

Multiple sclerosis: patient-reported quality of life in the Świętokrzyskie Region

Jakość życia osób ze stwardnieniem rozсіяnym w samoocenie chorych z regionu świętokrzyskiego

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Słowa kluczowe: jakość życia, stwardnienie rozсіяne, samoocena dotycząca zdrowia, rejestr pacjentów.

Abstract

Introduction: Comprehensive epidemiologic data for multiple sclerosis (MS) in Poland are limited.

Aim of the research: To analyse patient-reported quality of life and selected clinical and socio-demographic factors of patients registered in the Świętokrzyskie Cohort of the Polish Registry of Multiple Sclerosis (RejSM).

Material and methods: Participants were residents of Świętokrzyskie Province, and the data were collected between January 1st 2014 and December 31st 2015 by the RejSM web portal. After registration by doctors, the respondents assessed their quality of life individually using the Polish language versions of self-assessment questionnaires, the EuroQol (EQ-5D and EQ-VAS), and the Multiple Sclerosis Impact Scale (MSIS-29).

Results: Of 1525 registered patients, 765 agreed to perform self-assessments of life quality and were included in the study. The mean degree of disability measured with the Expanded Disability Status Scale (EDSS) was 3.8 ±2.3. The mean EQ-5D index score was 0.78 ±0.28, and the mean EQ-VAS score was 65.6 ±23.8. Assessment score with MSIS-29 averaged 86.4 ±22.4 (64.2 ±19.6 for physical state and 24.7 ±7.8 for mental state). Only 34.7% of respondents were economically active. Lower quality of life was significantly associated with higher disability scores ($p < 0.001$), age over 40 years ($p < 0.001$), longer disease duration ($p < 0.001$), no access to therapy ($p < 0.001$), and unemployment ($p = 0.002$). No correlation was found between life quality and sex, course of disease, level of education, place of residence, or family status.

Conclusions: The main factors decreasing life quality among patients in Świętokrzyskie Province are advanced disability, old age, long disease duration, and limited access to both employment and immunomodulatory treatment.

Streszczenie

Wprowadzenie: Sytuacja epidemiologiczna i jakość życia chorych ze stwardnieniem rozсіяnym w Polsce są niedostatecznie rozpoznane.

Cel pracy: Analiza samooceny dotyczącej jakości życia oraz wybranych parametrów klinicznych i socjodemograficznych pacjentów ze stwardnieniem rozсіяnym zarejestrowanych w Kohorcie Świętokrzyskiej Polskiego Rejestru Chorych ze Stwardnieniem Rozсіяnym (RejSM).

Materiał i metody: W badaniu wzięli udział chorzy zamieszkujący województwo świętokrzyskie, a dane zbierano między 1 stycznia 2014 r. a 31 grudnia 2015 r. poprzez portal internetowy RejSM. Pacjenci po zarejestrowaniu przez lekarza samodzielnie oceniali jakość życia za pomocą polskich wersji kwestionariuszy samooceny EuroQol (EQ-5D i EQ-VAS) oraz *Multiple Sclerosis Impact Scale* (MSIS-29).

Wyniki: Spośród 1525 zarejestrowanych pacjentów do badania włączono 765 osób, które zgodziły się na samoocenę jakości życia. Średni indeks EQ-5D wynosił 0,78 ±0,28, a średni wynik w EQ-VAS 65,6 ±23,8. Ocena za pomocą MSIS-29

dała średni wynik 86,4 ±22,4 (dla stanu fizycznego 64,2 ±19,6 i dla stanu psychicznego 24,7 ±7,8). Jedynie 34,7% chorych było aktywnych zawodowo. Niższa jakość życia była istotnie związana z wyższym poziomem niesprawności ($p < 0,001$), wiekiem powyżej 40 lat ($p < 0,001$), dłuższym czasem trwania choroby ($p < 0,001$), brakiem dostępu do leczenia ($p < 0,001$) i brakiem zatrudnienia ($p = 0,002$). Nie stwierdzono zależności między jakością życia a płcią, przebiegiem choroby, wykształceniem, miejscem zamieszkania i stanem rodzinnym.

Wnioski: Na obniżenie jakości życia chorych ze stwardnieniem rozsianym z regionu świętokrzyskiego wpływa przede wszystkim zaawansowana niesprawność, starszy wiek, długi czas trwania choroby oraz ograniczony dostęp do pracy i leczenia immunomodulującego.

