Multiple sclerosis management for low-income minorities

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Low-income minorities with complex chronic diseases and physical disabilities have difficulty accessing appropriate healthcare often resulting in suboptimal care. A survey was performed to determine the impact of cultural and socioeconomic factors on the quality of care for low-income minorities with multiple sclerosis (MS) enrolled in Independence Care System (ICS), a Medicaid long-term managed care plan. All 92 ICS members with a diagnosis of MS were surveyed on three aspects of their care: specialty contact, immunomodulating drug therapy and osteoporosis prevention. Of those surveyed, 32% were never seen by an MS specialist. One third were not taking immunomodulatory medications, primarily due to noncompliance caused by a lack of understanding about these drugs. The prevention of osteoporosis and potential fracture in this high-risk population was largely neglected by providers despite the fact that the majority of those surveyed also reported balance difficulties and a history of falling. The survey revealed several deficiencies in the care of low-income minorities with MS. A major issue was the lack of adequate education, particularly about the immunomodulating drugs. Education about the importance of osteoporosis prevention, falls mitigation programmes and rehabilitation evaluations are critical interventions to decrease the risk of fracture.

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Key words: DEXA scans; immunomodulatory drugs; multiple sclerosis; osteoporosis

Introduction

Low-income minorities face significant difficulties in accessing appropriate healthcare, resulting in decreased use of health services and poor health outcomes. Low-income minorities with physical disabilities face additional challenges in obtaining optimal healthcare including architectural, transportation and attitudinal barriers. In view of the potential impact of cultural and socioeconomic factors on the quality of healthcare, we chose to evaluate several aspects of medical care for a population of disabled, low-income minority patients with a diagnosis of multiple sclerosis (MS) in New York City (Manhattan and Bronx). MS, which is two to three times more common in women, is a chronic neurological condition requiring sophisticated specialist management. Most minority patients who live in poverty, particularly minority women, receive care in hospital outpatient clinics or other facilities that have high volume practices. These patients receive their care primarily from junior rotating staff in various public hospital neurology clinics, resulting in suboptimal continuity of care. In addition, MS expertise is inconsistent and the focus in these clinics may not include prevention of secondary complications. The opportunities for patient education are often limited in these settings and Latino patients may face language barriers in communicating with their physicians or finding written information in Spanish.

Current therapeutic recommendations for MS include expensive, injectable, immunomodulatory medications. When the immunomodulatory drugs are considered appropriate options, patient education is a significant factor in the choice of medication, as well as compliance with medication. Therefore, specialist contact and adequate patient education are critical components of appropriate and successful therapeutic intervention for people with MS.

A significant secondary complication of MS is premature osteoporosis. There have been several studies in the literature over the past 10 years, which reveal an increased risk of premature osteoporosis in women with MS. The aetiology is probably multifactorial but there is an association between MS and bone loss. Studies have shown that bone density is significantly reduced in women with MS, even in the least severe forms of the disease. Steroid therapy, sedentary lifestyle and menopause are additional risk factors. One study reported that the extent of the decrease in bone density means that, on average, the female MS patient has a risk of fracture 2–3 times above that of healthy controls. Women are at a higher risk for osteoporosis than men, however men with MS are at higher risk compared to the general male population. Because the main consequence of osteoporosis is fracture, osteoporosis screening, prevention and treatment are particularly important for people with MS. A fracture is a devastating injury for people with physical disabilities, with a significant impact on functional independence. Osteoporosis prevention strategies include calcium and vitamin D supplementation, early screening...
with bone density (DEXA) scans and bone resorption inhibitors or comparable medications when necessary.

Independence Care System (ICS), a Medicaid long-term managed care programme for people with physical disabilities in New York City, conducted a survey to evaluate the medical care for members with a diagnosis of MS as part of a Performance Improvement study. ICS members have limited financial resources and 89% of members are minority men and women. Services covered by the plan include pharmacy, personal care aides, rehabilitation services and durable medical equipment. Medical services are not part of the managed care capitation and members choose their medical providers. Therefore, there are no potential incentives to limit physician and/or specialist contact. Lack of private insurance and lack of financial resources limit member options for specialty care. ICS care management teams, which consist of a nurse and a social worker for each member, facilitate appropriate healthcare services.

The goals of the survey were to evaluate the adequacy of care for ICS members with MS. The survey results would be used to devise a series of interventions to address any deficiencies. The ultimate goal is to establish a set of MS care guidelines for our organization. This initial investigation focused on three areas of MS care: 1) MS specialist contact, 2) treatment and compliance with immunomodulatory medications, and 3) osteoporosis screening, prevention and treatment.

