THE FIRST HOSPITAL-BASED REGISTRY OF PATIENTS WITH MULTIPLE SCLEROSIS IN CROATIA

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SUMMARY – The first hospital-based registry of patients with multiple sclerosis (MS) was established at the University Department of Neurology, Sestre milosrdnice University Hospital Centre, Zagreb, Croatia, in 2014. The aim of the registry was to continuously provide data on the number of hospital-managed MS patients, patterns of disease progression, predictors of disability progression, changes in lifespan and long-term outcomes. Relevant medical data included age and gender of MS patients, family history of MS, data on previous immunization, disease course, Expanded Disability Status Scale (EDSS) score, cerebral magnetic resonance imaging (MRI) lesion load quantification, and cerebrospinal fluid analysis. Lifestyle habits in MS patients including smoking and alcohol consumption were also analyzed. All data were obtained from primary medical records between January 1, 2014 and January 1, 2015, and entered into the database. Data were evaluated retrospectively according to age and gender differences. Results showed that the majority of patients enrolled in the registry had the remitting relapsing course of disease, with low EDSS score indicating no disability or minimal disability. Cerebrospinal fluid analysis showed that oligoclonal bands were present in the majority of MS patients, with affected blood-brain-barrier permeability. According to the remitting relapsing course of the disease, cerebral MRI quantitative analysis demonstrated a significant lesion load in the majority of patients. When stratified by lifestyle habits, smokers and alcohol consumers were more prevalent among male patients. Our hospital-based registry might be considered as a prototype for the national MS registry and should be improved for reliable statistical analysis.

Key words: *Multiple sclerosis; Registries; Medical records; Disease progression; Croatia*

Introduction

Multiple sclerosis (MS) is characterized by heterogeneous clinical expression, an unpredictable course, and a variable prognosis. The etiology of MS is still unknown, but it is widely accepted that it is an immune mediated demyelinating process, precipitated by unknown environmental factors, in genetically susceptible people. MS affects an estimated 2-2.5 million people worldwide, of whom approximately 630 000 are in Europe[1,2]. The incidence of MS is about 7 cases *per* 100 000 persons *per* year. The prevalence rate varies between races and geographical latitudes, ranging from 50 to 120 *per* 100, with the highest prevalence observed in northern European countries[1-3]. Currently, there are no statistical reports on MS patients in Croatia. There is not even an estimated number of MS, or data on the prevalence of MS disease patterns in Croatia. There is still a significant lack of the information

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required to improve health service for MS patients. Details on how MS impacts their everyday lives are also unknown. The establishment of MS patient registries addresses some of deficient MS data and provides an insight into the potential causative and risk factors in MS. Also, patient registries offer data with respect to disease progression, predictors of disability progression and changes in lifespan, and improve long-term outcomes. Epidemiological data help in creating better MS outcome; thus, in 2014, we established the hospital-based registry of MS patients at the Clinical Department of Neurology, Sestre milosrdnice University Hospital Centre in Zagreb, as the first one in Croatia. We aimed to capture the number of hospital managed MS patients, relevant medical records, and lifestyle habits, with intention to expand the MS registry at the national level in the future. Primary objectives of this MS registry were as follows: to adapt the functional clinical system within specialist clinical centers with identifiable data to the register; to build an anonymous register of MS patients; to build suitable analytical tools for use of the register; and to expand it at the national level. A multi-faceted approach was accepted, combining technical developments, security measures, and quantitative and qualitative methodologies with participatory design. The information collected in this registry provides enough evidence to launch the national Croatian registry, with more MS clinical centers joining in the future.

Subjects and Methods

Hospital-based MS registry formed at the Clinical Department of Neurology, Sestre milosrdnice University Hospital Centre, tracked medical records of a total of 240 MS patients. To be eligible, patients should have experienced the first symptom suggestive of MS between January 1, 2014 and January 1, 2015. To be finally included as MS cases, patients had to meet the revised 2010 McDonald criteria for MS[4]. The main source of case identification were hospital medical files, with relevant medical data routinely collected by neurologists at the Neuroimmunology and Neurogenetics Unit, Clinical Department of Neurology, Sestre milosrdnice University Hospital Centre in Zagreb, Croatia, during hospitalization. Relevant registry data included the following: age and gender; family history of MS; data on previous immunization: vaccination for morbillivirus (measles virus), parotitis virus (mumps) and rubella virus, hepatitis B virus (HBV), and other nonspecific vaccination; MS disease course (primary progressive MS (PPMS), remitting relapsing MS (RRMS), or secondary progressive MS (SPMS); Expanded Disability Status Scale (EDSS) score; cerebral magnetic resonance imaging (MRI) T2/FLAIR lesion load quantification: moderate lesion load (0-9), significant lesion load (10-20) and progressive lesion load (more than 20); cerebrospinal fluid (CSF) examination: protein index for evaluation of intrathecal IgG synthesis, evaluation of the blood-brain-barrier permeability, presence of oligoclonal bands (OCBs); evaluation of polyspecific, intrathecal humoral immune response against viral agents including antibodies to measles, rubella and varicella zoster virus (MRZ) reaction (MRZR); and further CSF analysis for *Borrelia burgdorferi,* neurotropic viruses, and central nervous system (CNS) parasites. Lifestyle habits, smoking and alcohol consumption were also analyzed. All data obtained from medical records were examined and entered into the database.