Introduction

Multiple sclerosis (MS) is a progressive inflammatory demyelinating disease of the central nervous system, whose aetiology is unknown [1]. The onset of this disease usually begins between the ages of 20 and 40 years and is one of the main causes of disability among young people. Globally, the number of people with MS exceeds 2.5 million, of which approximately 600,000 live in Europe [2]. It is estimated that in Poland there are around 45,000 persons with MS, with around 2000 new cases diagnosed each year [3]. Epidemiological studies published so far, often with outdated findings, have collected data from only a few Polish regions [4–10]. Systematic patient registry commenced in 2010 with Świętokrzyskie Province, as all neurological and rehabilitation hospital departments, clinics, and private neurological units were able to successfully collaborate [11, 12]. Later, the registration was extended to include the whole country. Demographic and clinical data were gathered. Since life quality analysis is presently the recommended method for assessing disease progression, treatment efficacy, and the quality of MS patient management, each respondent was asked to self-assess their quality of life by means of selected questionnaires available in Polish language and standardised to suit the Polish population.

Aim of the research

Our study aimed to evaluate disease impact on quality of life (QoL) based on self-assessment reports by patients in Świętokrzyskie Province, and to analyse the demographic and clinical data of respondents entered into the Polish Registry of Multiple Sclerosis (RejSM).

Material and methods

The survey was conducted in over a dozen neurological centres in Świętokrzyskie Province that provide MS treatment. All data were collected via the web portal of the Polish Multiple Sclerosis Registry (RejSM) (www.rejsm.pl). Following diagnosis, as per the McDonald criteria (2010) [13], patients were prospectively and retrospectively registered and followed at each visit. The scope of the registered data included: age, sex, family status, place of residence, level of education, and family history. Also collected were data connected directly with the disease: date and nature of first symptoms, date of diagnosis, presentation of

disease, comorbid conditions, relapses, additional examination (MRI, examination of cerebrospinal fluid, evoked potentials), and type of therapy (modifying course of disease, symptomatic, treating relapses). The patients were evaluated with the Expanded Disability Status Scale (EDSS) proposed by Kurtzke [14]. Next, the patients were asked to individually and independently fill out a questionnaire assessing their QoL using the EuroQol (EQ-5D and EQ-VAS) [15] and the Multiple Sclerosis Impact Scale (MSIS-29) [16]. The EQ-5D questionnaire consists of two parts: the EQ-5D descriptive system and EQ Visual Analog Scale (EQ-VAS) [15]. The EQ-5D descriptive system covers the following five dimensions: mobility, self-care, everyday activities, pain/discomfort, and anxiety/depression. Each of these dimensions has three levels: 1 = no problem, 2 = some problems, and 3 = severe problems. A respondent is asked to indicate his or her state of health by ticking the box next to the most appropriate statement for each of the five dimensions. The combination of one level from each dimension defines the individual's state of health. The EQ-5D utility value calculated from these health states (EQ-5D index) ranges from -0.523 (the lowest QoL) to 1.0 (the highest QoL). The EQ-VAS is a standard scale for recording an individual's rating of their current health status. The ends of the scale are defined as the "best imaginable health state = 100" and the "worst imaginable health state = 0", respectively. A Polish version of the EQ-5D is available and it is standardised for the general Polish population [17, 18].

The Multiple Sclerosis Impact Scale (MSIS-29) is a disease-specific health-related quality of life (HRQoL) instrument, developed using patients' perspective on disease impact [16]. It consists of 29 questions divided into two subscales assessing MS physical impact (MSIS-29-PHYS) with 20 questions and MS psychological impact (MSIS-29-PSYCH) with nine questions. The responses are recorded on a Likert scale (1–5) and summarised to give a maximum of 100 with MSIS-29-PHYS and 45 with MSIS-29-PSYCH [19].

Written informed consent was obtained from each participant or the next of kin before any interview or neurological examination was conducted. All individual data were automatically anonymised by replacement of the personal identity numbers (PESEL number; Universal Electronic System for Registration of the Population) with unique number codes for use in the study. The study protocol was approved

by the Regional Medical Ethics Committee of the Świętokrzyskie Medical Council in Kielce.

