Multiple sclerosis in South Africa

Girish Modi, Andre Mochan, Madelein du Toit, Ivan Stander

Since there are no well-documented epidemiological studies on multiple sclerosis (MS) in South Africa, we devised a questionnaire to determine qualitative data. Responses were obtained from 430 patients: 91% had magnetic resonance imaging (MRI) scans, 64% had lumbar punctures and 49% had evoked potentials to establish the diagnosis of MS. A total of 71% of the respondents were aged 30 - 59 years, 73% were female, and 89% were white. In terms of MS type, 46% had relapsing-remitting MS, 13 % secondary progressive MS, 12% primary progressive MS, 12% benign MS, and 17% not known. Disease-modifying treatment was not used by 32% of respondents, and 30% were treated with methotrexate and 22% with interferon beta. These findings are similar to those in the literature, except for the under-utilisation of interferons as disease-modifying treatment.

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Three geographical zones based on worldwide prevalence are distinguishable for MS.[1] High-incidence regions have a prevalence of >30 sufferers per 100 000 of the population, and include most of Europe, Israel, Canada, northern USA, south-eastern Australia, New Zealand and eastern Russia. Medium-frequency regions (5 - 30 per 100 000) include the southern USA, the rest of Australia, South Africa (SA), the southern Mediterranean basin, Russia (including Siberia), the Ukraine and parts of Latin America. Prevalence rates of <5 per 100 000 include the rest of Asia, Africa and northern South America.[1] Regional categorisation of MS is based on extrapolations of known or documented prevalence and incidence statistics on MS from the USA, the UK, and parts of Europe.[2] In the USA, the prevalence rate for MS is approximately 1 in 700 (0.14%). An extrapolated SA prevalence rate of 1 in 700 is described – 63 497 MS sufferers. These figures, while inaccurate,[2] also indicate a scarcity of literature on the prevalence and incidence of MS worldwide, including SA; we found only four such articles concerning SA.[3-6] These discuss MS in the white population, differences in prevalence rates between immigrant and non-immigrant white populations, and the possibility of an increased MS prevalence in Afrikaans-speaking white people.[6] There are no reported nationwide epidemiological studies, and qualitative demographic data are also not available.

Division of Neurology, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg
Girish Modi, PhD, FCP (SA), FRCP
Andre Mochan, FCP (SA)
Multiple Sclerosis Society of South Africa
Madelein du Toit
Ivan Stander

Corresponding author: *G Modi (gmodicns@mweb.co.za)*

Design and methods

A patient-orientated questionnaire was distributed in a countrywide survey. It was made available on the website of the Multiple Sclerosis Society of South Africa (MSSA) (www.multiplesclerosis.co.za), which has 1 760 members, and also distributed by email to 269 members and by post to 853 members.

Results

Data from 430 patients, who responded over a period of 18 months, were categorised as follows:

Regional distribution: Gauteng – 40%, Western Cape – 28%, KwaZulu-Natal – 12%, Eastern Cape – 7%, Free State – 5%, Mpumalanga – 3%, Northern Cape – 1%, North-West Province – 1%, Limpopo – 1%, not disclosed – 2%.

Age (in years): 0 - 29 – 4%, 30 - 39 – 19%, 40 - 49 – 28%, 50 - 59 – 24%, 60 - 69 – 14%, 70 - 79 – 5%, not disclosed – 6%.

Gender: Female – 73%, male – 26%, not disclosed – 1%.

Ethnicity: White – 89%, mixed ancestry – 3%, Indian – 3%, black – <1%, not disclosed – 5%.

Type of MS: Remitting and relapsing (RRMS) – 46%, secondary progressive (SPMS) – 13%, primary progressive (PPMS) – 12%, benign (BMS) – 12%, not known – 17%.

Diagnosis ascertainment: We established the diagnostic methods used to determine a diagnosis of MS: 7% had no tests, 1% had a lumbar puncture only, 1% had a lumbar puncture and evoked potential tests, 11% had magnetic resonance imaging (MRI) scans and evoked potential tests, 18% had MRI scans only, 25% had MRI scans and a lumbar puncture, and 37% had MRI scans, a lumbar puncture and evoked potential tests. The diagnosis of MS was made in 91% of respondents by a neurologist.

Current treatment: Low-dose naltrexone – 1%, imuran – 2%, alternative homeopathic medication – 15%, interferon – 22%, methotrexate – 30%, no medication – 32%.

Discussion

The MSSA estimate that there are 5 000 MS sufferers in SA.[8] Our survey sample size of 430 respondents is therefore adequate for appropriate conclusions to be drawn. To obtain qualitative epidemiological information on MS in SA, we determined the categories identified and presented to be most pertinent.