Descriptive statistics was used to describe the basic data characteristics. Quantitative analysis was performed to provide summaries of the sample and measures.

Results

Analysis of the hospital-based registry included 240 MS patients admitted to the Clinical Department of Neurology, Sestre milosrdnice University Hospital Centre between January 1, 2014 and January 1, 2015. There were 55 (22.92%) male and 185 (77.08%) female patients, mean age 34.4 (range 18-65) years. In the total group of patients, family history of MS was positive in 3.7% of male *vs.* 1.61% of female patients. Stratification according to MS disease subtypes showed that PPMS was present in 6.38% of male and none of female patients; RRMS in 89.36% of male *vs.* 92.13% of female patients; and SPMS in 4.26% of male *vs.* 7.09% of female patients. Functional disability stratification showed the mean EDSS score of 1.81 in male *vs.* 1.79 in female patients. Cerebral MRI T2/FLAIR CNS lesion load quantification showed that 31.58% of male *vs.* 37.82% of female patients had 0-9 lesions; 52.63% of male *vs.* 53.21% of female patients

10-20 lesions; and 15.79% of male *vs.* 8.97% of female patients more than 20 lesions. CSF protein index finding was positive in 17.86% of male *vs.* 5.88% of female patients. Blood-brain-barrier permeability was affected in 70.37% of male *vs.* 50% of female patients. OCBs were present in 90% of male *vs.* 88.96% of female patients. MRZR was negative in all patients. CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites was negative in 91.8% of male *vs.* 98.08% of female patients. Data on previous immunization showed that 87.18% of male *vs.* 75.53% of female patients were immunized. HBV vaccination was positive in 30% of male *vs.* 35.19% of female patients. Other nonspecific vaccination was positive in 10.53% of male patients and negative in female patients. When stratified by lifestyle habits, there were 33.85% of smokers among male *vs.* 21.8% of female patients. There were 15.63% of alcohol consumers among male *vs.* 5.29% of female patients.

Stratification according to gender and age (0-18, 18-45, 45-55, 55-65 and >65 age groups) showed age group differences in the group of male patients.

In the group of male MS patients aged 1-18 years, there were 3 patients (mean age, 17 years). Family history of MS was positive in 50% of patients. According to MS form, RRMS was present in all patients, with the mean EDSS score 1. Cerebral MRI T2/FLAIR lesion load quantification showed that 66.67% of patients had 10-20 lesions and 33.33% had more than 20 lesions. CSF protein index finding was positive in 50% and the blood-brain-barrier permeability was affected in all patients. OCBs were present in all patients, while MRZR and CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization showed that all patients were immunized. HBV vaccination was negative and nonspecific vaccination positive in all patients. When stratified by lifestyle habits, there were no smokers or alcohol consumers in this subgroup.

In the subgroup of male MS patients aged 18-45 years, there were 41 patients (mean age, 29.2 years). Family history of MS was positive in 3.23% of patients. According to MS form, PPMS was present in 6.45%, RRMS in 90.32% and SPMS in 3.23% of patients. The mean EDSS score was 1.73. Cerebral MRI T2/FLAIR lesion load quantification showed that 31.43% of patients had 0-9 lesions, 57.14% had 10-20 lesions, and 11.43% had more than 20 lesions. CSF

protein index was positive in 14.29% and the blood-brain-barrier permeability was affected in 74.29% of patients. OCBs were present in 93.55% of patients, while MRZR and CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization showed that 91.67% of patients were immunized. HBV vaccination was positive in 45.45% of patients, while nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were 36.84% of smokers and 16.22% of alcohol consumers in this subgroup.