Statistical analysis

Univariate statistics were used to describe the results of the survey, using the mean and standard deviation for continuous variables, and absolute values and percentages for categorical ones. All continuous variables were tested for normal distribution and equality of variances. Mean values of the EQ5D index, EQ VAS, MSIS-29-PHYS, and MSIS-29-PSYCH were compared in each subgroup using Student's *t*-test. Potential baseline differences with respect to sex and disease duration were analysed using the Mann-Whitney *U* test. *P*-values < 0.05 were considered statistically significant. The statistical analysis was performed using Statistica software, version 8.0 (2007; StatSoft, Inc.).

Results

On December 31st 2015, 1525 patients with MS living in Świętokrzyskie Province were registered in the Polish Registry of Multiple Sclerosis (PwMS), of which 765 individually assessed their QoL. The group was comprised of 518 (67.7%) women and 247 (32.3%) men (female to male ratio 2.1 : 1) with clinically diagnosed multiple sclerosis, according to the McDonald criteria (2010). The clinical and socio-demographic characteristics of the study group are presented in Table 1.

The average degree of disability on the EDSS scale was 3.8 ± 2.3 . Relapsing-remitting MS was suffered by 65.2% of respondents, secondary-progressive MS by 26.6%, and primary-progressive by 8.3%. The average age was 44.9 ± 10.8 years, and the average disease duration was 15.3 ± 8.4 years. First symptoms usually appeared around the age of 31 years. On average, the time between first symptoms and diagnosis was 2.6 ± 1.8 years.

Disease Modifying Therapies (DMT) (interferon β , glatiramer acetate, natalizumab, or fingolimod) were used with 35% of respondents, 6.6% underwent these treatment methods in the past, whereas 58.4% had never received such treatment. Symptomatic treatment was employed in 98% of cases.

65.3% of patients were married, while the rest had not decided to enter into a marital relationship or were single due to widowhood, divorce, or separation. Women who suffered from MS usually gave birth to one child (54.6%) or none at all (31.4%). 11.8% of women had 2 children and 3.2% had 3 or more. Of the 765 self-assessing patients, only 34.7% were economically active. The rest supported themselves with social benefits or pension, or relied on family help. A positive family history, defined as the diagnosis of MS in parents, siblings, or cousins, was observed in 20 (3.9%) of the female and in 12 (4.9%) of the male self-assessing patients.

The average EQ-5D index score was 0.78 ± 0.28 , and the mean score for EQ-VAS was 65.6 ± 23.8 . Scores significantly reduced with patient age and disease duration. Self-assessment ratings for the state of health measured with the EQ-5D questionnaire indicated that 2/3 of patients experienced problems with mobility and everyday activities, the same proportion of patients felt pain/discomfort and anxiety/depression, while approximately half reported problems with self-care (Figure 1).

QoL in patients with MS assessed with the EQ-5D scale was strongly impacted upon by the patients' level of disability ($p < 0.001$), age ($p < 0.001$), disease duration ($p < 0.001$), economic activity ($p = 0.002$), and DMT used ($p < 0.001$). However, no association was found between QoL and sex, course of disease, level of education, place of residence, or family status. The above-mentioned factors had a similar impact on QoL, as measured by the EQ-VAS (Table 2).

The average assessment of the Polish population of patients suffering from MS conducted with MSIS-29 was 86.4 ± 22.4 (physical state = 64.2 ± 19.6 ; mental state = 24.7 ± 7.8). The MSIS-29 questionnaire revealed that, in terms of physical and mental states, reduced QoL was reported by persons of over 40 years of age, suffering from MS for over 10 years, with a higher degree of disability, unemployed, and those not receiving DMT. No correlation was observed between the scores and sex, course of disease, place of residence, level of education, or family status (Table 2).

Discussion

Quality of life assessment is one of the key elements of the diagnostic process for chronic diseases, and its improvement by minimising negative disease impact on patients' everyday functioning has become a major aim of therapies [20]. In Poland, numerous attempts have been made to evaluate QoL among pa-