**Methods**

Survey sample

ICS eligibility Membership in ICS requires Medicaid eligibility and a DMS-1 score greater than or equal to 60. The DMS-1 score is a New York State Department of Health mandated assessment tool that measures functionality for all long-term managed care plans. A score of 60 implies nursing home level of care and is based on identifying home health care and skilled nursing needs as well as limitations of activities of daily living and incidental activities of daily living. All ICS members live in the community.

Database The ICS database consists of demographic and medical information which is self-reported. All medical information is formally confirmed and signed by the treating physician at the time of enrolment. The diagnoses in the database of 600 members of ICS were reviewed. Ninety-two members with a diagnosis of MS were identified, all of who participated in the survey. Demographic information on the 92 members with MS was retrieved from the ICS database.

Gender, race and ethnicity Of members with MS, 81% were women; 77% of these were minority women (46% African American, 31% Hispanic or Latino) and 23% of women surveyed were Caucasian. Of members with MS, 19% were men; 67% of these were minority men (39% African American, 28% Hispanic or Latino) and 33% were Caucasian.

**Level of disability** For this study, level of disability was divided into three categories: ambulatory without assistance; ambulatory with assistance; wheelchair user. Wheelchair users were further divided into categories of transfer independently or with assistance. These categories were self-reported and confirmed by the care management teams. Of members surveyed, 52% were ambulatory; 8% of ambulatory members were independent and 92% required assistance. Of members surveyed, 48% were nonambulatory, wheelchair users; 22% of these members could transfer independently and 78% needed assistance with transfers.

**Duration of MS (Table 1)** Self-reported mean duration of disease from time of diagnosis was 12.8 years with a range of 1–38 years.

**Age (Table 2)** Of members surveyed, 68% were under 50 years of age. The age range was 21–71.

**MS care** ICS members participating in the survey received their ongoing care at a variety of hospital neurology clinics, outpatient facilities and MS centres in New York City.

Survey development

Surveys were designed to be administered by the care management staff and to specifically address the three areas of MS care to be investigated: 1) specialist contact, 2) treatment and compliance with immunomodulating drugs, and 3) osteoporosis screening, prevention and treatment. The survey consisted of 25 questions. Information requested in the specialist contact questions included names of physicians seen for MS diagnosis and treatment as well as previous or present site of care including MS centre, hospital neurology clinic or private office. Questions pertaining to treatment with immunomodulatory medications included whether or not these medications were prescribed; if prescribed was the member compliant; if initially compliant, reasons for discontinuation; if never compliant reasons for refusal. Osteoporosis questions included inquiries about DEXA scans, as well as calcium and vitamin D supplementation. The survey also inquired about diagnoses of osteoporosis or osteopenia and medications prescribed. Additional questions related to level of disability, balance difficulty and falls. The survey was developed and approved by the Medical Director and the

**Table 1** Age distribution

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<tr>
<th></th>
<th>21–30 (%)</th>
<th>31–40 (%)</th>
<th>41–50 (%)</th>
<th>51–60 (%)</th>
<th>61–70 (%)</th>
<th>71+ (%)</th>
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<tbody>
<tr>
<td>Women</td>
<td>5</td>
<td>26</td>
<td>34</td>
<td>24</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Men</td>
<td>5</td>
<td>22</td>
<td>56</td>
<td>17</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>African American</td>
<td>5</td>
<td>26</td>
<td>33</td>
<td>24</td>
<td>7</td>
<td>5</td>
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<tr>
<td>Hispanic/Latino</td>
<td>11</td>
<td>33</td>
<td>37</td>
<td>19</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Caucasian</td>
<td>4</td>
<td>9</td>
<td>48</td>
<td>26</td>
<td>13</td>
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Performance Improvement Committee. The Performance Improvement study design was reviewed and accepted by Island Peer Review Organization (IPRO) in conjunction with the New York State Department of Health.

Procedure
Participation in the surveys was voluntary and without compensation. An introductory note was given to each member explaining the purpose of the survey. Surveys were administered in the member’s home by the care management team. The results of each survey were recorded in a database.

Results

Specialist contact
Of members with MS surveyed, 32% were never seen by an MS specialist. Furthermore, many of these members could not name their neurologist, and several incorrectly believed that clinic housestaff (interns and residents) were MS specialists.

