Requirements of the National Multiple Sclerosis Disease Registry System: A Review of Experiences

Ulusal Multipl Skleroz Hastalığı Kayıt Sisteminin Gereklilikleri: Deneyimlerin Gözden Geçirilmesi

Niloofar Mohammadzadeh[1], Ehsan Ghazanfarisavadkoohi[2], Sahar Khenarinezhad[3], Mohammad Saleh Safari[3]

[1]Department of Health Information Management, School of Allied Medical Sciences, Tehran University of Medical Sciences, Tehran, Iran.
[2]School of Allied Medical Sciences, Tehran University of Medical Sciences, Tehran, Iran.
[3]Department of Health Information Technology, Faculty of Para Medicine, Mazandaran University of Medical Sciences, Sari, Iran
[4]Veterinary Faculty of Science and Research Branch Islamic Azad University, Tehran, Iran

ABSTRACT

Background: Creation Multiple Sclerosis (MS) disease registries to comprehensive analysis and reduce the burden of the disease is important. The aim of this study was to identify and describe the structures of the MS registries and key features.
Methods: This is a comparative descriptive study. The keywords used for the search including Multiple Sclerosis, MS, Registry system, Data bases and combination them with Boolean operators AND/ OR. The relevant articles published in the English language were extracted, without any time limitation.
Results: The Oslo, European database and German Pregnancy registry are local, Also Croatia and Australia registries are at the hospital and international level. Regular follow-up is done in ten registries. In the eight registries, the diagnostic criteria item is recorded.
Conclusions: Knowledge of the incidence, survival, and death rate of MS disease enables health policymakers to identify at-risk groups and provide regular care for them. MS registry provide valuable information on the occurrence and distribution of MS in a specific area. So it appears that the identified information elements and use of them in the MS registries are at the core of the national MS control program and can lead to appropriate decisions at the national level.

Key words: Multiple Sclerosis, Registry system, Databases, Minimum data set, Data Element

ÖZET

Amaç: Multipl Skleroz (MS) hastalık kayıtlarının oluşturularak kapsamlı analizi ve hastalığın yükünü azaltmak için önemlidir. Bu çalışmanın amacı, MS kayıtlarının yapılarını ve temel özelliklerini tanımlamak ve açıklamaktı.
Yöntem: Bu karşılaştırmalı tanımlayıcı bir çalışmadır. Multipl Skleroz, MS, Kayıt sistemi, Veri tabanları dahil arama için kullanılan anahtar sözcükler ve bunları Boole operatörleri VE / VEYA ile birleştirin. İngilizce yayınlanan ilgili makaleler herhangi bir süre sınırlaması olmaksızın çıkarıldı.
Bulgular: Oslo, Avrupa veri tabanı ve Alman Gebelik kaydı yereldir, Ayrıca Hırvatistan ve Avustralya kayıtları hastane ve uluslararası düzeydedir. On adet kayıtta düzenli takip yapılmaktadır. Sekiz kayıtta, tanı kriterleri maddesi kaydedilir.
Sonuç: MS hastalığının insidansı, sağkalımı ve ölüm oranı hakkındaki bilgi, sağlık politika yapıcılarının risk altındaki grupları belirlemesine ve onlara düzenli bakım sağlamasına olanak tanır. MS kaydı, MS'nin belirli bir alanda oluşumu ve dağılımı hakkında değerli bilgiler sağlar. Bu nedenle, tanımlanan bilgi unsurlarının ve bunların Üye Devlet kayıtlarında kullanımının, ulusal Üye Devlet kontrol programının merkezinde yer aldığı ve ulusal düzeyde uygun kararlara yol açabileceği görülmektedir.