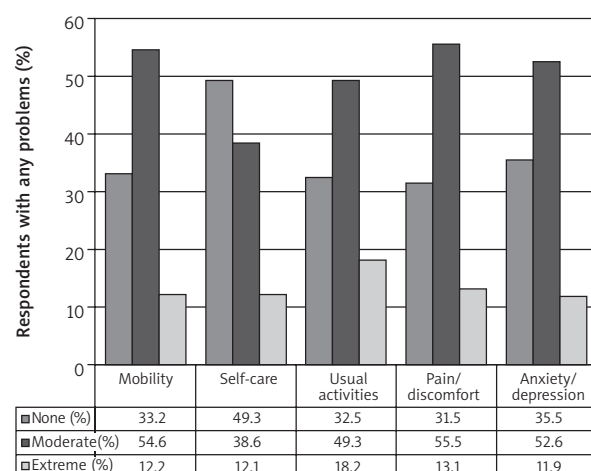


Figure 1. Self-assessment of EQ-5D

Table 1. Clinical and socio-demographic characteristics of study patients

Variable	Female (n = 518)	Male (n = 247)	P-value
Age, mean ± SD (range) [years]:			
At the last visit	44.3 ±10.6 (16–76)	45.6 ±11.2 (18–82)	NS
At disease onset	34.7 ±10.2 (16–58)	35.3 ±10.8 (18–56)	NS
At first symptoms	31.8 ±8.2 (16–54)	31.2 ±9.4 (18–52)	NS
Disease duration, mean ± SD [years]	15.6 ±8.6	14.9 ±8.2	NS
EDSS, mean ± SD	3.8 ±2.3	3.9 ±2.2	NS
Initial signs at onset, n (%):			NS
Pyramidal	195 (37.6)	88 (35.6)	
Sensory	77 (14.9)	44 (17.8)	
Visual	125 (24.1)	61 (24.8)	
Brainstem	75 (14.5)	28 (11.3)	
Cerebellar	46 (8.9)	26 (10.5)	
Disease course subtypes, n (%):			NS
Relapsing remitting	331 (63.9)	164 (66.4)	
Secondary progressive	149 (28.8)	60 (24.4)	
Primary progressive	38 (7.3)	23 (9.3)	
Treatment during the follow-up period, n (%):			NS
Interferon β	123 (23.7)	54 (21.9)	
Glatiramer acetate	45 (8.7)	23 (9.3)	
Other (natalizumab or fingolimod)	15 (2.9)	9 (3.6)	
Place of residence, n (%):			NS
Country	224 (43.2)	112 (45.3)	
Town	294 (56.8)	135 (54.7)	
Occupational status, n (%):			0.024*
Employed	168 (32.4)	95 (38.4)	
Unemployed	350 (77.6)	152 (61.6)	
Marital status, n (%):			NS
Single	158 (30.5)	96 (38.9)	
Married	360 (69.5)	151 (61.1)	
Educational level, n (%):			
High	146 (28.4)	54 (21.9)	0.023*
Secondary	235 (45.4)	108 (43.7)	NS
Vocational	54 (10.4)	56 (22.7)	0.004*
Elementary	82 (15.8)	29 (11.7)	0.038*

*Statistically significant.

tients with MS, but these are usually limited to small patient groups, and are used for immediate purposes [21–25].

The present study is the result of the countrywide PwMS project, which is planned to extend over many years. In an earlier publication, we presented QoL self-

assessments of 2385 randomly selected patients living in different parts of the country [26]. The present analysis covers a more representative part of the registry – the Świętokrzyskie Cohort – and includes 765 respondents. Patients in the Świętokrzyskie region have been under continuous observation since diagnosis,

Table 2. Health-related Quality of Life using EQ-5D Index, EQ-VAS, and MSIS-29, according to socio-demographic and health-related factors