Immunomodulating therapy (Tables 3 and 4)
Of members with MS, 32% were not taking immunomodulating medications at the time of the survey; 47% of these members were prescribed immunomodulating drugs but stopped taking them. Reasons for discontinuing medications included lack of improvement (40%) and side effects (47%). Of the 53% who never were treated with immunomodulating medications, 56% refused to take these medications due to fear of needles (6%), fear of side effects (12%) and lack of belief in medications (38%). Of the members in this group, 25% were never offered immunomodulating therapy by their physician.

Osteoporosis screening, prevention and treatment (Figure 1, Tables 5 and 6)
Risk factors for osteoporosis in this MS population included steroid therapy (75%), nonambulatory status (48%) and postmenopausal status (40% of women). Forty-one per cent of women/25% of men took calcium supplements and 18% of women/19% of men took vitamin D supplements; 57% of women/78% of men did not have a DEXA scan; 34% of women/40% of men who had a DEXA scan were given a diagnosis of osteoporosis and 53% of them were not being treated. Of members,

<table>
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<th>Table 2</th>
<th>Mean duration of MS</th>
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<tr>
<td>Total population</td>
<td>12.8 years</td>
</tr>
<tr>
<td>African American</td>
<td>12.21 years</td>
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<tr>
<td>Hispanic/Latino</td>
<td>11.87 years</td>
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<tr>
<td>Caucasian</td>
<td>14.43 years</td>
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Other 13%

Afraid of needles 6%

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Discussion
Our survey revealed several deficiencies in the care of this low-income minority population with MS, in each of the three focus areas.

Specialist contact
MS specialist evaluation is important for diagnosis confirmation, increasingly complex therapeutic interventions, symptom management and prevention of secondary complications. In addition, referrals to MS specialists would minimize the variability of care, which is an important factor in the success of any disease management program. Almost one third of members with MS were never seen by an MS specialist. Many members incorrectly believed that their doctors, family practitioners and neurology housestaff, were specialists in MS. The limited specialist contact is most likely due to the lack of private insurance and limited financial resources. The majority of MS centres and specialists in New York City (Manhattan and Bronx) do not accept Medicaid. Many members may not have been aware of the few remaining facilities which accept Medicaid and are staffed by senior MS specialists. Two thirds of members have been seen by MS specialists at least once. This is probably due to the fact that 66% of members also have Medicare coverage which allowed for more access to specialist consultations. The lack of specialist contact is a significant deficiency in this population. In addition to the more obvious benefits, care by MS specialists has been correlated with a greater likelihood of patient education about and compliance with the interferons.

Immunomodulating therapy
The immunomodulating drugs are the most effective medications presently available for people with relapsing-remitting MS. Because the majority of members were presently or previously taking immunomodulatory drugs, the limited specialty care access did not seem to have a significant impact on the prescription of these medications. Only 25% of the group of members who never took immunomodulatory therapy were never offered the treatment. As we do not have MS classified by type in our database, these members may not have been appropriate candidates for these medications. The majority of reasons cited for discontinuing medications or refusing to start the prescribed medications suggest that the purpose, benefits and realistic side effect profile of these medica-

<table>
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<th>Table 4 Immunomodulating drugs: never treated</th>
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<tr>
<td>Not offered</td>
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<td>Do not believe in medication</td>
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<tr>
<td>Other</td>
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<tr>
<td>Afraid of side effects</td>
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<tr>
<td>Afraid of needles</td>
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84% reported balance difficulty; 61% had a history of falling and 17% had a history of fracture.
tions were not clearly understood. Almost half (47%) of those not taking immunomodulatory medication chose to stop the medicine. Lack of symptom improvement was cited by 40% of survey participants as the reason for discontinuing medication. This implies an inadequate understanding of the purpose of these medications whose benefits are primarily to decrease the frequency of relapses and slow the progression of disability. Side effects were cited by 47% as a reason for discontinuing medications. However, these participants were not switched to another potentially better tolerated drug. Furthermore, a lack of education regarding expected side effect profile and appropriate treatment for side effects may have contributed to the decreased compliance and medication self-discontinuation in this group. Major reasons for refusal to start the prescribed medications included lack of belief in these medications and fear of side effects. These refusals were likely due in part to a lack of adequate patient education as to the potential benefits of therapy and minor nature of most side effects. Furthermore, for members who refused to take immunomodulating drugs due to needle phobias, desensitization protocols, and alternatives to independent self-injection (assistance of visiting nurse service and other medical professionals) were not offered.