Anahtar Sözcükler: Multipl Skleroz, Kayıt sistemi, Veritabanları, Minimum veri seti, Veri Elemanı

ORCID IDs: N.M. 0000-0001-7586-9227, E.G. 0000-0002-9974-5517, S.K. 0000-0001-8860-3225, M.S.S. 0000-0003-1584-4639

INTRODUCTION

Multiple sclerosis (MS) is a disease of the central nervous system (CNS) that is characterized by impairment of the functional and sensory system, that leading to inflammation and damage to the axon. This inflammation damages the oligodendrocyte and affects the nerve signal in every part of the body. For this reason, MS is the most common causes of neurological disability in young adults. This disease usually occurs in young adults 20-50 years of age. A peak of this disease is at the age 30 but may occur in rare cases in children or older people(1-3). Common signs and symptoms of MS include numbness, motor weakness, visual disturbances, diplopia, dizziness, fatigue, urinary urgency, sexual dysfunction, ataxia, and loss of bladder control(1, 4). The prevalence of MS has increased significantly in the world and varies in different countries. This disease has affected more than 2 million people worldwide(5). According to Kurtzke study, the prevalence of MS in the world is divided into three categories: a) prevalence of less than 5 per 100,000 population as low-risk areas, b) the prevalence of 5-30 as intermediate risk, c) and prevalence of over than 30 as high-risk areas(6). MS is more common in European countries and less frequent in Asian and Africa countries. The highest prevalence reported in the Orkney Islands in Scotland with a prevalence of 402 per 100000(7). Based on Kurtzke classification, the Middle Eastern countries especially Iran, were considered as a areas with low MS prevalence, although the prevalence in Iran has increased significantly in currently(8). The prevalence of MS in Iran is reported between 89 per 100000 to 148.1 per 100000 in 2019(9). Improve prevalance and control every disease need to adequate and correct patient information. So collect, store and retrevial of information, through accurate and appropriate ways by health information management systems are very important (10). A disease registry system is a type of information management systems which collects clinical and non-clinical data to evaluate outcomes in a particular population or specific situation. The data stored in these types of systems can be used to hospital care improvement(11). Information elements must be accurate, complete, and consistent with clinical objectives to create registry systems. These information elements are generated from different sources but they are using the same definitions and words. The information elements in the registry systems can be divided into two general categories. a) The general patient information elements include demographic data; b) The specific patient information elements include the progress note of the disease. Since disease registry systems are databases that often use available information elements to facilitate analysis(12-14). MS registry can be an essential tool for service delivery to ms patient. Also it is useful in monitor and control health care, and estimate the overall cost of the disease. Other abilities of ms registries are provide comprehensive information about the burden of disease in national level. Therefore, the purpose of this article was to study the requirements of the national MS Disease registry system based on a review of the experiences in different countries.

METHODS

This is a comparative-descriptive study . The keywords used for the search including Multiple Sclerosis, MS, Registry system, Data bases and combination them with Boolean operators AND/ OR. The relevant articles published in the English language were extracted, without any time limitation, by searching scientific and authoritative databases such as PubMed, Google scholar, Scopus, Web of science. Fifteen ms registry were studied based on the search strategy. MS patient registry systems and database are available in Swiss, Sweden, Denmark, North America, Germany, Norway, Oslo, Europe, Croatia, Australia, Italy, Europe and Iran. Our inclusion criteria were: Full text papers with the keywords in the title or abstracts, and studies published in English language. We excluded resources such as reports and registry systems that did not have sufficient information about data elements or we could not retrieved these items. We have classified existing registry based on features. These features include: name and type of MS registry, domain, objective, institution of establish, number of patients, the year of start activity and do follow-up or not(table 1). Then, comparison was performed using a series of categories. These categories include: demographic data, diagnosis data, diagnostic tests, treatment data, lifestyle data and visit data(table 2). there is only one registry system for multiple sclerosis patients in Austria treated with natalizumab is available, which does not retrieve details of system data so deleted from this study(15).

RESULTS

German and Denmark have two diffierent systems. In Denmark, there are two registry systems including the Danish MS registry and the Danish MS treatment registry which Danish MS registry system in 1948 collect information to estimate the prevalence and burden of MS disease. Treatment registry was developed by the MS Group in 1996 and was on only registry to investigate the long-term effects of interferon-beta drugs. Also in Germany, two existing registry systems are the MS registry and the Pregnancy registry for MS patients. The MS registry System since 2001 collected MS patients to estimate the prevalence and burden of disease, as well as cost-effectiveness of long-term treatment. Pregnancy registry in MS patients was established in 2013 to determine the impact of interferon-beta exposure during pregnancy on pregnancy outcomes. The main purposes of these registries were as follows: a) epidemiology surveillance and disease burden estimation (n = 7 registries), b) cost and effectiveness of long-term treatments (n = 5 registries), c) data collection (n = 5 registries), d) clinical research (n = 3 registries), E) health care quality management (n = 1 registry), F) determining the effect of interferon-beta drugs during pregnancy on pregnancy outcomes (n = 1 registry) , G) sharing MS patients data at different centers (n = 1 registry), H) improving the care and treatment of MS patients (n = 1 registry).
The European countries use a database called Edmus to record MS patient. this European MS database is supported by the European community commission. Edmus collect data on genetic information and medical history of the disease, data on the patient's biological sample, current status score, immunological treatments, signs and symptoms, results of current investigations such as electrophysiology, magnetic resonance imaging and cerebrospinal fluid analysis(16).

