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Emergency Medical Care of Multiple Sclerosis Patients: Primary Data from the Mount Sinai Resource Utilization in Multiple Sclerosis Project

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Background and Purpose There has been no systematic analysis of emergency department (ED) utilization in the multiple sclerosis (MS) population. We investigated the acute-care needs of MS patients using ED as a route for entry into healthcare services.

Methods ED visits made by MS patients were identified. Data extracted included demographics, medical/neurological history, and workup/management in the ED.

Results The Mount Sinai ED received 569 visits from 224 MS patients during a 3-year period, of whom 33.5% were covered by Medicaid and 12.9% were uninsured. Patients with an Expanded Disability Status Scale score of ≥ 6 accounted for 54%, 50.5% of relapsing remitting MS patients were being treated with disease-modifying therapies, and 74.5% of the ED visits were non-neurological. Patients with mild-to-moderate MS were more likely to present to the ED for issues directly related to MS such as acute exacerbations, while those with severe MS presented more often due to medical issues indirectly related to MS, such as urinary tract infections ($p < 0.0001$).

Conclusions Most MS patients seeking ED care suffer from acute nonneurological problems. The MS patients presenting to the ED tended to be underinsured, had high levels of disability, and were undertreated with disease-modifying therapies. The acute-care needs of MS patients evolve over the disease course, as do the resources that must be utilized in providing emergency care across the spectrum of MS severity. Understanding the characteristics, problems, and needs of MS patients utilizing the ED is an important step in improving care in this population from both clinical and public health perspectives.

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Key Words multiple sclerosis, underinsured, emergencies, healthcare access, utilization.

Introduction

Multiple sclerosis (MS) is one of the leading causes of disability among young adults¹ and presents a major health burden in the US and other Western countries. Although most MS patients initially experience the relapsing remitting form of MS (RRMS), about 40% of untreated RRMS patients will

develop progressive neurological disability.² As the clinical picture evolves, so too do the comorbidities: patients with severe disability have a higher risk of infectious complications such as urosepsis, pressure ulcers, and pneumonia, which confer significant secondary morbidity and mortality. A study of the costs associated with MS relapses found that MS patients rely heavily on the emergency department (ED) for acute care and that most of the MS-related healthcare costs were attributable to ED visits and inpatient hospital stays.³ While such previous studies have looked at the financial costs of MS, there has been no systematic analysis of ED utilization in the MS population.

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In this study we investigated the acute-care needs of the MS population, with a focus on characterizing the MS population using the ED as a route for entry into the healthcare system. The study was performed at Mount Sinai Hospital, which is an academic medical center in New York with 1100 inpatient beds and that has an active ED with a catchment area that includes the affluent Upper East Side and the lower-income and ethnically diverse Harlem and Spanish Harlem communities. The Department of Neurology at Mount Sinai Hospital comprises both inpatient and outpatient services including the Corinne Goldsmith Dickinson Center for Multiple Sclerosis and a Medicaid clinic for MS patients.

Methods

This retrospective project was submitted and approved by the Mount Sinai Hospital Institutional Review Board after expedited review and waiver of informed consent had been granted. The Mount Sinai Hospital employs an information technology infrastructure called the Mount Sinai Data Warehouse (MSDW), which collects data generated by the many patient care and business transactional computer systems at Mount Sinai Hospital. Tools are available to produce reports for clinical research, quality-of-care initiatives, and process and financial improvement projects based on patient data from 2005 onwards.⁴

The MSDW was used to identify all patients who visited the Mount Sinai ED between January 1, 2005 and December 31, 2007. All of the diagnosis codes for the International Classification of Diseases, 9th edition applied to these patients then were searched to identify a cohort that contained the patients that had been evaluated in the ED with a diagnosis of MS recorded in their medical record. A total of 318 patients met these criteria. After thorough chart reviews performed by MS-specialized neurologists on the research team, 94 patients were excluded, either because the patient was not yet diagnosed with MS at the time of their ED visit or it was a false-positive diagnosis (the MS diagnosis was either a clerical error, or was ultimately found to be clinically incorrect). Overall, the final study population consisted of 224 MS patients who entered the ED during the 3-year study window.

