



## Original Research Article

## Quality of life in Polish patients with multiple sclerosis

Krystyna Mitosek-Szewczyk<sup>a,\*</sup>, Alina Kułakowska<sup>b</sup>, Halina Bartosik-Psujek<sup>c</sup>,  
Roman Hożejowski<sup>d</sup>, Wiesław Drozdowski<sup>b</sup>, Zbigniew Stelmasiak<sup>c</sup>

<sup>a</sup> Department of Paediatric Neurology, Medical University in Lublin, Lublin, Poland

<sup>b</sup> Department of Neurology, Medical University of Białystok, Białystok, Poland

<sup>c</sup> Department of Neurology, Medical University in Lublin, Lublin, Poland

<sup>d</sup> Medical Department, Bayer sp. z o.o., Warszawa, Poland

## ARTICLE INFO

## Article history:

Received 1 March 2013

Accepted 2 July 2013

Available online 16 March 2014

## Keywords:

Multiple sclerosis  
EQ-5D questionnaire  
Quality of life  
QoL

## ABSTRACT

**Purpose:** This study is a pilot evaluation of the quality of life (QoL) in Polish patients with multiple sclerosis (MS).

**Material/methods:** Data from 21 centers in Poland were collected from May 2008 to January 2009. QoL was assessed using the questionnaire Euro Quality of Life (EQ-5D), with Polish population norms. Demographic profile of patients, duration/form/relapsing activity of the disease, disability and comorbidity were also analyzed.

**Results:** Data from 3521 patients (F/M ratio 2.4:1) were collected. The average EQ-5D index was  $0.8 \pm 0.27$  and the mean score in a visual analog scale (EQ-VAS) was  $65.6 \pm 21.5$ . There was a highly significant positive correlation between both indices ( $r = 0.7334$ ,  $p < 0.0001$ ). The mean patient age was 40.7 years (11.2–92.3 years) and disease duration was  $10.3 \pm 8.8$  years (0.04–53 years). 74.2% of subjects had relapsing-remitting form of MS, while 17.2% were classified as secondary progressive and 8.6% as primary progressive. In the group of relapsing-remitting MS subjects there were 2.5% patients with “benign MS”. The average degree of disability on EDSS scale was  $3.6 \pm 2.2$ , while disability  $\geq 6$  was observed in 20.3% of patients. Most patients did not have other diseases besides MS.

**Conclusions:** This is the first large study of QoL in patients with MS in Poland (approximately 18% of all patients). Our results confirm a reduction in QoL compared with the general population. Further studies are indicated to identify the modifiable risk factors (e.g. type of treatment) that may affect QoL.

© 2014 Medical University of Białystok. Published by Elsevier Urban & Partner Sp. z o.o. All rights reserved.

## 1. Introduction

Multiple sclerosis (MS) is a common chronic autoimmune inflammatory disease of the central nervous system. Its prevalence in Poland is about 55–57 per 100,000 [1,2]. It develops mainly in people aged 20–40 years, being the second most common cause of disability among young adults, after injuries [3]. According to currently available knowledge, pathogenesis of MS is associated with an increased pro-inflammatory T-lymphocytic response against myelin protein antigens. In the early stages of MS there are usually periods of relapses (neurological deterioration) and remissions. Later, it slowly progresses to physical and intellectual disability. To date, there have been several immunomodulatory drugs identified as mitigating the clinical course of MS. However,

the efficacy of these drugs, assessed through their impact on the frequency of relapses and the progression of disability, is limited [4].

The quality of life (QoL) in chronic diseases is now considered one of the important markers of treatment efficacy, not only for medical reasons, but also in terms of measurable economic costs [5]. The term “quality of life” is ambiguous and is conditioned by many factors. It depends on cultural differences and the general prevalent moral and social standards. Overall, a good QoL is the physical, mental and social well-being of an individual. In medical research this general interpretation is narrowed down and the analysis of QoL is only dependent on the state of health (HRQoL) [6]. In 1987, an international group of experts (EuroQoL Group) affiliated with the WHO prepared a standardized, generic questionnaire to study QoL in patients: EQ-5D [7,8]. The format of EQ-5D is independent of the type of disease being evaluated. This questionnaire, considered a generic quality of life scale assesses life problems from the patient's subjective point of view, along with ease of understanding the questions and the ability of patients to complete the questionnaire within a short time. So far,

\* Corresponding author at: Department of Paediatric Neurology, Medical University in Lublin, Chodźki 2, 20-092 Lublin, Poland. Tel.: +48 81 718 5440; fax: +48 81 724 4540.

E-mail address: [krystyna.mitosek@gmail.com](mailto:krystyna.mitosek@gmail.com) (K. Mitosek-Szewczyk).

the EQ-5D questionnaire has more than 70 language versions, which are being successfully used in clinical trials for efficacy and economics of health care. There is also a validated version of the EQ-5D questionnaire in Polish. In addition, there are many other questionnaires assessing QoL in patients, both nonspecifically (e.g. *Short Form Health Survey* – SF-36; *Life Satisfaction Questionnaire* – LSQ) and specific to certain chronic diseases (e.g. *Multiple Sclerosis Quality of Life Instrument* – MSQoL-54, *Quality of Life in Epilepsy* – QOLIE-89) [9–12].