Table 1. Key features of 13 MS registries

Country	Name and type of MS registry	Domain	Objective	Institution	Nomber of patient data	Start	Follow up
Swiss(17)	Swiss MS registry (SMSR)	National	-epidemiological surveillance - estimate the burden of MS - clinical research	Swiss MS Society	1605	2016	semi-annual
Sweden (18, 19)	Swedish MS registry (SMSreg)	National	- assess the cost - assess effectiveness of long-term treatments	Swedish MS Society (SMSS)	16000	2001	Yes
Denmark (19-21)	Danish MS registry (DMSR)-	nationwide	- epidemiological surveillance - estimate the burden of MS	Danish Multiple Sclerosis Society	20000 (12.500 were still alive)	1956	No
	Danish MS treatment register (DMSTR)	National	- assess the cost - assess effectiveness of long-term treatments	Danish Multiple Sclerosis Group (DMSG)	more than 8,400	1996	3 months after treatment start, every 6 months
North American (19, 22, 23)	Narcoms Registry	National	- epidemiological surveillance - estimate the burden of MS - clinical research	Consortium of Multiple Sclerosis Centers	38000	1993	Semi-annual
German (19, 24-26)	MS registry in Germany (DMSG)	nationwide	- epidemiological surveillance - estimate the burden of MS - assess the cost - assess effectiveness of long-term treatments - collect data of all MS patients	German MS Society, European Multiple Sclerosis Platform (EMSP)	~ 30,000	2001	NO
	German MS and Pregnancy registry (Gmspr)	Local	- determine the effect of interferon-beta exposure during pregnancy on pregnancy outcomes in multiple sclerosis patients	local institutional review board of the Ruhr University Bochum	~ 251	2013	NO
Norway(19, 27)	Norwegian MS registry and biobank	National	- clinical research - assess the cost - assess effectiveness of long-term treatments - Quality management of health care	University Hospital in Bergen	~ 6000 patient + 2200(DNA) + 700 family member control + 300(CSF) + 80(MS brain)	1998	one year for patients without DMDs, six months for patients with DMDs
Oslo(28)	Oslo MS-registry	Local	- epidemiological surveillance - estimate the burden of MS	Multiple Sclerosis Society of Norway	1274	1990	Unknown
Croatia(24, 29)	Croatia MS registry	hospital-based registry	- epidemiological surveillance - estimate the burden of MS - assess the cost - assess effectiveness of long-term treatments	Association of MS Societies of Croatia, Sestre milosrdnice University Hospital Centre	2477	2007	Annually
Australia(30)	MSBase registry MS database	international	- epidemiological surveillance - estimate the burden of MS - collect data of all MS patients	international Scientific Advisory Board (SAB), MS International Federation	3700	2004	Annual
Italy(31, 32)	Italian MS registry	National	- collect data of all MS patients	Multiple Sclerosis Database Network (MSDN)	50000	2000	Every 2/3 months per year
European(16)	EDMUS, European Database for Multiple Sclerosis	Local	- improving the care and treatment of patients with MS - sharing of the essential data on their patients with MS	committee of the European Concerted Action for MS, Commission of the European Communities	-	1990	Yes
Iran(33)	Msregistry	-local, regional and hospital facilities in some centers. As a Pilot project	- collect data of all MS patients	Ministry of Health	2000	2018	Yes

The information elements in this systems can be divided into 6 general axes of demographic information, diagnostic information, diagnostic tests, treatment information, lifestyle information, and visit information (Table 2).