The patient charts, both paper and electronic, were systematically reviewed by applying a custom-designed data abstraction form that extracted demographic data, medical history, neurological history, workup, and management performed in the ED and during hospitalization (if admitted). The patient's disease status at each visit was assessed using the Expanded Disability Status Scale (EDSS) and estimated to be mild (EDSS <4), moderate (EDSS 4–5.5), or severe (EDSS ≥6) based on the neurological history, documented neurological

examination, and use of an assistive device for ambulation. The study database was created and maintained using SPSS version 16.0 (SPSS Inc., Chicago, IL, USA), and all of the statistical analyses were performed using this software. Generalized estimating equations with repeated measures were used to test for relatedness between correlated categorical variables. Generalized linear models with a Tukey adjustment or mixed models with repeated measures were used for continuous variables.

Results

General demographics

Between January 1, 2005 and December 31, 2007, 569 visits to the Mount Sinai ED were made by 224 MS patients. The number of visits per patient ranged from 1 to 15, with a mean of 2.5 visits per patient. The patient demographics are summarized in Table 1, and insurance coverage is shown in Fig. 1.

Table 1. Patient demographics

Total visits	n=569
Total patients	n=224
Number admissions to hospital	285
Sex, n (%)	
F	165 (73.7)
M	59 (26.3)
Age, years	
Mean (range)	47.7 (17–85)
MS disease duration, years	
Mean (range)	12 (0–53)
Median	7.3
Clinical course at first visit, n (%)	
RRMS	99 (42.4)
SPMS	70 (31.2)
PPMS	18 (8.0)
PRMS	2 (0.9)
Not documented	35 (15.6)

F: female, M: male, MS: multiple sclerosis, PPMS: primary progressive MS, PRMS: progressive relapsing MS, RRMS: relapsing remitting MS, SPMS: secondary progressive MS.

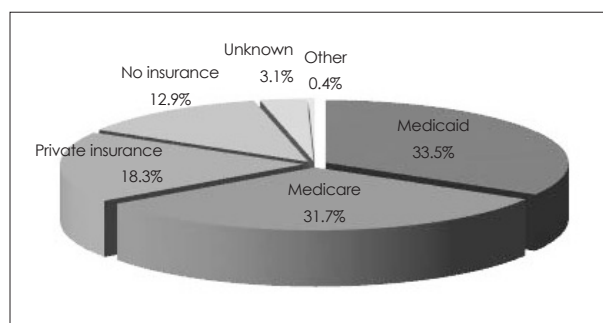


Fig. 1. Breakdown of insurance types.

MS-related demographics

Relapsing remitting of MS was the most common clinical subtype reported (42.4%), while progressive forms of MS were found in 40.1% of patients (secondary progressive, 31.2%; primary progressive, 8.0%) (Table 1).

The evaluation of disease severity at the time of the ED visit revealed that mild MS (defined as EDSS <4) was present in 32.1% of patients, moderate MS (EDSS 4–5.5) was present in 13.8%, and severe MS (EDSS ≥6) was present in 54.0%. Of the 54.0% of patients needing assistive devices for mobility, 75.0% were wheelchair-dependent.

The median duration of the disease was 11.8 years, with means of 5.0 and 6.0 years in the patients with mild and moderate MS, respectively, increasing significantly to 17.0 years in patients with severe MS ($p < 0.0001$). In addition, 41.5% of all patients reported receiving disease-modifying therapy (DMT) at the time of their visit; this percentage was 50.5% in the RRMS subgroup.

Referrals and timing of ED presentations

Emergency department visits were evenly distributed across all four seasons and on all days of the week, and occurred during the daytime, between 9 a.m. and 5 p.m., in 64.9%. Visits that occurred “after hours” (nighttime and weekends) did not vary significantly with the acuity of the medical issue ($p = 0.11$), the EDSS score (i.e., the severity of the underlying MS; $p = 0.56$), the neurological or nonneurological chief complaint ($p = 0.80$), or the patient demographics. In 68.0% of cases the patients visited the ED of their own accord rather than being referred there by a physician.