Diagnosis statistics are important in our setting because of the few neurologists and limited availability of MRI. In 7% of our respondents, MS was diagnosed purely on clinical grounds or by excluding other illnesses through laboratory tests. No specific MS-related tests were done. A further 1% of patients had a lumbar puncture as the only MS-confirming test. In 18% of cases, the only investigation was an MRI scan. In the remainder, a combination of tests was performed to assist in diagnosing. In total, 91% had MRI scans, 64% had lumbar punctures, and 49% had evoked potentials. Diagnoses of MS were originally based on the Poser criteria,[9] but more recently are influenced by the McDonald criteria[10] that are more biased by MRI use. Seven per cent were diagnosed without the use of MRI or laboratory evaluations. It is not known whether these respondents were diagnosed by neurologists who did not have MRI equipment available or were comfortable using Poser's clinical criteria. Our survey trend towards MRI to diagnose MS, consistent with international trends, also allows more meaningful interpretations. The surprisingly high use of lumbar punctures and evoked potentials to help in establishing the diagnosis will probably change as public sector MRI availability increases and costs become less prohibitive. Data were not available on gadolinium enhancement and multiple-region MRI scans.

Despite the small number of neurologists in SA (60 estimated in active practice – unpublished Neurological Association of South Africa statistics), the diagnosis of MS was made by a neurologist in 91% of respondents.

Most respondents were from Gauteng and Western Cape, although these provinces only account for 19.2 and 9.9% of the total population respectively,[11] which is not surprising as they are the major centres of activity of support groups such as the MSSA. The low response rate from KwaZulu-Natal (20.6% of the country's total population) corresponds with its small number of MSSA members.

Most respondents were in the 40 - 49-year category (28%), followed by 50 - 59 years (24%), 30 - 39 years (19%), 60 - 69 years (14%), 70 - 79 years (5%), and 0 - 29 years (4%); 6% did not disclose their ages. The 30 - 59-year group comprised 71%. Our survey is consistent with MS literature which shows that two-thirds of patients have their disease onset between the ages of 20 and 40 years;[12] the remaining one-third develop the disease before the age of 20 years.[12] The respondents could not accurately recall either date of diagnosis or date of disease onset, and we therefore only recorded their current ages. The largest group was in the 40 - 49-year age category, which would be consistent with age of onset of between 20 and 40 years.

Respondents were predominantly female (73%). The female-to-male ratio of approximately 3:1 is consistent with the literature.[12] The ethnicity of our respondents was predominantly white (89%), reflecting the demography of the respondents, and is a point-of-entry bias. The disease is considered rare in African blacks,[1-6] with only 12 reported black patients from South Africa and Zimbabwe with possible MS.[13] It has been postulated that the phenotypic expression of MS in black African patients is different to that of whites/Caucasians, and this possibly explains the lack of cases.[14,15] The traditional myth among our clinicians that MS does not occur in the black population may also contribute to the paucity of described MS cases in blacks. Our experience is that black patients with an apparent phenotype of MS are actively investigated for possible alternative explanations and left with a diagnosis of 'uncertainty' or idiopathic/nonspecific CNS demyelination. MS in patients with mixed ancestry and of Indian descent represented 3% of our respondents.

Remitting-relapsing MS constituted the predominant MS type (46%); 17% were not aware of their respective MS type; 12% were categorised as benign MS, and 12% as PPMS. Our data are similar to those from New York and the New York State MS consortium.[16,17]

Concerning treatment, most respondents used no disease-modifying therapy (DMT); 39% used methotrexate as their DMT; only 22% used a beta-interferon for disease modulation, although 59% would be candidates for this treatment option (46% with RRMS and 13% with SPMS); and 15% used alternative treatments. Funding issues largely determine the treatment of MS in SA in the public and private sectors. Beta-interferons have only recently been accepted as DMT in RRMS and SPMS. In other forms of MS, beta-interferon therapy is not subscribed to. Glatiramer acetate has only very recently become available in SA. Methotrexate is more readily used because of easier access from funding agencies and lower cost.

Our data indicate that MS in SA is widely described in the white population but only rarely in the black community; most people with the disease fall into the 40 - 49-year age group; it predominantly afflicts females (F:M = 3:1); there is a spread of disease types, with RRMS being the most common; and DMTs, in particular the beta-interferons, are not advocated or used as extensively in treatment as elsewhere.

Biases in our study include website availability, and postal services and telecommunications as the central point of data entry is determined by respondents. This limitation probably explains the skewed distribution of more respondents from Gauteng and Western Cape. Our survey cannot provide accurate prevalence and incidence data, but provides qualitative epidemiological data on MS in this country. The under-utilisation of beta-interferons as DMT is disturbing and a cause for concern among public and private health care funders, health care providers and patients.

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