Table 2: Data collected in the 14 surveyed MS registries

Category	Sub-category	1	2	3	4	5	6	7	8	9	10	11	12	13	14
demographic data	- ID number	-	*	-	-	-	-	-	*	-	-	*	*	*	-
	- Registration date	-	*	-	-	-	-	-	-	-	-	-	-	-	-
	- patient name	-	*	*	-	-	-	-	*	-	-	-	-	*	*
	- Patient last name	-	*	-	-	-	-	-	-	-	-	-	-	*	*
	- father's name	-	-	-	-	-	-	-	-	-	-	-	-	-	*
	- Date of birth	-	*	*	-	*	-	-	*	-	-	*	-	*	*
	- Age	-	-	-	*	*	*	-	-	*	*	-	-	*	-
	- Sex	-	*	-	*	*	*	-	*	-	*	*	-	*	*
	- race	-	-	-	-	*	-	-	-	*	-	-	-	-	-
	- National Code	-	-	-	-	-	-	-	-	-	-	-	-	-	*
	- place of birth	-	-	*	-	*	-	-	-	-	-	-	-	*	*
	- Address	-	-	-	-	*	-	-	-	*	-	-	-	*	*
	- Calling number	-	-	-	-	-	-	-	-	-	-	-	-	-	*
	- telephone number	-	-	-	-	-	-	-	-	-	-	-	-	-	*
	- Employment status	*	-	-	-	*	*	-	-	-	-	-	-	-	-
	- Family history of MS	*	-	-	-	*	-	-	*	-	*	-	*	*	*
	- Informed consent	-	*	-	-	-	-	-	*	-	-	-	-	*	-
	- Insurance	*	-	-	-	*	-	-	-	-	-	-	-	-	-
diagnosis data	- Primary symptoms	*	-	*	-	*	*	-	*	*	-	*	*	*	-
	- Start date of the first symptoms	-	*	-	*	-	-	-	*	-	-	*	*	*	*
	- Age of signs	*	-	-	-	*	-	-	-	*	-	-	-	*	-
	- Time of diagnosis by the doctor	-	*	*	*	*	*	*	*	*	-	*	*	-	*
	- Disease course	*	*	-	-	*	*	-	*	-	*	-	*	*	-
	- type of disease	*	*	-	-	*	*	-	-	*	-	*	*	*	*
	- Number of relapses	*	-	-	-	-	-	-	*	-	-	*	*	*	*
	- Become SPMS	-	*	-	-	-	-	-	-	-	-	-	-	-	*
	- diagnostic criteria (McDonald, poser)	-	*	*	-	-	*	-	*	*	*	-	*	*	-
	- EDSS	*	*	-	-	*	*	-	*	-	*	*	*	*	*
Diagnostic tests	- Brain and spinal cord MRI	-	*	*	*	-	-	-	*	-	*	*	*	*	*
	- Compare new MRI with previous	-	*	-	*	-	-	-	-	-	-	-	-	-	*
	- number of new T2 lesions	-	*	-	-	-	-	-	*	-	-	-	*	-	*
	- number of GD lesions	-	*	-	-	-	-	-	*	-	-	-	*	-	*
	- JVC testing	-	*	-	*	-	-	-	*	-	-	-	-	-	-
	- Lumbar Panchter	-	*	-	-	-	-	-	-	-	-	-	-	-	-
	- CSF	-	*	*	-	-	-	-	*	*	*	*	*	*	-
	- Evoked potentials	-	-	*	-	-	-	-	*	*	*	*	*	*	-
Treatment Data	- drug name	-	-	-	-	-	-	-	-	-	-	-	-	-	*
	- dosage of drug	-	*	-	-	-	-	-	-	-	-	-	*	*	-
	- year of the drug beginning	-	*	-	-	-	-	-	*	-	-	*	*	-	*
	- Year of treatment stop	-	*	-	-	-	-	-	-	-	-	*	*	-	*
	- reason for stopping treatment	*	*	-	-	-	-	-	*	-	-	-	*	-	*
	- Side effects of drug	*	*	-	*	-	-	-	*	-	-	-	*	*	*
	- Non-pharmacological treatments	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- Interventions against side effects	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- complementary and alternative drug	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- drug for Co-morbidities														
	- Treatment of corticosteroids	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- Modifying drugs	-	*	-	-	-	*	*	-	-	-	*	*	*	-
	- incurable	*	*	-	*	*	*	*	-	-	-	-	*	*	-
	- Treat for relapses	-	-	-	-	*	-	-	*	-	-	-	-	-	-
		-	-	-	-	-	-	-	-	-	-	-	-	*	-
Lifestyle data	- Weight	*	-	-	-	-	-	*	-	-	-	-	-	-	-
	- smoking	*	-	-	-	*	-	*	*	-	*	-	-	-	-
	- alcohol consumption	*	-	-	-	*	-	*	-	-	*	-	-	-	-
	- Nutrition	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- Childhood illness	*	-	-	-	-	-	-	-	-	-	-	-	-	-
	- physical activities	*	-	-	-	*	-	-	-	-	-	-	-	-	-
	- level of vitamin D	-	-	-	-	-	-	-	*	-	-	-	-	-	-
	- presence Co-morbidities	*	-	-	-	*	-	-	*	-	-	-	-	-	-
Visit data	- time of doctor's visit	*	*	-	-	-	-	-	-	-	-	-	*	-	-
	- Name of the physician	-	*	-	-	-	-	-	-	-	-	-	-	-	*