Chief complaints and diagnoses

Of the 569 ED visits, 145 (25.5%) were for neurological chief complaints, while 424 (74.5%) were for nonneurological chief complaints. Of the neurological chief complaints, the most common were weakness (46.2%) and altered mental status (14.5%). Among the 424 nonneurological chief complaints, pain was the most common (18.3%), consisting of predominantly musculoskeletal pain and other acute physical pain complaints such as those resulting from injury, as opposed to primary MS-related sensory phenomena. The category “other chief complaints” (20.3%) comprised pregnancy-related issues, wound checks, ulcers, suture removals, ophthalmologic complaints, and psychosocial problems. The chief neurological and nonneurological complaints are depicted in Fig. 2.

Diagnosis at ED visits as a function of MS severity

We classified the diagnoses given for each visit to the ED into those that were directly related to the underlying MS diagnosis (e.g., acute exacerbations), those that were indirectly related to MS [e.g., urinary tract infections (UTIs) and pressure ulcers], and those that were unrelated to MS (e.g., heart attacks, abdominal pain, and dog bites). MS patients with mild-to-moderate disease (EDSS <6) were more likely to be given diagnoses that were directly related to MS, while patients with severe MS (EDSS ≥6) were more often diagnosed with medical issues that were indirectly related to MS ($p < 0.0001$). In addition, 206 visits (36.2%) were made by patients not requiring an assistive device (EDSS <6) and 363 visits (63.8%) by patients with EDSS ≥6. This disparity was

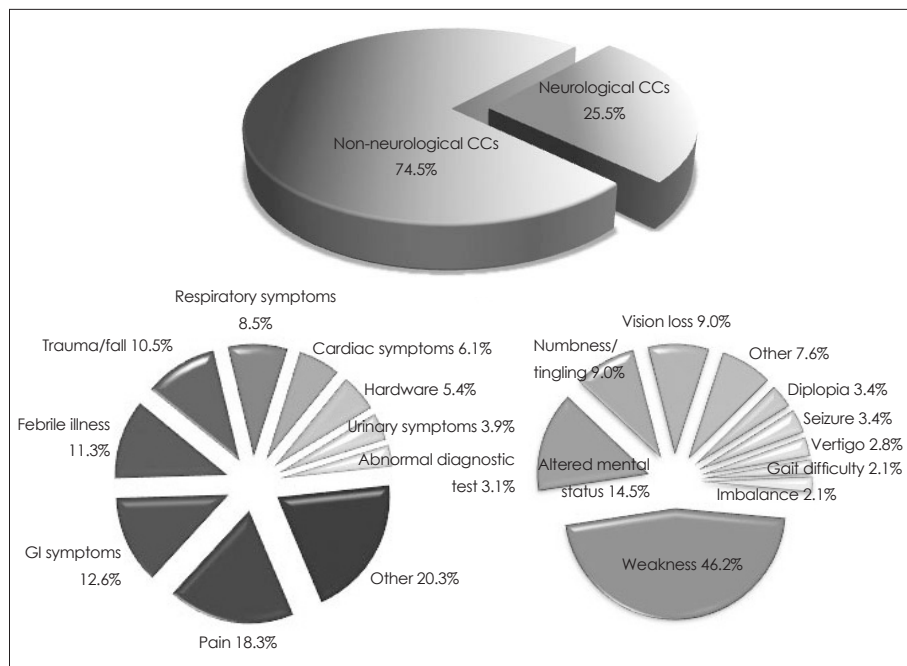


Fig. 2. Neurological and nonneurological chief complaints. CCs: chief complaints, GI: gastrointestinal.