Variable	Categories	EQ-5D Index Mean ± SD	P-value	EQ-VAS Mean ± SD	P-value	MSIS-29 PHYS Mean ± SD	P-value	MSIS-29 PSYCH Mean ± SD	P-value
Total		0.78 ±0.28		65.6 ±23.8		64.2 ±19.6		24.7 ±7.8	
Age [years]	18–40 > 40	0.71 ±0.34 0.53 ±0.28	< 0.001*	68.4 ±27.2 41.5 ±17.6	< 0.001*	56.4 ±16.2 67.2 ±19.1	< 0.001*	20.9 ±7.2 28.4 ±8.5	< 0.001*
Sex	Female Male	0.73 ±0.32 0.69 ±0.22	0.275	66.2 ±26.4 64.8 ±18.4	0.326	58.9 ±22.1 62.6 ±21.4	0.632	24.5 ±8.2 22.7 ±7.7	0.452
Disease duration [years]	1–10 > 10	0.84 ±0.36 0.62 ±0.28	< 0.001*	74.2 ±28.6 55.4 ±18.2	< 0.001*	53.8 ±19.2 74.1 ±30.5	< 0.001*	21.4 ±8.7 28.6 ±9.8	< 0.001*
Type of MS course	Relapsing-remitting Progressive forms	0.76 ±0.28 0.74 ±0.26	0.142	66.1 ±22.6 64.2 ±21.6	0.535	57.8 ±20.2 62.4 ±18.6	0.386	23.9 ±8.6 25.3 ±8.9	0.754
EDSS	Mild 0.0–3.5 Moderate or severe ≥ 4.0	0.72 ±0.36 0.54 ±0.16	< 0.001*	74.5 ±23.7 56.4 ±17.2	< 0.001*	54.4 ±21.6 74.2 ±27.2	< 0.001*	21.9 ±7.4 28.5 ±8.1	< 0.001*
DMT	Treated Untreated	0.84 ±0.32 0.61 ±0.24	< 0.001*	78.2 ±32.7 52.6 ±14.2	< 0.001*	45.9 ±14.4 64.8 ±20.6	< 0.001*	24.8 ±8.6 30.4 ±9.8	< 0.001*
Education	Primary Secondary or more	0.78 ±0.34 0.84 ±0.46	0.542	64.8 ±24.6 61.8 ±21.8	0.215	53.8 ±18.2 55.3 ±19.6	0.631	24.7 ±8.8 22.6 ±7.2	0.412
Employment	Working Not working	0.84 ±0.38 0.66 ±0.22	0.002*	66.5 ±24.1 61.5 ±20.2	0.155	59.4 ±12.8 68.2 ±17.6	0.022*	26.6 ±8.2 21.2 ±7.2	0.032*
Place of residence	Town Country	0.73 ±0.32 0.69 ±0.26	0.566	68.2 ±24.8 66.2 ±23.6	0.634	59.4 ±18.4 64.5 ±19.2	0.323	26.6 ±8.2 30.2 ±9.6	0.084
Marital status	Single/widow/separated Currently married	0.68 ±0.24 0.72 ±0.22	0.653	65.6 ±24.6 62.6 ±21.8	0.843	55.6 ±17.4 57.2 ±18.6	0.632	22.4 ±7.6 24.2 ±8.2	0.325

*Statistically significant. EQ-5D – EuroQol 5-Dimensions, VAS – Visual Analogue Scale, MSIS-29 – Multiple Sclerosis Impact Scale.

and their state of health is monitored at least once a year. On December 31st 2015, the Świętokrzyskie Cohort consisted of 1525 persons, with over half performing a self-assessment of QoL by means of the Polish versions of the EQ-5D and MSIS-29 questionnaires.

EQ-5D was the first QoL questionnaire standardised for the Polish population. The validation study was conducted by Golicki *et al.* [17, 18] in 2008 and in 2014 on a population representative of age and sex within the general group of respondents.

The average EQ-5D index score for the Polish population was 0.893 ± 0.21 , and the average EQ-VAS score was 73.7 ± 14.4 . The most frequently reported conditions were pain/discomfort (45.8%) and anxiety/depression (33.3%), while the least common were self-care problems (9.4%) [18].

In our study, moderate problems in at least one of the assessed domains were reported by 50.1% of the respondents, while severe problems were reported by 13.5%. Pain or discomfort was reported by 68.6% of the respondents, daily activity by 67.5%, problems with mobility by 66.8%, anxiety or depression by 64.5%, and self-care by 50.7%.

The use of the EQ-5D questionnaire enables a direct comparison of mean results obtained from patients with MS matched for their age group with the general population. This comparison clearly shows the reduction in QoL of patients with MS relative to that of the healthy Polish population (EQ-5D index = 0.78 ± 0.28 ; EQ-VAS = 65.6 ± 23.8).

In the present study's cohort, QoL was considerably lower in all age groups, with a clear tendency for EQ-5D and EQ-VAS scores to decrease with age. This change resulted from an increase in disability from longer disease duration and the appearance of new MS symptoms or age-related comorbid conditions.

Our observations are consistent with the results of Papuć *et al.* [21], who compared the QoL of 173 patients with MS to that of 86 healthy people. The WHO-QoL-100 questionnaire revealed a major decrease in QoL in patients, with respect to both the global assessment and the physical and mental aspects, compared to a healthy population [21].

In another study with over 3500 respondents conducted by Mitosek-Szewczyk *et al.* [27], the average EQ-5D index score was 0.8 ± 0.27 , and the average EQ-VAS score was 65.6 ± 21.5 . Patients in this group usually reported pain or discomfort (40%), anxiety or depression (38%), and problems with mobility (16%). In a study by Pierzchała *et al.* [28], with 640 respondents from the Gorný Slask region, the mean EQ-VAS score was 66.11 ± 20.12 .

