	82 (51.6%)	
Low	5 (4.2%)	9 (9.3%)	9 (5.7%)	
Occupational activity N(%)				
Unemployed	60 (50.4%)	43 (44.3%)	61 (38.4%)	0.0592
Employed before MS diagnosis	41 (34.5%)	45 (46.4%)	80 (50.3%)	
Employed after MS diagnosis	6 (5%)	6 (6.2%)	11 (6.9%)	
Never working	12 (10.1%)	3 (3.1%)	7 (4.4%)	
Decrease in income due to MS N(%)	57 (47.9%)	38 (39.2%)	59 (37.1%)	0.0067
Disability pension N(%)	59 (49.6%)	42 (43.3%)	54 (34.0%)	0.0294
Knowledge about existence of MS Society in the place of residence N(%)	36 (30.3%)	40 (41.2%)	93 (58.5%)	<0.0001
Membership of MS Society in the region of residence N(%)	16 (13.5%)	23 (23.7%)	27 (17.0%)	0.1383

statistically significant differences between men and women ($p=0.6172$). Statistically significant differences were found in the probability of the duration of patients' professional

activity and MS variant, place of residence, level of education, employer's knowledge about the diagnosis, as well as the support received from the employer (Fig. 1–3).

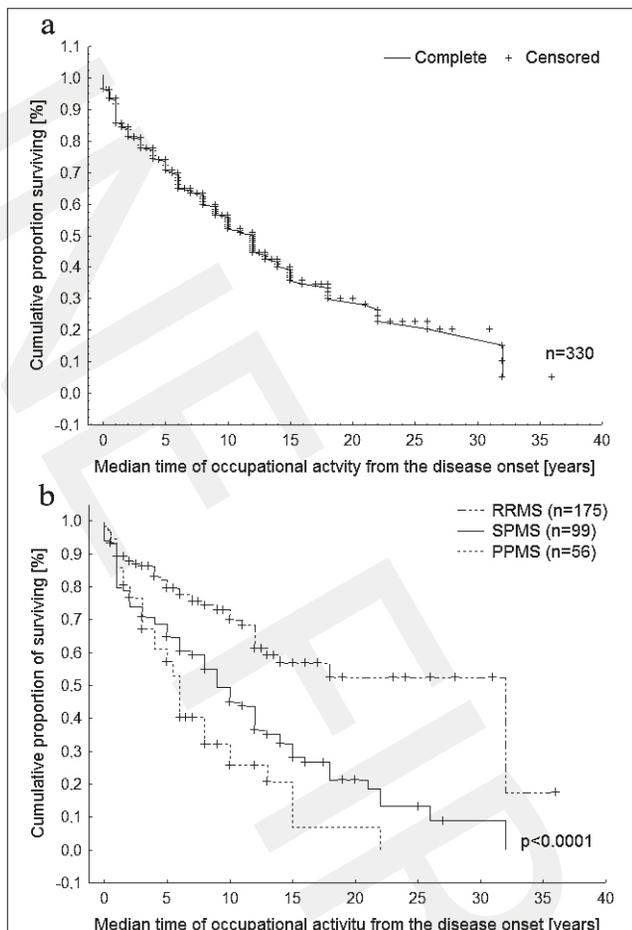


Figure 1. Distribution of the time of patients' occupational activity in relation to: a) MS duration for the entire study cohort, b) MS course variant