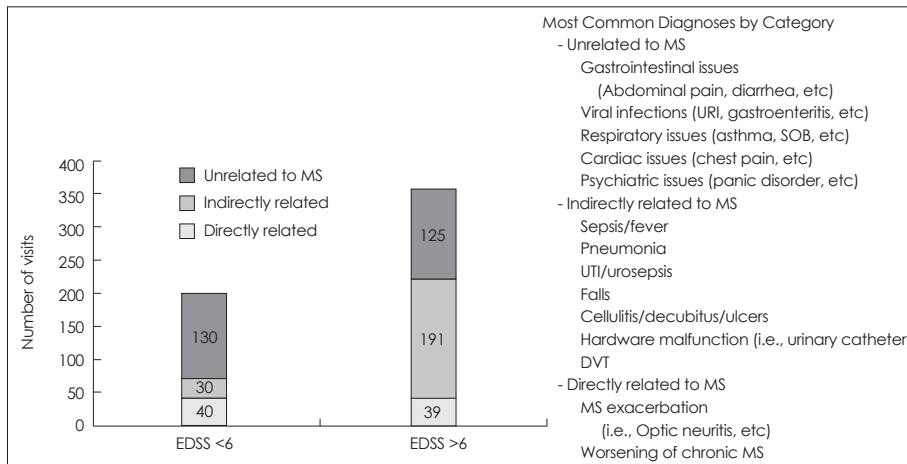


Fig. 3. EDSS severity by relationship of emergency diagnosis to MS. DVT: deep vein thrombosis, EDSS: Expanded Disability Status Scale, MS: multiple sclerosis, SOB: shortness of breath, URI: upper respiratory infection, UTI: urinary tract infection.

attributable entirely to issues indirectly related to the MS diagnosis such as UTIs, falls, and indwelling hardware ($p < 0.0001$) (Fig. 3). MS exacerbations were diagnosed in 13.2% of all MS patient visits to the ED.

Consultations

Neurological consultations were requested in 28.1% of all patient visits, for a total of 160 neurological and MS-specialist consultations. Other common consultations requested for this population were urology (38 consultations), psychiatry (18 consultations), and plastic surgery/wound (16 consultations) care.

Inpatient admissions

Half (50.1%, $n=285$) of the 569 ED visits led to a hospital admission. MS patients with neurological chief complaints were significantly more likely to be admitted to the hospital (70.3%) than those with nonneurological chief complaints (43.2%, $p < 0.0005$). The most common admitting services were medicine (54.7%) and neurology (25.6%). For the 285 admissions, the mean length of stay was 8.49 days, with a range of 1–190 days. There was a total of 2430 inpatient days for the MS patients admitted after evaluation in the ED during the 3-year study period.

Discussion

Considerable attention has been focused on the long-term management of patients with MS, with an emphasis on the development of disease-modifying therapies aimed at reducing the occurrence of relapses and slowing the accrual of disability. The acute-care needs of the MS patients has received comparatively little attention, despite the known impact of emergency medical and neurological care on patient outcomes.

Demographically, MS patients utilizing the ED for acute care tended to be underinsured, having either no insurance or being solely covered by Medicaid, which is consistent with

previous studies of ED utilization for other conditions.⁵ The disease severity of the patients in our population was greater than that in the general MS population, since 40% of them had progressive forms of MS and more than half of the patients required an assistive device for mobility. In comparison, the MSBase, a research database for the collection of epidemiological information on people with MS globally, reports that only 32% of patients are affected by progressive MS. Only 19% of these patients had an EDSS score of between 5.5 and 8,⁶ whereas in our population this proportion was 54.0%.

The patients in our study were also an undertreated population, with only 50% of RRMS patients reporting receiving a DMT. Data published in 2000 by the National Consortium of Multiple Sclerosis Centers⁷ demonstrated that 67% of patients were taking a DMT and despite the increasing use of these agents over the past decade, the rate of DMT use in our cohort was considerably lower at 41.5%. In summary, we found that MS patients seeking medical care at the Mount Sinai ED were in general underinsured, undertreated, and more severely impaired than the general MS population. These data suggest that this population of MS patients is using the ED as a source of primary care.

