

Retrospective Analysis of Multiple Sclerosis Patients' Records in a Reference Hospital Center

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ABSTRACT

Objective: This study aims to identify sociodemographic and hospitalization characteristics of the multiple sclerosis (MS) patients admitted to a reference center in Turkey.

Patients and Methods: This is a single-center retrospective study which reviews MS patient records in 66 months. The study covered between April 1, 2010 and September 30, 2015. Data was collected on age, gender, number of admissions, number of hospitalizations (dates and durations), requests for laboratory tests and Magnetic Resonance Imaging (MRI), existence of disability reports and provision of home care. Total number of admissions for home care was 78.

Results: We determined 6996 MS admissions by 1578 patients in 66 months. 65.8% (n: 1038) of patients were females; mean age was 37.0. There were 4.4 admissions per patient. 584 (37.0%) patients had MRI requests. Blood tests were requested in 25% of all admissions. We identified 5213 (74.5%) admissions of 400 (25.3%) patients who have admitted at least five times to the center. For this group, mean admission per patient was 13.0, MRI request per patient was 2.1. 38.7% (n=152) of these patients was hospitalized at least once.

Conclusion: The use of resources for MS patients in a hospital setting is remarkable, which includes admissions, hospitalizations, blood tests and MRIs. However, when the number of patients with MS diagnosis taken into consideration, it is noteworthy that the number of demands for homecare is very small. Our study will be a guide for reducing cost of illness and improving care pathways.

Key words: Multiple sclerosis, sociodemographic characteristics, hospitalization, Turkey

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INTRODUCTION

Multiple sclerosis (MS) is a chronic and autoimmune disorder of the central nervous system (CNS) involving demyelination at the axons or progressive neurologic symptoms and attacks, the etiology of which involves both environmental and genetic factors [1-3]. The number of patients increased over years, due to the advances in diagnostic methods, and MS became the second most common cause of neurologic disability [4-6]. MS is a chronic disease, with a part of the disease involving attacks and the other having a progressive course from the beginning to the end.

Nusrat and his colleagues found that annual admissions with MS as primary or secondary diagnosis increased from 102,473± 3,485 in 2001 to 144,716±3,902 in 2010. It was stated that this was more than 40% increase compares to a 4% rise in overall hospitalizations at the same time in the USA [7]. It is estimated that there are 2 to 2.5 million individuals with MS worldwide. The incidence of MS in Turkey is estimated at one in every 2000-2500 individuals, and it is most frequent in women aged 20 to 40 years [4]. Although MS has a low rate of mortality, it deteriorates quality of life and deaths occur usually due to the complications of the disease and treatment [8]. Recent studies show

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that patients under regular follow-up will have a better management of the comorbidities and complications and more improvement in quality of life [9, 10].

The current literature is quite rich on the epidemiology of the disease and its management, but we have limited knowledge about the disease in developing settings, including Turkey. Limited information on disease epidemiology, existing care pathways and cost of illness in Turkey challenge both clinicians and policy makers to take action for better management of this growing concern. The present study aims to identify sociodemographic and hospitalization characteristics of the MS patients admitted to a reference center in Turkey. This is the first phase of a larger project that aims to explore care pathways for MS patients in the country.

PATIENTS AND METHODS

This is a single-center retrospective study which reviews MS patient records of 66 months in Ankara Numune Training and Research Hospital (ANH). Ethical approval was obtained from the ethics committee of the same hospital. The study covered between April 1, 2010 and September 30, 2015. For each patient data was collected on age, gender, first admission, number of admissions, number of hospitalizations (including dates and durations), requests for laboratory tests and radiologic imaging, number of Magnetic Resonance Imaging (MRI), existence of disability reports and provision of home care. This first level data will feed the second phase of the study where care pathways of MS patients will be further explored.

Statistical analysis was performed by using the SPSS 20.0 software (Statistical Package For Social Sciences), with statistical significance set at 5%. Descriptive statistics were given as numbers and percentages. The relation between hospitalization status and demographic characteristics were analyzed using the t test and chi-square analysis. The analysis was conducted under three subtitles: general descriptive characteristics of patients presenting with MS, characteristics of the patients who have at least five admissions during the study period, and the patients who were hospitalized at least once in our hospital.

RESULTS

ANH has extensive experience in research and training since 1881 and is accepted as the reference hospital by Turkish Ministry of Health. It has 1200 bed capacity. There is an almost 5000 staff in the team; almost 1000 being physicians. Health care services run in 38 different specialties; and residency trainings are given in 31 specialties. The hospital also has a neurology department considered as a reference center.

We determined 6996 MS admissions by 1578 patients at ANH in 66 months. The findings of the study are given below in three sub-titles as in conducted analysis described in Methods section.