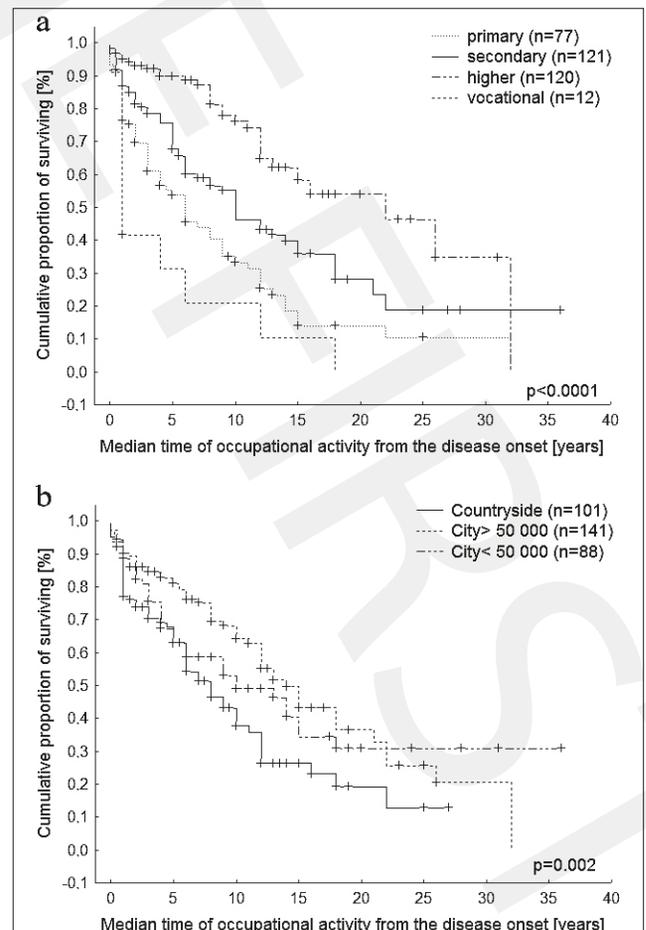


Figure 2. Distribution of the time of patients' occupational activity in relation to: a) level of education, b) place of residence

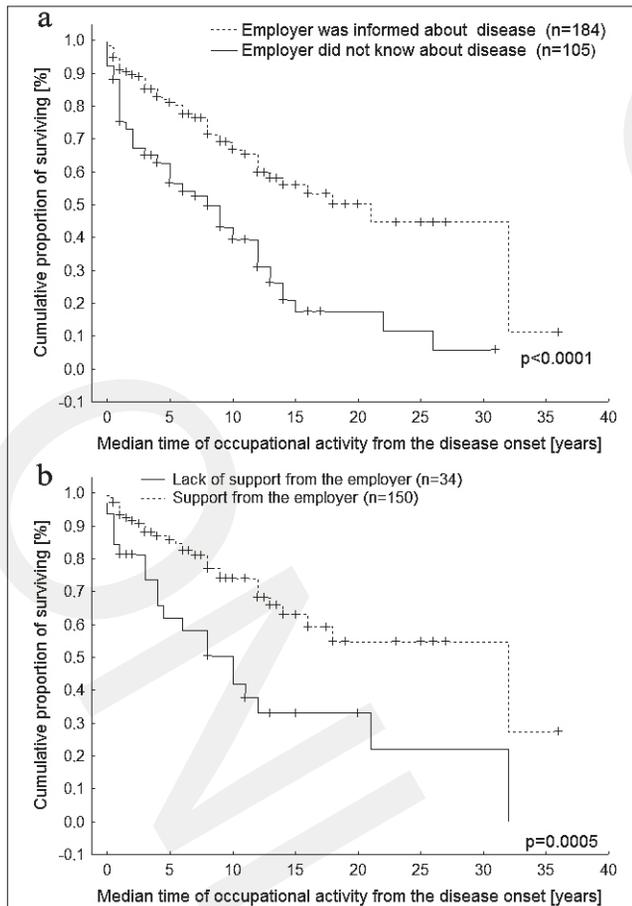


Figure 3. Distribution of the time of patients' occupational activity in relation to: a) employer's knowledge about the diagnosis, b) support obtained from the company

Table 3. Change in patients' relationship with life partner with regard to MS duration

MS duration	Change in patients' relationship with life partner					
	Unchanged		Deterioration		Improvement	
	N	%	N	%	N	%
Below 10 years	150	67,0	30	13,4	44	19,6
10-20 years	47	60,3	20	25,6	11	14,1
20-30 years	7	50,0	6	42,9	1	7,1
Above 30 years	3	50,0	3	50,0	0	0,0