1- Swiss; 2- Sweden; 3- Denmark (Danish MS Registry); 4- Danish MS Treatment Registry; 5- North American ; 6- German; 7- German Multiple Sclerosis and Pregnancy Registry; 8- Norway; 9- Oslo; 10- Croatia; 11- Australia; 12- Italia; 13- European database for multiple sclerosis;14-Iran.

Registration of information elements based on diagnostic criteria
The registries of Sweden, Denmark, Germany, Norway, Oslo, Croatia, Italy and the European database report that MS patients were registered according to diagnostic criteria. The Oslo registry system is the only MS registry system that has used the Poser criteria to diagnose patients with MS, while Denmark has three diagnostic criteria include Poser, McDonald and Allison. Also European Registry has two diagnostic criteria , Poser and McDonald. The rest of the registries were based on the McDonald's diagnostic criterion. Danish and German registry used the McDonald diagnostic criterion of 2005 and the Norwegian and Croatia registry of McDonald diagnostic criterion of 2010, respectively. The German registry system is the only country that use the latest version of the McDonald's diagnostic criteria in its registry.

Registration specific information elements
The five registry in Denmark, Italy, Australia, North America, and swiss collected information on clinically isolated syndromes (CIS). The Italian Registry, in addition to registration clinically isolated syndrome, also collected radiologically isolated syndrome (RIS) in patients with MS. It used the MedDRA coding system to report adverse drug reactions. The European database (EDMUS) collects radiologically separated syndrome (RIS) in MS patients, and has an international nomenclature standard that used as a thesaurus for information exchange and analysis.

Scope of registry systems
Most of the registries obtained were national expect Oslo, Europe and Pregnancy registries of Germany, Croatia, Australia which were used local, local, local, hospital, international respectively. Also nine of registries in this study was collected the list of patients from MS associations in combination with other sources**.**

Type of data import
The number of patients in existing MS registry systems ranges from 251 to 50,000. In ten registries, regular follow-up was intended, mainly annually or every three months or six months (Table 1). Registration is mainly performed by neurologists whereas both patients and neurologists document related data in the Italian and Australian registries. Italian registry records medical history, demographic data and expanded disability status scale (EDSS) each time at entry visit and also paraclinical test, neurological status, relapses, disease course and treatment are recorded annually from neurologists by the European Multiple Sclerosis database (MSDN) network. This network is used by the Imed system. The Imed system is a clinical database and a new electronic surveillance system for MS patients which recently developed by the Serono international foundation. The system also now holds more than 500 variables(30-32). Australian registry also done registration MS patient information through Imed's electronic patient registry system. MSBASE is an online and international database, to designed to share, track and evaluate data on MS patients, started with a collaboration of neurologists in Australia. Data collection in MSBASE is performed using an electronic patient record software called Imed(30). The registration of MS patients information in the Swiss registry is done by patients through a structured questionnaire. Longitudinal data were collected in four registries, where different data of one patient obtained in one or more centers at different locations, which were used to evaluate outcome of long-term Different treatments results in MS.

