

P103

Challenges in the Diagnosis of Primary Progressive Multiple Sclerosis in Egypt

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Background: Recent researches trend toward focusing on primary progressive multiple sclerosis (PPMS) specifically after introduction of recent disease modifying treatments for PPMS. Our objective was to highlight the causes of delayed and misdiagnosis of PPMS in Egypt to shorten the time of diagnosis and improve the prognosis for patients with PPMS.

Methods: This is a retrospective descriptive study. Data of PPMS patients was extracted through imed system at ain shams MS unit registry. We retrieved the proportion of patients diagnosed with PPMS as per 2010 McDonald criteria, time to diagnosis, and disease progression. We also identified, through a questionnaire applied (direct and via phone calls) on PPMS patients the factors affecting delayed and misdiagnosis.

Results: Among 1500 clinically definite MS patients, we observed decreasing trend of PPMS diagnosis: Only 27 patients were diagnosed with PPMS representing (1.8%) of the MS patients. The mean age was 40.07±9.14 years at time of PPMS diagnosis and the majority of PPMS were males (63%). Median time between disease onset to diagnosis of PPMS was 60 (range 24-385) months. The median expanded disability status scale (EDSS) at time of diagnosis was 6.5 (range 4.5-8) and the most common presenting symptoms were motor and focal spinal (74.1%). Only 33.3% of the patients consulted a neurologist and 66.7% consulted non neurologist 66.7% (p-value= 0.023). The median time to neurologist referral was 24 (range 1-288) months. Initial alternative diagnosis was performed by non neurologist in 51.9% of the patients. PPMS was misdiagnosed as relapsing remitting MS (RRMS) by neurologist in 25.9% of the patients and the proportion of patients who delayed first doctor consultation was 11.1%.

Conclusions: The delayed diagnosis of PPMS in Egypt was mainly due to delayed referral to neurological consultation (66.7% non neurologist) and initial alternative diagnosis. Additional causes include the trend of misdiagnosing PPMS as (RRMS) by some neurologist and the reluctance of some patients to seek medical advice. This delay had a bad impact on the patient and is reflected by a high EDSS at time of PPMS diagnosis (median 6.5). Education about the disease to non neurologist especially neurosurgeons, orthopedics and ophthalmologists is important to speed up diagnosis and treatment initiation.