Decrease in income due to MS was reported by 154 respondents – 93 (35.8%) women and 61 (53%) men ($p=0.0005$). A decrease in income was experienced by 71 (38.6%) patients who informed their employer about the disease, and 60 (57.1%) who did not divulge such information to their employer ($p<0.0001$). Among patients who experienced a decrease in income due to MS, there were 7 (50%) with primary, 56 (65.9%) with vocational, 53 (37.3%) with secondary and 38 (28.4%) with a higher level of education ($p<0.0001$). The decrease in salary due to MS was significantly more often experienced by rural inhabitants than urban inhabitants and patients with progressive variants of the disease (Tab. 1 and 2). Respondents who were better educated statistically more often reported a high economic status ($p<0.0001$). MS type significantly influenced the self-assessment of patients' economic status (Tab. 1). There was no significant impact of the respondents' place of residence on this parameter (Tab. 2).

At the time of the survey, 155 (41.3%) patients received disability pension and 32 (8.5%) were retired. The average EDSS score for patients receiving disability pension, as well as retirement pension, was significantly higher than for subjects who did not use these social benefits (4.9 ± 1.4 vs. 2.9 ± 1.4 and 5.1 ± 1.5 vs. 3.6 ± 1.7 , respectively) ($p < 0.001$). Disability pension was received by 38.5% of women and 47.8% of men ($p=0.0895$), together 9 (64.3%) patients with primary, 58 (68.2%) with vocational, 58 (40.9%) with secondary and 30 (22.4%) with higher education ($p=0.0294$). Disability pension was significantly more often received by rural residents and patients with progressive variants of the disease (Tab. 1 and 2). The median time from MS diagnosis to the start of applying for the disability benefit was 1 year.

DISCUSSION

When considering the clinical course of MS, the global standardization of the assessed parameters and scales enables easy comparison of results between studies. Due to the lack of international consensus, evaluation of the sociological and economic aspects of the disease has not been unified. In addition, cultural and economic differences between the surveyed cohorts and assessments of MS socio-economic aspects by psychologists, physiotherapists and nursing staff also result in a varied view of this issue.

The results of the current survey identified a large gap between some socio-economic aspects of MS patients in urban and rural areas of the analyzed region in northern Poland. Subjects living in rural areas had a significantly shorter time of occupational activity, more often experienced a decrease in income, received disability pension, had worse access to information via the MSS, and were less educated than urban residents. However, the disease variant had a greater impact on the socio-economic aspects of patients' daily lives than the place of residence, and additionally significantly affected their economic status, relationships with a life partner and membership of the MSS. Thus, subjects with RRMS had a significantly longer time of occupational activity, higher economic status, higher level of education, better relationships with a life partner, and were less likely to benefit from disability benefits, as well as membership of the MSS than patients with progressive types of the disease. At the same time, the obtained findings indicate that respondents who informed their employer about the diagnosis of MS significantly more often received support from the company, were professionally active for longer, and less likely to experience a decrease in income.

In the study cohort, the percentage of rural residents was 10% lower than for the general population in Poland. This may reflect the lower availability of MS centres for this group of patients, and confirm previously reported poorer access for rural residents to specialist medical care [5, 28]. The average size of respondents' households highlighted that the socio-economic consequences of MS affected the daily life of several times more persons than the estimated population of patients.

Distribution of the education level of patients was dominated by secondary education, which was similar to other studies evaluating Polish MS cohorts [29, 30]. Taking into account the increasing availability of higher education in Poland in recent years, the wide age range of respondents

(18–72 years) and an older age of PPMS patients, precise analysis of educational level in relation to MS variant was hindered. A higher educational level among inhabitants of big cities probably could have resulted from a better educational offer in their place of residence and their higher economic status. In this aspect, the obtained results are in line with the research of other authors concerning Poland, and other regions of the world [31, 32, 33]. It is worth noting that 23.9% of patients with higher education graduated from university after diagnosis of MS in a median time of 2 years.