Informed consent
Patients' informed consent is required in 8 registries and in 6 registries are no longer mandatory informed consent. In the Italian registry because data were collected through Imed system before to creation of a national registry, data were incorporated into the designed registry system without informed consent(31).

DISCUSSION

According to the research findings, the emphasis of existing multiple sclerosis registry systems is more on epidemiological surveillance and cost-effectiveness of long-term treatment(17, 18, 20-22, 25, 27-31). Another study on MS registry systems available in Europe in 2014(24) emphasizes the results. In the patient demographic information section, the Swedish, Norwegian and EDMUS databases record patient identification number and informed consent. Although in the Australian and Italian registries there is only the patient identification number. In the Australian and European registries in addition to the identification number for Each patient is assigned a specific MSBASE and EDMUS identification number(30). In Iranian registry uses of patient national code. The use of national code identification in information management systems, especially registry systems, is essential because it prevents patient re-registration(34). In the Swedish and European registries the patient name, patient's last name and date of birth are recorded. In Iranian registry besides that the names of father is collected. While in the Danish and Norwegian registries the patient's name and date of birth are recorded, and in the North American and Australia registry only the date of birth. The Danish MS treatment registry, North America, Germany, Croatia, and Europe registries are collected age and sex information items, and in Sweden, Norway, Australia, Iran the age information is not recorded. On the other hand, in the North American and Oslo registries, in addition to recording patient age item, the data element that is unique in this section is the patient race, which does not record at other registries. The North American, European, and Iranian registries also record patient birth information and address information, but the Danish registry only records the birthplace item and the Oslo registry collected address information. The Swiss and North American registry records occupation status, MS family history and insurance information items, while the German registry only records occupation status and Norway, Italy, Croatia, Europe and Iran registries have MS family history information. The Iranian registry collects patient demographic information much more items than other existing registries, for example the father's name, national code, patient contact number, and cell phone are data elements that considered in the Iranian registry system, However, the German Pregnancy registry have no information elements in patient demographic information section(26).

In the diagnostic data section of the Swiss, North American, Oslo, and European registry records the primary symptom and the age of onset of the symptoms items, while the registry of Denmark, Germany, Norway, Australia, Italy contains only symptom items. In the Swedish registry, Denmark treatment, Norway, Oslo, Australia, Italy and Iran records the date of onset of symptoms and the date of diagnosis by a physician. The registry of Denmark, North America, Germany, Germany Pregnancy only record item date of diagnosis by the physician and the European registry only the item records is the onset date of symptoms. The registries of swiss, Sweden, North America, Germany, Italy, and Europe record the information elements of the disease progress and the type of disease. the Norwegian, Croatian registeris have disease progress. Oslo, Australian and Iranian disease registrations only have the disease type item. The registries of Sweden, Germany, Norway, Croatia, Italy, and Europe record diagnostic criteria information item and EDSS score while in Denmark and Oslo registries only diagnostic criteria item and registries of swiss, North America, Australia and Iran there is only EDSS score item. the registry of Swiss, Norway, Australia, Italy, Iran, and Europe also records the number of attacks and relapses that do not exist in other registry systems. about majority registries completely record all data elements in the diagnostic data section and only two registries of Iran and Sweden record the disease progress and secondary progressive MS, although other registries don't have these items.

In the diagnostic tests section, Swedish and Iran registries record brain and spinal mri information elements, comparison of new and previous MRIs, new t2 lesions, GD gadolinium lesions number, while in norway and italy there are brain and spinal mri Information items, new T2 lesions number, the number of gadolinium GD lesions. in the Danish, Croatia, Australia and European registries are the only brain and spinal mri items and in the Danish treatment registry brain and Spinal mri and comparisons of new and previous MRIs. The registry of Denmark, Norway, Oslo, Croatia, Australia, Italy, and Europe records cerebrospinal fluid (CSF) and visual evoked potential (VEP) Information. The Swedish registry only has the CSF information section. also the Swedish, Danish and Norway registries has jcv test registry, which no other registry has this item. The diagnostic test information elements in the database of the National Swedish Registration System are more comprehensive and cover almost all the information needs of diagnostic test data. Lumber panchter data is the unique data elements of this registry system that does not exist in other registries(18)and the Swiss(17), North American(22), German(25), and German pregnancy(26) have no information in diagnostic tests section.

