

The need for a multiple sclerosis registry in the Gulf Region

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Multiple sclerosis (MS) is a chronic inflammatory demyelinating disease of the central nervous system. Multiple sclerosis has become one of the most prevalent neurological disorders among adults aged 20-40 years. The MS prevalence rates are expected to increase with time. The Gulf region was previously thought to be a low-risk region for the development of MS. However, recent reports from Dubai, the United Arab Emirates, and Qatar showed an increase in both the prevalence and incidence rates of MS.^{1,2} It is expected that other Gulf countries would show a similar increase in the rates, given improvements in both case ascertainment and case definitions. Diagnostics and therapeutics for MS have certainly evolved over the last decade, resulting in increased awareness among health care providers, treating physicians, and patients. Our objective is to discuss the need to establish a MS registry in the gulf region by addressing the advantages of having a unified database in our region.

Despite tremendous advances in MS research over the past few decades, the disease continues to place a substantial burden on patients and their families, health care systems, and the society. The clinical presentation and characteristics of MS in the Middle East are similar to the disease's features in Western countries.³ There is no available data on the natural history of MS in the Gulf region, and it may differ from the known history of MS in Western countries, given differences in genetic and environmental predispositions. There is increasing interest in studying disease characteristics in large cohorts after different disease-modifying therapies (DMTs) were introduced to assess changes in the natural history of MS after treatment, and to monitor the future long-term outcomes of disease progression.

Disease registry generation is a systemic process of collecting secondary data related to patients with a specific diagnosis or condition, or who have undergone a specific procedure. Disease registries are a valuable source of information for health care policy makers and planners. In contrast to clinical databases, registries collect a larger amount of core data and contain information on demographics, disease course, disability, and medication, and on other important socioeconomic data, hospitalization, mortality rates, and the use of health care services.⁴ Data from disease registries help to improve health care delivery and research. An MS registry in the Gulf region would serve as an important source of national and regional epidemiological data. The MS registries would provide the opportunity to follow populations of MS patients over decades and focus on certain groups, such as patients with aggressive or progressive disease and the pediatric population. Most randomized clinical trials (RCTs) focus on a particular subgroup of MS patients, namely, those with only a relapsing-remitting course, those with a certain degree of disability, and/or those who have not received previous treatment (naïve patients).⁵ However, regional and national registries would include nearly all patients within the area regardless of the disease course, disability measures, or treatments, which would result in the comprehensive assessment of the demographics of an MS population. Detailed data on the characteristics of

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MS patients and their disease across the Gulf region could provide new insights into the causes of the disease.

National and regional registries allow accurate measurements of prevalence, and incidence rates, which can be used to predict the future risk of developing MS. Recent and frequent revisions of the diagnostic criteria for MS have led to an increase in the number of diagnosed cases. Although this phenomenon might not represent a true increase, case ascertainment using specific diagnostic criteria through MS registries would enable us to accurately assess the prevalence and incidence rates in specific regions, and thus to assess the true incidence over time. Registries monitor trends in MS epidemiology, including gender- and age-specific incidence and prevalence, to provide insights into the role of possible etiological agents across populations within a region.

This additional information could help with informing health authorities on the specific needs of the MS population, including the need to establish multidisciplinary MS centers. In addition, MS registries can be used to adequately allocate resources for diagnostics and treatment facilities, which would result in better assessment and monitoring of patients' health. With the increasing treatment options in the last 3 years, implementation and adherence to consensus guidelines can also be monitored.³ After receiving valuable information on the disease, health authorities may promptly establish awareness campaigns that increase understanding of, and knowledge of MS, and allow the MS Society to participate in planning and decision-making.

Unemployment after diagnosis is another aspect that needs to be studied in the Gulf region. Most MS patients are in their productive years, and the impact of losing their jobs cannot be underestimated, as this results in a significant socioeconomic burden. Longitudinal data on medical and socioeconomic status can be used to assess and compare the impact of medical and social services offered to people with MS. Furthermore, quality-of-life measures could be collected through MS registries, which would enable health care stakeholders to assess the need for specialized support personnel, such as social workers, occupational therapists, and psychologists.

Once well-designed registries are established, they can be compared to other long-term international registries and databases. Collaboration between MS centers and national registries has been already established to promote research projects, resulting in significant statistical power given the inclusion of large cohorts of patients in different countries. The European Register for Multiple Sclerosis (EURMS) was founded in 1989 and has representatives in 34 European countries. The

EURMS aims to collect comparable, reliable data on MS from across the region, and these data have the potential to fill in several gaps in the understanding and management of this disorder. The registry also promotes the development of joint action programs with national MS societies in Europe that aim to improve the quality of their activities and services and act as a focal point for liaising with institutions of the European Union (EU) to study and propose measures to improve the autonomy of handicapped people and to promote their full participation in society.⁴

Consistency between registries could take multiple forms, including the following: having all databases focus on the same time period; comparing similar, complete data for a specific time period; or comparing data from different registries in response to the same question during the same time period. A registry can be a powerful tool for assessing predictors of the conversion of clinically isolated syndrome (CIS) patients into clinically definite MS (CDMS) patients, monitoring the rates of disabilities and measuring the incidence of comorbidities in MS. Although combining registries from different countries or regions may result in bias caused by the heterogeneity of the populations and differences in case definitions and ascertainment, a long-term database on a chronic condition such as MS is invaluable for acquiring better knowledge of MS.

In summary, the information collected through a registry should provide a foundation for evaluating and understanding the natural history, geography and clustering of MS; variances in the gender ratio of the disorder; the disease burden on socioeconomic status; and changes in health care practices. A national registry would allow the future planning of health care, the detection of changes in health practices, and the promotion of advocacy, and would support a wide range of research initiatives.

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