Chronic and progressive diseases like MS seem to particularly modify an individual's QoL. This is confirmed by studies conducted in Sweden, Germany, Spain, the United States and Canada [13–17]. However, because of cultural and social differences and the organization of the health care system, the results of these studies cannot be directly linked to MS patients in Poland [18]. Thus far, there has been no research in Poland concentrating on QoL in MS patients using a questionnaire specifically validated for the Polish population.

The aim of this study was to collect data on QoL, demographics profile and health status in MS patients in Poland. The results obtained will help to assess the social costs of this disease and improve health care for MS patients, by indicating their specific needs for pharmacologic treatment and rehabilitation.

## 2. Material and methods

### 2.1. Selection of the study population

Cross-sectional data collection started in May 2008 and was completed in January 2009. This project involved 21 of more than 60 clinical centers (university clinics, hospital wards, outpatient clinics and private surgeries) that provide medical care to MS patients, represented 14 of all 16 provinces of Poland. Every patient with MS available in the site was included into the study; therefore, the risk of selection bias did not occur. Doctors participating in the survey were asked to collect data from all MS patients under their care, regardless of their age, disease form or degree of disability, where MS was diagnosed based on MacDonald's criteria [19,20]. This project was not associated with any medical intervention.

Data on QoL were obtained from 3521 patients. Women accounted for 70.6% of the analyzed group and males for 29.4% (ratio 2.4:1). Total mean age for the entire group of patients was  $40.7 \pm 11.9$  years (range 11.2–92.3 years), with a mean age of the women being  $40.7 \pm 11.7$  years (range 11.2–92.3 years) and mean age of the men  $40.6 \pm 12.1$  years (range 11.8–88.2 years). Detailed parameters characterizing patients and the disease course are presented in Table 1.

The degree of disability was assessed by The Kurtzke Extended Disability Scale (EDSS) [21].

**Table 1**  
Baseline demographics and disease characteristics of MS patients.

	Females	Males	All patients <sup>a</sup>
Number of patients	n = 2446	n = 1020	n = 3521
Proportion: female/male	—	—	2.4:1
Age (years) – mean (SD)	40.7 (11.8)	40.6 (12.1)	40.7 (11.7)
Disease duration (years) – mean (SD)	10.2 (8.7)	10.4 (9.1)	10.3 (8.8)
Age at disease onset – mean (SD)	30.5 (10.0)	30.2 (9.2)	30.4 (9.8)
Total number of prior relapses – mean (SD)	5.25 (4.09)	5.20 (4.09)	5.23 (4.08)
EDSS mean score (SD)	3.31 (2.16)	3.47 (2.28)	3.34 (2.20)

<sup>a</sup> Gender was not specified in 55 cases.

### 2.2. Methods

The study was conducted with a specially designed form, which included:

1. Questions about demographics, family history, concomitant diseases, the first symptoms, as well as duration, character and relapse frequency of the disease, degree of disability according to EDSS scale [21], methods of diagnostics, immunomodulating and immunosuppressive treatment. The epidemiological data collected during this study have been published in Kułakowska [22].
2. QoL questionnaire EQ-5D [7,8].

### 2.3. EQ-5D

The EQ-5D questionnaire consists of 2 parts: the EQ-5D descriptive system and EQ Visual analog scale (EQ-VAS). The EQ-5D descriptive system covers the following 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each of the dimensions has 3 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 5 dimensions. The combination of one level from each dimension defines the individual's state of health. A total of 243 possible states are thus defined. The EQ-5D utility value calculated from these health states (EQ-5D index) ranges from –0.523 (the worst QoL) to 1.0 (the best QoL).

EQ-VAS is a standard, vertical, 20 cm-long VAS (similar to a thermometer) for recording an individual's rating of their current state of health (HRQoL). The ends of the scale are defined as the “best imaginable health state = 100” and the “worst imaginable health state = 0”, respectively.

EQ-VAS does not influence EQ-5D index but provides additional information about QoL.

A Polish version of the EQ-5D is available and its validity and reliability has been demonstrated for the general Polish population [23,24].

### 2.4. Statistical analysis

The collected data were analyzed using Statistica 7.1 (StatSoft, USA) and GraphPad Prism 5.0 (GraphPad Software, USA). Descriptive statistics of the distribution for the collected data were calculated, with mean/median values, quartiles, standard deviations and 95% confidence intervals.

## 3. Results

The degree of disability was assessed by The Kurtzke Extended Disability Scale (EDSS) [21]. The average EDSS score was  $3.35 \pm 2.20$  (range 0–9.5). Patients with mobility restriction that required the use of a cane (EDSS  $\geq 6$ ) accounted for 20.3% of the study group. Patients who were not able to walk independently and were forced to use a wheelchair constituted 5% of the sample.

Most study subjects (74.2% of patients) had a relapsing-remitting form of the disease, 17.2% were secondary progressive – and 8.6% were primary progressive (PPMS). The present study also highlighted “benign MS,” which was defined as occurrence of relapses after complete remission with very minor detriment and the disability (EDSS  $\leq 3$ ) after 10 years of illness. This form was presented by 2.5% of patients.

This study also collected data on the occurrence of concomitant diseases beside MS. The absence of any other disease (other than MS) was observed in 67.2% of patients. The remaining patients

Download English Version:

<https://daneshyari.com/en/article/2032028>

Download Persian Version:

<https://daneshyari.com/article/2032028>

[Daneshyari.com](https://daneshyari.com)