In the subgroup of male MS patients aged 45-55 years, there were 8 patients (mean age, 49.5 years). Family history of MS was negative in all patients. According to MS form, all patients had RRMS form. The mean EDSS score was 2.19. Cerebral MRI T2/FLAIR lesion load quantification showed that 37.5% of patients had 0-9 lesions, 37.5% had 10-20 lesions, and 25% had more than 20 lesions. CSF protein index finding was positive in 33.33% and the blood-brain-barrier permeability was affected in 83.33% of patients. OCBs were present in all patients, while MRZR and CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization showed that all patients were immunized. HBV vaccination was positive in 25% of patients, while nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were 25% of smokers and 12.5% of alcohol consumers in this subgroup.

In the subgroup of male MS patients aged 55-65 years, there were 2 patients (mean age, 56.5 years). Family history of MS was negative in all patients. According to MS form, all patients had RRMS form. The mean EDSS score was 1. Cerebral MRI T2/FLAIR lesion load quantification showed that all patients had 10-20 lesions. CSF protein index finding was negative and the blood-brain-barrier permeability affected in all patients. OCBs were not present, and MRZR as well as CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization showed that all patients were immunized. HBV vaccination and nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were no smokers or alcohol consumers in this subgroup.

In the subgroup of male MS patients older than 65 years, there was 1 patient. Family history of MS was negative. According to MS form, the patient had RRMS. The mean EDSS score was 1. Cerebral MRI T2/FLAIR lesion load quantification showed that the patient had 0-9 lesions. CSF protein index finding was negative, and the blood-brain-barrier permeability was affected. OCBs were present, and MRZR as well as CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative. Data on previous immunization were positive, while HBV vaccination and nonspecific vaccination was negative. The patient was a smoker and alcohol consumer.

Stratification according to gender and age (0-18, 18-45, 45-55, 55-65 and >65 age groups) showed age group differences in the group of female patients.

In the subgroup of female MS patients aged 0-18 years, there were 8 patients (mean age, 17.5 years). Family history of MS was negative in all patients. According to MS form, RRMS was present in 83.33% and SPMS in 16.67% of patients. The mean EDSS score was 1.1. Cerebral MRI T2/FLAIR lesion load quantification showed that 83.33% of patients had 10-20 lesions and 16.67% had more than 20 lesions. CSF protein index was negative and the blood-brain-barrier permeability affected in all patients. OCBs were present in all patients, while MRZR and CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization showed that 40% of patients were immunized. HBV vaccination was positive in 66.67% of patients, while nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were 12.5% of smokers and no alcohol consumers in this subgroup.

In the subgroup of female MS patients aged 18-45 years, there were 149 patients (mean age, 32.7 years). Family history of MS was positive in 1.56% of patients. According to MS form, RRMS was present in 92.22% and SPMS in 6.67% of patients, while the benign course was detected in 1.11% of patients. The mean EDSS score was 1.82. Cerebral MRI T2/FLAIR lesion load quantification showed that 44.44% of patients had 0-9 lesions, 45.37% had 10-20 lesions, and 10.19% had more than 20 lesions. CSF protein index finding was positive in 4.63% and the blood-brain-barrier permeability affected in 54.08% of patients. OCBs were present in 93.52% of patients, and MRZR

was negative in all patients. Serology for *Borrelia burgdorferi* and neurotropic viruses was positive in 10.42% and serology for CNS parasites was positive in 2.44% of patients. Data on previous immunization showed that 79.41% of patients were immunized. HBV vaccination was positive in 36.11% of patients, while nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were 20.98% of smokers and 5.63% of alcohol consumers in this subgroup.

In the subgroup of female MS patients aged 45-55 years, there were 25 patients (mean age, 50.4 years). Family history of MS was positive in 5.26% of patients. According to MS form, all patients had RRMS. The mean EDSS score was 1.53. Cerebral MRI T2/FLAIR lesion load quantification showed that 22.73% of patients had 0-9 lesions and 77.27% had 10-20 lesions. CSF protein index finding was positive in 6.25% and the blood-brain-barrier permeability was affected in 52.94% of patients. OCBs were present in 75% of patients, while MRZR was negative in all patients. CSF analysis for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites was negative in all patients. Data on previous immunization showed that 66.67% of patients were immunized. HBV vaccination and nonspecific vaccination was negative in all patients. When stratified by lifestyle habits, there were 12.5% of smokers and 4.7% of alcohol consumers in this subgroup.

In the subgroup of female MS patients aged 55-65 years, there were 4 patients (mean age, 59.5 years). Family history of MS was negative in all patients. According to MS form, all patients had RRMS. The mean EDSS score was 1. Cerebral MRI T2/FLAIR lesion load quantification showed that 50% of patients had 0-9 lesions and 50% had more than 20 lesions. CSF protein index finding was negative in all patients, and the blood-brain-barrier permeability was affected in 25% of patients. OCBs were present in all patients, while MRZR, as well as serology for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization, HBV vaccination and nonspecific vaccination were negative in all patients. When stratified by lifestyle habits, there were 75% of smokers and no alcohol consumers in this subgroup.