Characteristics of MS admissions

Of the 1578 patients, 65.8% (n: 1038) were females and 34.2% (n= 540) were males, with a female-to-male ratio of 1.92. Patients' mean age was 37.0 + 11.4 (min: 15 - max: 88), and by specific age ranges, 58.8% were aged 20 to 40 years (Table 1). Other characteristics of the patients (Number of admissions, type of admissions, hospitalization status, MRI and blood test requests) grouped by year are given in Table 2.

Table 1. The demographic characteristics of patients admitted with a diagnosis of Multiple Sclerosis (n=1578)

	Number	%
Gender		
Female	1038	65.8
Male	540	34.2
Age		
0-19	49	3.1
20-40	928	58.8
41-60	538	34.1
60+	63	4.0
Total	1578	100

The possible relationship between patients' gender and age was investigated separately and is given in Table 1. There were no significant differences between mean ages by gender ($p=0.487$), but when examined by age groups, there was a difference at the margin of statistical significance between females and males by the age groups they belonged. Male patients aged 0-20 years (4%) were numerically twice the females (2%), while the proportion of the two genders was comparable in the other age groups ($p=0.045$); being difficult to be interpreted due to low number of patients in these groups.

When all admissions were examined patient-based, there were 4.4 admissions per patient (min: 1 max: 74). Of the 6996 admissions, 92.0% (n=6439) was to the Department of Neurology, 3.0% (n=205) to the Emergency department, 0.6% (n=33) to the Department of Ophthalmology and 0.4% (n=21) was to the Department of Physical Therapy and Rehabilitation. Other outpatient departments represent 4.0% (n= 298) of all admissions.

Detailed examination of the MRI request registry demonstrated that 584 (37.0%) of the 1578 patients had an MRI request, and 897 admissions of these patients (12.8% of the total admissions) involved 1439 MRI requests in total. When all patients were taken into account, number of MRI request per patient was 0.9, and when the patients with MRI requests were specifically examined, there were 2.5 MRI requests per patient. Of the MRI requests, 93.6% (840) were made by the Neurology department. Blood tests were requested in 25% (n=1751) of all admissions. Twenty-four patients received home care coordinated by our hospital, accounting for 78 admissions overall.

Table 2. Characteristics of admitted patients by year (Registration, Admission, MRI and blood test requests)

Characteristics	Years							TOTAL
	2010 (1 st Mar-31 st Dec)	2011	2012	2013	2014	2015 (1 st Jan-30 th Sep)		
Number of Admissions	854	1154	1273	1194	1474	1047	6996	
Form of Follow-up	Outpatient	747	924	1066	937	1297	927	5898
	Hospitalized	107	230	207	257	177	120	1098
State of hospitalization	Inpatient	41	40	26	26	39	18	190 (%18,4)
	Daily	66	190	181	231	138	102	908 (%81.6)
MRI requests n (%)	132 (15,1)	157 (13,6)	177 (13,9)	165 (13,8)	116 (7,9)	150 (14,3)	897(%12.8)	
Blood test requests n (% of)	227 (26,6)	266 (23,7)	273 (23,7)	369 (29,0)	269 (22,5)	359 (24,4)	254 (24,3)	1751 (%25.0)

Of the patients, 99.2% (n= 6939) had social security coverage.

Characteristics of patients with multiple admissions

We observed that some patients admitted only once or twice at our hospital and were not considered under follow-up of our teams. We considered the patients who have admitted at our hospital five or more times during the study period as under our follow-up and examined this group separately.

We identified 5213 (74.5%) admissions of 400 (25.3%) patients who have admitted at least five times. For this group mean admission was 13.0 (Minimum: 5, Maximum: 74). Females accounted for 68.7% (n: 275) of the 400 and males for 31.3% (n= 125). Mean age was 36.0 + 10.0 (Minimum: 17, Maximum:78). Sixty-six % of the patients were between ages 20-40.

Of these admissions 16.6% (n=869) ended up with hospitalization, which accounts for 38.7% (n=152) of the patients. Daily hospitalizations constituted 93.4% (n=812). Fifty-seven admissions ended up with inpatients with an average duration of 7.8 days (Median:6, min:2, maksimum:34)

MRI was requested in 238 patients (59.5%). The total MRIs requested were 847. In the whole group MRI request per patient was 2.1, whereas this is 3.5 per patient among MRI requested patient group. Twenty-five percent of the admissions (n=1273) involved blood tests. Nine patients received home care for 53 times from our hospital services.

Characteristics of hospitalized patients

Of all the admissions, 15.6% (n=1098) resulted in hospitalization and 84.5% in ambulatory care. Of all patients (n=1578), 340 (21.5%) was hospitalized at least once in study period. Mean number of hospitalizations for the hospitalized patients was 3.2 (min=1, max=31).

Of the hospitalized patients, 62.9% (n: 214) were females and 37.1% (n= 116) were males. Their mean age was 35.8 ±10.6 years (Minimum: 17, Maximum: 74).