Neither the acuity nor severity of the presenting complaints were correlated significantly with presenting to the ED after hours or on weekends, when outpatient medical and neurological care would be unavailable. Furthermore, most ED visits were not referred by a physician, which suggests that these patients were often using the ED as a source of first-line healthcare. Care and resources are provided to patients seen in the Mount Sinai ED or admitted to the hospital irrespective of their insurance status or ability to pay. While this ensures that acute-care needs are met, ongoing outpatient care needs may be more difficult to fulfill. Previous studies have shown that a lack of insurance is a barrier to primary healthcare access.⁸ This finding also appears to pertain to our population, since

despite the background of an MS diagnosis, neurological chief complaints accounted for only one-quarter of the ED visits, and a diagnosis of an MS exacerbation was made only 13% of the time. In 2008, Marrie et al.⁹ reported that medical comorbidities are common in MS patients: 77.1% of their population had at least one comorbid condition. Our results support these findings, since 1) most of the chief complaints were nonneurological and 2) most of the diagnoses made in the ED were either indirectly related or unrelated to the underlying MS diagnosis. Our results suggest that improved outpatient management of the comorbidities in this MS population could yield a decreased reliance on the ED for these purposes.

The severity of a patient's MS was associated with the reason for their visit to the ED. Patients with EDSS scores reflecting mild-to-moderate MS were significantly more likely to present with complaints directly related to their MS, such as MS exacerbations, optic neuritis, and worsening of their chronic symptoms. In contrast, patients with EDSS scores reflecting severe MS were more likely to present with problems indirectly related to their MS such as pneumonia, UTIs, falls, pain, decubitus ulcers, and sepsis. MS patients with severe disease (EDSS ≥ 6) were more than threefold more likely to be given diagnoses that were indirectly related to MS (52.6%) than patients with an EDSS score of < 6 , in whom diagnoses that were indirectly related to MS were made only 14.6% of the time ($p < 0.0001$). Notably, in patients with an EDSS score of ≥ 6 , diagnoses directly related to MS accounted for only 10.7% of visits. This provides a clear indication of the evolving acute-care needs during the disease course, and the resources that must be utilized across the spectrum of MS severity. Recognizing that medical comorbidities and indirectly related complications of MS are the main causes of ED visits for MS patients, care should be taken to avoid "over-ascribing" the symptoms of an acutely ill MS patient directly to their underlying diagnosis of MS.

Three-quarters of the MS patients who sought ED care in this study did so for nonneurological chief complaints, and similarly three-quarters of those admitted were admitted to nonneurology inpatient services. These data validate the importance of interdepartmental awareness of the medical needs of the MS population. In 2005, Stettler et al.¹⁰ reported that neurology education in emergency-medicine residency training programs focuses on the management of neurological emergencies rather than on issues pertaining to the management of chronic neurological conditions. The results of the present study indicate that there should be a renewed emphasis on optimizing ED education pertaining to MS, so as to meet the acute-care needs of MS patients for interdisciplinary care.

This study was subject to several limitations. As a retrospective chart review, the quality of the analyses is limited by

the documentation upon which it is based. For visits where a neurologist was not consulted, the neurological history and examination was performed and documented only by the ED, limiting our ability to precisely calculate the EDSS categories. However, there was sufficient documentation to characterize disease severity into mild, moderate, and severe categories. In addition, this study involved a single-center population, and as our study hospital is a large, urban, tertiary-care academic medical center, the results may reflect this selection bias and may not be generalizable to other populations. The patient populations seen at different types of hospital may have a different mix of socioeconomic status, insurance coverage, and DMT utilization. While the demographics of this population are specific to the catchment area served by Mount Sinai Hospital, the associations between high disease severity, poor insurance status, and underutilization of MS treatments are likely to be universal. Studies have suggested that a rural location can also limit the access to healthcare in general¹¹ and to MS patients in particular.¹²

The purpose of this resource-utilization project was to identify opportunities to improve the ED management of MS patients by describing the population most likely to utilize the ED and to report several trends in their presentations, hospital courses, and resources utilized in their care. Subsequent studies in this project will look specifically and in detail at the assessment and management of MS relapses in the ED, the diagnostic accuracy of the ED in managing MS patients, and factors that lead to the disproportionate usage of the ED by a subpopulation of MS patients. Future objectives include repeating these analyses on data covering subsequent years, and determining how ED utilization and acute-care management in the MS population affect both short- and long-term disease outcomes, as well as improving MS patient care through interdisciplinary education.

Conflicts of Interest

The authors have no financial conflicts of interest.

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