In the subgroup of female MS patients older than 65 years, there were 3 patients (mean age, 61.4 years).

Family history of MS was negative in all patients. According to MS form, all patients had RRMS. The mean EDSS score was 2. Cerebral MRI T2/FLAIR lesion load quantification showed that all patients had 10-20 lesions. CSF protein index finding was negative in all patients, and the blood-brain-barrier permeability was affected in 66.67% of patients. OCBs were present in all patients, while MRZR and serology for *Borrelia burgdorferi*, neurotropic viruses and CNS parasites were negative in all patients. Data on previous immunization, HBV vaccination and nonspecific vaccination were negative in all patients. There were 33.33% of smokers and 33.33% of alcohol consumers in this subgroup.

Discussion

Multiple sclerosis is the most common chronic neurologic disease in adults between 20 and 50 years of age, with the peak onset in early thirties, which is in accordance with data collected in this registry. Women are generally affected approximately twice as often as men[1-3]. Our hospital registry data demonstrated that women were affected with MS three times as often as men. Positive family history of MS increases the risk of developing the disease. Registry data showed positive family history of MS in 3.7% of male *vs.* 1.61% of female patients. The natural history of MS suggests that there are different patterns of disease course[5-8]. RRMS presentation is observed in the majority of MS patients (80%-85% of MS population), which is in accordance with the results of our study, where the remitting relapsing course was present in 89.36% of male and 92.13% of female patients.

Approximately 65%-70% of RRMS patients experience gradual accumulation of disability and fewer relapses later in the course of disease, which evolves into SPMS characterized by neurodegenerative features. The median time for patients with RRMS to progress into SPMS is about 10 years[7,8]. According to the results of our registry, the SPMS course was present in 4.26% of male *vs.* 7.09% of female patients. PPMS patients experience progression of disability from the onset of disease. Stratification according to MS disease type in our study showed that PPMS was present only in 6.38% of male patients.

Disability accumulation refers to worsening in EDSS score, either due to incomplete recovery from relapses or occurring independently of relapses, irrespective of the MS course. Functional disability stratification in the total group of patients showed that the mean EDSS score was 1.81 in male and 1.79 in female patients, referring to the range of no disability or minimal disability according to functional scores, possibly due to appropriate treatment of patients.

A patient with the relapsing course but no relapses, and new or unequivocally enlarging T2 lesions during the assessment period could be considered inactive, as well as a patient with PPMS with no acute attacks and no MRI activity[9,10]. Cerebral MRI T2/FLAIR lesion load analysis showed that 31.58% of male *vs.* 37.82% of female patients had moderate (0-9 lesions) lesion load; 52.63% *vs.* 53.21% had significant (10-20) lesion load; and 15.79% *vs.* 8.97% had progressive (more than 20) lesion load. In the majority of patients, MRI quantification verified significant lesion load, which was in accordance with the prevalent RRMS course of the disease.

Cerebrospinal fluid IgG levels or IgG index are consistently elevated in MS, due to increased intrathecal IgG synthesis, resulting in abnormal OCBs. Detection of OCBs has been established as the most useful CSF marker to aid in the diagnosis of MS[11]. In our study, CSF protein index finding was positive in 17.86% of male *vs.* 5.88% of female patients. Blood-brain-barrier permeability was affected in 70.37% of male *vs.* 50% of female patients, and OCBs were present in 90% of male *vs.* 88.96% of female patients. The majority of patients with MS display MRZR. However, a positive MRZR can also be found in patients with CNS vasculitis, raising the question whether it is a high specificity marker of MS or nonspecific marker of CNS autoimmunity. In our study, MRZR was negative in all female and male patients. Further investigations of MRZR in rare autoimmune conditions, which were not available for analysis in this study, are reasonable to refine further the specificity of this parameter. A variety of neurotropic viruses have been linked to MS. Data on previous immunization including measles and rubella virus showed that 87.18% of male and 75.53% of female patients were immunized. HBV vaccination was positive in 30% of male and 35.19% of female patients. Other nonspecific vaccination was positive in 10.53% of male patients and negative in all female patients. In our group of patients, serology data on *Borrelia burgdorferi* and neurotropic viruses, and se-

rology data on CNS parasites were negative in 100% of male and 98.08% of female patients.