Nine hundred and eight hospitalizations (81.6%) lasted one day only. The patients who remained in the hospital for more than one day (n=190, 19%) had a mean duration of hospitalization of 7.1 days. Blood tests and MRI was requested in 25.8% (n=284) and 13.3% (n=147) of the hospitalized patients, respectively.

DISCUSSION

This study gives us a good picture of the actual MS admissions in a reference neurology center. The study shows that the admitted patients at ANH have similar profile of age and gender distribution with local and international studies [4-6, 11-13].

The admissions per patient is quite high (4.4 admission/patient) in general study population and even much higher (13 admissions/patient) for the patients that are followed-up by ANH, in this study period. MRI requests are high (37% and 59.5 % of all patients and followed-up patients, respectively). We also determined that 21.5% of all patients and 38.7% of followed-up patients have been hospitalized at least once during 66 months.

There are two important limitations of our study that may be listed as follows: the study covers only one center and might not necessarily reflect other centers in the country, and being a chronic disease of 66 months does not cover the whole patient journey. The major strength, on the other hand, is that it provides important data on the patients with MS diagnosis, by capturing a high number of patients in a relatively long period. The data is retrieved from a reliable data source of a reference center and reflects real world. This adds to limited literature available on disease epidemiology in Turkey and also contributes to the international literature.

Although the disease is managed mainly by neurology departments, the contribution of Emergency, Physical Therapy and Rehabilitation and Ophthalmology departments are also observed and reflects the multidisciplinary follow-up need of the disease course. Attacks and attack-like symptoms and other symptoms associated with complications and drug side effects; optic neuritis; rehabilitation programs scheduled to reduce disability especially in progressing patients are expected to be the main reasons for admissions to other disciplines [14].

MS tends to induce gradual loss of function in some affected individuals. During the 10 years following diagnosis, 25 to 30% of the patients require walking aids and wheelchairs for mobility. The need for inpatient care is frequent considering that most patients develop anorectal, urinary and sexual dysfunction, and because the disease course involves attacks, and because patients taking disease-modifying agents (DMA) should be monitored regularly [7,15,16]. In our study, 21.5% of all admitted patients received at least one hospitalized care over the 66-month period. There was a considerable amount of resource use with admissions, hospitalizations, multi-disciplinary disease management processes, blood tests and MRIs. The resource use needs to be separately analyzed and cost of disease needs to be calculated.

Positive correlations between total healthcare costs and scores on the Expanded Disability Status Scale (EDSS) and Incapacity Status Scale (ISS) of MS dysfunction had been demonstrated [16]. Indirect costs have the biggest place in overall cost burden. MS can cost an individual 40% of their lifetime earnings [18-20]. In the literature there were cost of illness studies of MS performed in US, Australia and some European countries [16,21-23]. To our knowledge there is limited study in Turkey on MS patients with a focus on economical aspects of the disease management. In the study which was conducted by Karabudak R and colleagues total cost per patient/year was 18,700 TL (5,843€). Total costs for patients with mild, moderate, and severe disability were 15,418 TL (4,818€), 26,002 TL (8,125€), and 44,208 TL (13,815€) per patient/year [24].

Our results also revealed that the use of homecare services is quite limited. Home care service is a right for every patient in need in Turkey [25] and mostly regulated by primary care facilities in collaboration with hospitals. ANH has its own home care unit. Considering the high volume of patients, the number of patients who were found to be receiving home care was quite low. This needs to have a separate attention in order to understand whether this is due to patients being missed, being not knowledgeable on the services or simply receiving care from other facilities. Home care is an important part of the overall management of MS and collaboration is needed between service providers [26].

We found that 25.3% of the patients (who admitted more than 5 during study period) represented 74.5% of all admissions. There were many patients who admitted only once or a few times. This is identified as another gap in data, as we were unable to follow journey of these patients. This could either be due to the patient was misdiagnosed beforehand so was dropped off follow-

up, might have changed the center, might have discontinued follow-up for different reasons, or they might just have admitted to ANH for a second-opinion as it is a reference center. Further investigation on this is important to ensure that such a disease with a need of multi-disciplinary care and with important outcomes, such as disability and low quality of life, is well-coordinated and managed.

MS is an important cause of disability in young adults worldwide, and its early diagnosis and containment of the disease on the long run and limiting the long-term disability through appropriate treatment approaches is therefore important. Regular monitoring of the patients for drug adverse effects and progression following diagnosis and treatment, and reducing or avoiding complications by ensuring timely treatment in case of an attack is important in improving patients' quality of life and in reducing the economic burden.

This study demonstrates the demographical characteristics of the MS patients in a reference center in Turkey and provides an opportunity to have real world data in hand. The use of resources for MS patients in a hospital setting is remarkable, which includes multidisciplinary care, admissions, blood tests, MRIs, hospitalizations and home care. The study findings contribute to very limited knowledge that comes from Turkish MS patients and also from developing settings. We believe the findings of this study can be used to build up future studies on care pathways and cost of illness.

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