In the study group, 14.1% of patients were single, and the remaining 85.9% were in a relationship with a life partner. The vast majority of patients (73.9%) were married and the duration of marriages was significantly longer than that of civil partnerships. In the study group, the percentage of married patients was higher than in the available studies of the Polish cohort: Broła et al. – 55.5%, Pierzchała et al. – 68.9%, and Jaracz et al. – 60% [29, 30, 34]. MS did not affect the relations of the majority of patients with a life partner. Almost half of the respondents indicated the life partner as the main support in everyday life with MS, which strengthens the role of these relations while struggling with the disease. Of the assessed parameters, the duration and variant of the disease appeared to affect a patient's relationship with the life partner, which is consistent with previous reports. In the study by Pflieger et al, after 5 and 24 years of the disease, the proportion of patients remaining in a relationship with the same life partner was 86% and 33%, respectively [9]. In the group in the current study, despite the median duration of MS of 9 years, the proportion of patients remaining with the same life partner was higher than that seen after 5 years of MS in the Pflieger group. These differences could be explained by the cultural and religious diversity between the assessed cohorts. A higher percentage of worsening relationships with the life partner in patients with progressive MS and longer disease duration could be a consequence of disability accrual. In the study cohort, 40 (12.5%) relationships between patients and their life partner broke down due to the disease. Among them, civil partnerships and relationships concluded after the diagnosis of MS were more likely to break down. In the confrontation with the disease, marriages were significantly more stable than civil partnerships. Interestingly, the awareness of the life partner of MS diagnosis at the time of entering into a relationship with the patient, did not improve its stability. Perhaps everyday contact with a person suffering from MS suppressed the life partner's idea of the disease. It is worth mentioning that the percentage of divorced MS patients in the studied group was lower than the estimated 30% in the Polish population [28]. MS did not affect the relationships of the majority of respondents with family members other than the life partner, and the support from family and friends was obtained in a total of 90.2% of patients. These results coincide with the needs of MS patients in the study by Koopman et al., where the support from family and friends was expected by 93.4% of subjects [35]. Importantly, the patients' place of residence did not affect relations with their life partner and other family members. Therefore, rural residents were neither exposed to the deprivation of social contacts nor to the experience of less social support than urban dwellers. Due to the lack of available literature data on this issue, it was not possible to compare the obtained results with other studies.

In the studied group, only 45.1% of patients were aware of the existence of the MS Society (MSS) in area of residence.

Statistically, they were more often inhabitants of urban areas and patients with progressive variants of the disease. In turn, 38.9% of the respondents did not have any information about the existence of such an association. Membership of the MSS was declared by 17.6% of respondents. Interestingly, statistically significantly more often these associations included patients with progressive variants of the disease and more advanced disability. The observed differences may suggest the fear of patients in the early stages of MS before contacts with subjects with a longer disease duration and more severe disability. On the other hand, there was no statistically significant difference in membership of the MSS with regard to patients' place of residence and their educational level. The findings of the current study may emphasize the potential role of support from the life partner and relatives of patients living in rural areas in reaching MSS meetings, despite having less access to knowledge about the existence of such associations. Due to the lack of data on this issue in the literature, it was not possible to compare the obtained results with other studies.

The percentage of professionally active patients decreased from 86.4% at the time of the diagnosis to 50.4% at the time of the current survey. The duration of MS influenced the time of patients' occupational activity. In the study group, the median time from disease onset to the end of professional activity was 4 years. Patients with bout onset MS, better educated, residents of large cities, as well as those who informed the employer about the disease and received support from him, worked longer. The current results are in line with the study by Salter et al. and Koziarska et al., in which PPMS and more severe disability were among the factors associated with not working [10, 36]. Patients who did not work at the time of the study most often received a disability pension. The vast majority of them applied for this benefit within one year of the diagnosis of MS. The disability pension was mainly used by the less educated respondents, those with progressive MS variants and more advanced disability, which coincides with the shorter time of their professional activity, and remains consistent with the results of authors from various regions of the world [36, 37, 38]. In the presented study, more frequent use of disability pension by patients living in the countryside is consistent with the available data for the Polish population, and can be closely related to the shorter time of their occupational activity [14, 39].