The MSIS-29 questionnaire, standardised to suit the Polish population [19], also indicated a varying impact of MS on the QoL of the present study's cohort.

As seen in the present study and others [21–25], the QoL of MS patients depends on many factors and clinical parameters, such as disability level, disease duration, age, occupational status, and employed immunomodulatory therapy. These studies often differed methodologically because they were performed with various questionnaires and on different, often culturally divergent, populations. It is, therefore, difficult to compare them directly. It is certain that MS is a chronic, incurable disease, inevitably reducing QoL, as documented in our study. These findings are supported by other study results from other countries [29–31]. Older persons with progressive, long-lasting disease, reduced mobility, and not receiving DMT report much lower QoL than younger persons receiving immunomodulatory treatment and with lower EDSS scores. It seems that the largest impact on QoL comes from disease duration and EDSS-assessed level of disability. These dependencies, regardless of the QoL assessment methods used, are confirmed by the vast majority of researchers [32–36].

Fernández *et al.* [32], in a study with 1992 respondents from 15 countries, proved that decreasing QoL correlates most with age and deteriorating mobility. Other factors considered influential on QoL were: low education level, cognitive disturbances, living alone, and a recently experienced relapse. Relationships were observed in dimensions associated with physical and mental functioning assessed with both SF-36 and MusiQoL questionnaires. Also, Anagnostouli *et al.* [33] assessed a Greek population of respondents with MS using the MSQoL-54 questionnaire and found that disability level is the most important factor associated with stigmatisation and decreasing QoL. Researchers also observed the negative impact of no social support, lack of employment opportunities, and cognitive and mental disorders. Furthermore, Patti *et al.* [34] showed that patients in Italy with EDSS results below 3.0 perform better on all SF-36 subscales in comparison with patients with higher disability levels. A German study by Twork *et al.* [35] conducted with the MSQoL-54 questionnaire also proved that QoL decreases significantly with deteriorating mobility. Yamout *et al.* [36], on the other hand, emphasise that not only physical disability causes QoL to fall, and point to other equally important factors such as lack of social support, depression, pain, cognitive disorders, and tiredness. Such conclusions support earlier study results reported by Lobentanz *et al.* [37], in which the QoL of 504 respondents with MS was compared with healthy persons. The main factors affecting QoL were disability level and depression with sleep disorders and tiredness.

A specific factor deteriorating QoL levels among Polish patients is no access to DMT treatment. Only 35% of our respondents received immunomodulatory treatment. This is far more than according to MS

Barometer 2013, where Poland took the penultimate place in Europe, with only 11% of patients treated [38]. Polish therapeutic programmes are very restrictive, providing treatment only to persons with relapsing-remitting MS, in a limited scope (EDSS \leq 4.5), and in some regions of the country treatment is altogether unavailable. Therapy duration is also limited.

In our self-assessment based study, persons remaining out of work, as evidenced by their EQ-5D and MSIS29 scores, had significantly lower QoL. Only 34.7% of patients had any employment. It has been concluded that patients with MS resign from their jobs earlier, retire earlier, or are unemployed due to difficulty finding work that would suit their disability.

The present study has some limitations. Patients with high levels of disability remaining in care facilities or under family care, as well as young patients with mild MS without the need for frequent contact with the healthcare system, may not have been identified.

The range of collected data may also constitute a limitation. Our registry collaborates with the European EUREMS under the auspices of the European Multiple Sclerosis Platform (EMSP). In order to compare the QoL in different European countries, the scope of collected data has been standardised and limited to two questionnaires: the EQ-5D and MSIS-29. Compatibility between all registries has been achieved at the cost of extensive assessment based on such important factors as the impact of depression, tiredness, sleep disorders, social support, income, and caregiver burden. The role of these factors is underlined in many publications [39, 40].

Conclusions

We estimate that the present study included approximately 50% of the patient population with MS living in Świętokrzyskie Province. The self-assessment demonstrated that decreased QoL in the studied cohort was mainly a result of the level of disability, disease duration, advanced age, and limited access to employment and immunomodulatory therapy. Further observation may enable the collection of data from a complete population of patients, contributing to a comprehensive analysis of factors influencing their life quality. It is necessary to continue studies focusing also on other aspects, such as economic status, social support, and access to rehabilitation.

Conflict of interest

The authors declare no conflict of interest.

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