In the treatment data section, Sweden and Italy registries record dosage of drug , medication start, medication stop, reason of stopping medication information elements are recorded(18, 31), while in Norway and Australia registries, the items of medication start and reason of stopping medication and in the Iranian registry medication start, medication stop, reason of stopping medication and in the Swiss registry is only the reason of stopping medication and the European registry is the only drug dose item. Swiss, Sweden, Denish treatment, Italy, and Europe registries items of drug side effects and disease-modifying items are collected, whereas in North America, Germany, Germany pregnancy is the only disease-modifying drugs item and in the Norwegian and Iranian registries side effects of the drug are recorded. Swiss, Sweden, Germany, Germany, Pregnancy Germany, Australia, Italy, and Europe have treatment of corticosteroid information element, that are not available in any other registry systems. A unique feature of the Swiss registry system in the treatment information section is the ability to record non-pharmacological treatment, interventions against side effects, complementary and alternative drugs and drug for co-morbidities, that in the other systems are not available(17). In the Iran registry the only element that is most important in the treatment section is the drug name that is not available in any of the other registries. The unique item in the treatment section in the European database is the drug treatment for attack and relapse which is not exist in any of the other registry systems. The Danish, Oslo and croatia registries have no information elements in treatment section(20, 28, 29).

In the lifestyle section, Swiss and North American registries records information elements on smoking, alcohol consumption, physical activity, and the presence of comorbidities while in the German Pregnancy and Croatia registries smoking and alcohol consumption items and in the Norwegian registry smoking and comorbities are recorded. The Swiss and German Pregnancy registries records the weight that is not registered in any of the existing registry systems. An important advantage of the national Swiss registry is that comprehensive lifestyle data section. This system records nutrition and childhood illness information that there aren't in other registries. The only information the system does not record in lifestyle data section is patients' vitamin D levels. Vitamin D levels are a unique element of lifestyle information section that is only recorded by the Norwegian registry system(27). Also, the registries of Sweden(18), Denish MS(20), Denish treatment(21), Germany(25), Oslo(28), Australia(30), Italy(31), Iran(33), and Europe(16) have no information elements in lifestyle section.

The last section is related to the visit data used registry is the only registry that records complete information about the visit time by the physician and the physician's name, while the Swiss and Italian registry is the only data element of the visit time by physician and the Iran registry has physician name. The registries of Sweden(18), Denish MS(20), Denmark treatment(21), Germany(25), Oslo(28), Croatia(29), Australia(30), Italy(31), Iran(33), and Europe(16) have no data elements in the visit data section.

Edmus is a European database for Multiple Sclerosis, launched with collaboration of neurologists and supported of the commission of the European communities, which collects MS patient information in collaboration with neurologists using the same imed software(16). Ajami et al (2016) said EDMUS, MSBASE and IMED software, database and softwares can be used as a research and clinical tools and appropriate patterns for determining and consider the identification of key data elements in MS patients(35).

The MS registry in Italy collects MS patient clinical data from various MS centers using an Italian database network (MSDN). The network also uses the Imed software system to collect patient information(31, 32).Quality of life for MS patients is one of the components of disease management. quality of life measurement tools have been designed and developed for MS patients in order to monitor patients' activity and performance. Patient status information is provided by patient-reported questionnaire and only 4 registries use of this standard tools include MS impact scale (MSIS-29), (fss) fatigue severity scale, EQ-5D, visual functioning Questionnaire-25 (VFQ-25), MS functional composite (MSFC) and fatigue scale for motor and cognitive functions (FSMCs) (17, 18, 27, 36). In most registry systems used physician-based outcome measures such as the Expanded disability status scale (EDSS). Flachenecker's study on MS registration systems in Europe(24) show the same result.

CONCLUSION

Accurate, complete, timely, accurate and accurate data collection of MS is a prerequisite for prevention at the primary, secondary, tertiary levels of Care of the country's health care system. Knowledge of the incidence, survival, and death rate of MS disease enables health authorities and policymakers to identify at-risk groups and provide regular care for them. MS registry system collect, store, edit, classify, analyze, and distribute all MS patient information, and provide valuable information on the occurrence and distribution of MS in a specific area. so it appears that the identified information elements and use of them in the MS registry systems are at the core of the national MS control program and can lead to appropriate decisions at the national level.

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