Almost half of respondents (47.5%) declared a decrease in monthly income due to MS symptoms. The decrease in salary was statistically more frequently reported in men, patients with progressive MS, rural residents, the less educated, and among those who did not inform their employer about the disease. Therefore, MS type, place of residence, educational level and divulging knowledge to the employer about the disease influenced the time of patients' professional work and decrease in salary. In the study by Flachenecker et al., after an average duration of MS of 12.7 ± 9.2 years, 36.8% of respondents remained professionally active. However, the percentage of patients using social benefits due to disability was 39.4% [40]. In the study based on the NARCOMS registry, the percentage of professionally active patients after an average duration of MS of 18.09 ± 10.12 years was 43.8%. They were predominantly younger, better educated female patients [41]. In the study by Bøe Lunde et al., after an average disease duration of 18.9 ± 11.5 years, 45% of the patients

were professionally active. Predictors of early termination of patients' occupational activity were progressive MS variants, longer disease duration and advanced disability, which was in line with the current results [42]. Overall, the premature termination of occupational activity, greater decrease in salary and more frequent use of the disability pension among the participants of the current study who were rural residents, could be associated with the lower level of their education. This relationship has been confirmed in previous studies involving various cohorts, although there is no adequate data for MS patients [14, 43]. In the studied cohort, all respondents provided information about their economic status. The highest percentage of subjects (54.2%) declared the average financial situation at the time of the study. The economic status at the time of the study was statistically significantly influenced by the MS variant and the level of education of patients. In turn, the place of residence and relationship with a life partner did not cause such an impact.

The best financial situation was declared by patients with RRMS and a higher level of education. This relationship seems to be closely related to the longer occupational activity of these subjects. Available studies have differed in the methodology used to assess the economic status of MS patients. This status is also significantly influenced by the degree of industrialization of the region in which the research was carried out. In addition, many patients do not disclose their financial situation. All these issues make it impossible to compare results between studies. In the study by Pierzchała et al., 36.1% of patients did not provide information on economic status, 27.7% described it as low, 20.2% as high, 10.2% as very low, and 5.9% declaring a very high financial status [29]. In the group of Marrie et al., the highest percentage of patients (30.8%) reported an annual household income ranging from 50,000 – 100,000 dollars [44]. In the study by Minkler et al., the socio-economic status based on the annual income of households of patients referred to the poverty rate in the United States. The annual income of households in the largest percentage of patients (18%) ranged from 2 – 3 times higher than the assumed poverty rate, and the higher socio-economic status was associated with lower limitations in daily activity [45].

The current research presents complex relationships between socio-economic aspects of MS and the variant of the disease and the place of patients' residence. However, we are aware of its limitations. The first limitation of our study is its retrospective character. For this reason, the selected socio-economic parameters of patients at the beginning of the disease could not be assessed and their changes reliably monitored along with the time and disability progression. Another limitation was conducting a study on the limited area of Poland and the use of various MS diagnostic criteria, which might have an impact on patients' characteristic such as disease advancement. In addition, conducting a study in the hospital could lead to the selection of patients with a potentially more severe course of the disease. Other limitations were the lack of assessment of the average monthly income of patients as well as their absenteeism at work. Furthermore, due to the relatively low percentage of patients receiving IMDs and the short time of this treatment, its impact on the socio-economic aspects of patients' lives was not assessed. Nevertheless, the authors believe that the presented study provides a valuable contribution to the analysis of the socio-economic consequences of MS in

relation to the variant of the disease and the place of residence in the cohort of Polish patients. To the best of the authors' knowledge, this is the first study evaluating the profile of the patients as members of the MSS, as well as the consequences of informing the employer about the disease.

CONCLUSIONS

The obtained results describe the benefits of assessing the socio-economic aspects of multiple sclerosis, not only in the context of clinical parameters, but also the patients' place of residence and non-medical needs. Due to the enhanced risk of a decrease in salary, early termination of occupational activity and premature disability pension among patients who are rural residents, it would seem appropriate to recommend improvements in counselling and facilitate vocational activation in this group. Early information to the employer about the diagnosis of MS can be helpful in obtaining company support and extending the professional activity of patients. At the same time, the findings emphasize the need for a greater participation of patients with RRMS and mild disability in the MSS, as well as increasing the availability of information for rural residents about the activities of such an association in their area of residence.

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