There is strong evidence from meta-analysis and case-control studies that smoking is associated with MS[12-16]. Although self-reported smoking status can be reliable, the accuracy of this measure is reduced in lower socioeconomic groups, younger ages, and in some ethnic groups. When stratified by lifestyle habits, in our group of patients there were 33.85% of male smokers *vs.* 21.8% of female smokers. Possible alcohol abuse and drug misuse were associated with younger age, less severe MS related disability and being employed, as well as greater self-reported depressive symptoms[17]. In our study, there were 15.63% of male *vs.* 5.29% of female alcohol consumers.

There were several significant limitations of this study. Some data were not carefully monitored and were found unreliable, thus being excluded from the analysis. These were current treatments and long-term outcomes. We plan to improve this registry by expanding it to the national MS patient database and collecting relevant laboratory data, adverse events and comorbidity according to MS subtypes. A multi-faceted approach was accepted but not used correctly by the staff, thus limiting data collection. Quantitative and qualitative methodologies for relevant statistical analysis were ongoing during presentation of study results, thus reliable statistical analysis was not possible.

Conclusion

In conclusion, the results of our study showed that the majority of MS patients recorded in the Clinical Department of Neurology hospital-based registry were young adults, in early thirties, with the prevalent remitting relapsing course of the disease. Functional disability stratification of the total group of patients showed low EDSS score, referring to the range of no disability or minimal disability. Cerebral MRI quantification verified significant lesion load in the majority of patients, in accordance with the prevalent RRMS course of the disease. Blood-brain-barrier permeability was affected in the majority of patients, both male and female, with positive OCBs. In our study, MRZR was negative in all patients, further refining the specificity of this parameter. Data on previous immunization showed that the majority of patients, both male and female, had been immunized previously. When strati-

fied by lifestyle habits, in the total group of patients, smokers were prevalent among male patients, and there were three times more alcohol consumers in the group of male as compared with female patients. Accordingly, the hospital based MS registry established at the Clinical Department of Neurology, Sestre milosrdnice University Hospital Centre should be improved to provide all necessary data for a reliable statistical analysis. However, this registry could be considered as a prototype for the national Croatian MS registry, with more clinical hospital centers joining in the future. There is a potential, beyond this study, that the information provided in the MS registry could be inserted into clinical records, thereby directly influencing the care that MS patients receive.

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Sažetak

PRVI BOLNIČKI REGISTAR BOLESNIKA S MULTIPLOM SKLEROZOM U HRVATSKOJ

V. Bašić Kes, M. Lisak, M. Jurašić, I. Zavoreo, A. Dimitrović, I. Kobasić i *L. Zadro Matovina*

Prvi bolnički registar bolesnika s multiplom sklerozom (MS) u Hrvatskoj uspostavljen je 2014. godine u Klinici za neurologiju, Klinički bolnički centar "Sestre milosrdnice", Zagreb. Cilj registra je kontinuirano prikupljanje podataka o broju hospitalno obrađenih bolesnika s MS, oblicima bolesti, prediktorima napredovanja onesposobljenosti, životnim navikama i dugoročnim ishodima za bolesnike. Relevantni medicinski podaci u registru MS uključivali su procjenu dobi i spola bolesnika, obiteljsku anamnezu na MS, podatke o prethodnim imunizacijama, tijeku bolesti, procjenu funkcionalne onesposobljenosti, kvantitativni prikaz lezija mozga magnetskom rezonancijom (MRI) i analizu cerebrospinalnog likvora. Nadalje, analizirane su životne navike bolesnika uključujući pušenje i konzumaciju alkohola. Svi podaci iz bolničke medicinske dokumentacije koji su prikupljeni od 1. siječnja 2014. godine do 1. siječnja 2015. godine upisani su u bazu podataka. Retrospektivno smo analizirali podatke prema dobi i spolu. Relevantni rezultati su pokazali da većina registriranih bolesnika ima relapsno remitirajući oblik bolesti s niskim stupnjem funkcionalne onesposobljenosti. Analiza cerebrospinalnog likvora u većine bolesnika pokazala je pozitivne oligoklonske vrpce i poremećenu propusnost krvno-moždane barijere. Kvantitativna MRI analiza mozga pokazala je značajno opterećenje brojem cerebralnih lezija u većine bolesnika, što odgovara relapsno remitirajućem obliku bolesti. Podjela prema životnim navikama pokazala je da je bilo više pušača i konzumenata alkohola u skupini muških bolesnika. Naš bolnički registar može poslužiti kao prototip za uspostavljanje nacionalnog registra MS, ali ga treba poboljšati kako bi se osigurali svi potrebni podaci za pouzdanu statističku analizu podataka.

Ključne riječi: *Multipla skleroza; Registri; Medicinska dokumentacija; Bolest, napredovanje; Hrvatska*