Lack of information is a significant barrier to adequate care for members surveyed. While the lack of information about these medications may in part be due to the constraints on physician time in busy outpatient clinics, these members have additional challenges. There is a great deal of information about MS and the various medications in written materials and on the Internet. However, most low income, minority members are not computer literate, or do not have access to a computer. The significant percentage of Hispanic or Latino members raises the additional importance of Spanish translators and educational materials in Spanish.

Interestingly, a previous study of predominantly Caucasian, minimally disabled patients with MS who have private insurance also noted significant unmet information needs. This study focused on a comparison of the management of MS across different commercial healthcare delivery systems; health maintenance organization (HMO), independent practice association (IPA) and fee for service (FFS). The overwhelming majority of participants in each category were Caucasian (79% HMO, 97% IPA, 87% FFS). The IPA sample which had higher levels of employment and a smaller proportion of minorities than the other two samples had the fewest unmet information needs. The authors suggested a potential relationship between these sociodemographic factors and unmet information needs. Regardless of the system of care, a high proportion of patients with MS in this study reported having their need for information unmet. It is reasonable to assume that these unmet needs would be even higher for our population of low-income minorities. Lower levels of employment and education, as well as higher levels of poverty and public insurance coverage pose significant barriers to access of optimal healthcare including health education, preventive services and specialty medical care.

Comparison of our survey results to other reviews in the literature has been difficult due to the lack of comparable populations or differences in the focus of the studies. Of the 2590 relapsing patients in the registry of MS Treatment

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<th>Table 5 Calcium and vitamin D supplements</th>
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<td>**Women (%)</td>
</tr>
<tr>
<td>Not taking calcium</td>
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<td>Not taking vitamin D</td>
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<table>
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<th>Table 6 Bone density (DEXA) screening</th>
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<td>**Women</td>
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<td>Not screened</td>
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and Care (MSTRAC) study, 92% were Caucasian, 5% Black and 2% Hispanic. The overwhelming majority had commercial insurance and none had Medicaid only coverage.¹⁸ In a profile of patients in the New York State MS Consortium registry (NYSMSC), the population studied was 93% Caucasian and 6% African American. Hispanic or Latino registrants were not separately designated in the remaining 1%. About 10% of total registrants had Medicaid as their primary insurance.¹⁹

There have been several studies focusing on African Americans with MS, but these studies were designed primarily to determine the clinical characteristics of African Americans compared to Caucasians with MS.²⁰⁻²³ However, these studies also raised questions and provided insights about the potential impact of socioeconomic factors on health outcomes in minority patients with MS. These studies suggested that African Americans with MS have more significant disability and more aggressive disease than Caucasians. Although noting that these differences may be racially (genetically) determined, the authors found significant differences in the socioeconomic status of these groups which may have played a role in access to care. One study specifically evaluating the MS characteristics of African American NYSMSC registrants revealed that a greater proportion of the African Americans were unemployed and less educated compared to the Caucasian patients.²⁰ In addition, 34.7% of African Americans had Medicaid as their primary insurance compared to 12.9% Caucasians. Access to care and particularly specialty care is more difficult for people with Medicaid. One study acknowledged that difficulty accessing optimal health care for African Americans with MS early in the course of their disease could have been a potential factor contributing to the poorer outcomes.²¹ With regard to quality of care, another study noted that therapies were switched more often and steroid therapy was offered more often in Caucasians as compared to African American patients.²² Furthermore, the authors recognized that although time to diagnosis and initiation of therapy in the two groups was comparable, the ongoing care provided by neurologists might have been a factor in ultimate clinical outcome. A study of African American and Caucasian nursing home residents with MS also focused on clinical differences, but noted that there was a significant racial difference in payment sources for nursing home care.²³ The primary coverage for African American residents was Medicaid whereas private health insurance and self-pay were predominant for white residents. White residents had more mental health evaluations and prescribed treatments, which the authors suggested might reflect the fact that these issues are underdiagnosed in African American residents. Additionally, white residents received more rehabilitative services despite greater needs of the African American residents. Whatever genetic influences are ultimately revealed, socioeconomic disparities clearly play a role in access to health services, quality of services and therefore health outcomes in African Americans, as well as other low income minorities with MS.

Osteoporosis screening, prevention and treatment

There are clear data in the literature regarding the increased risk of osteoporosis in people, particularly women with MS.⁷⁻¹³ Despite this information, this survey revealed that osteoporosis screening, prevention and treatment for our members were inadequate. Simple preventive measures were not prescribed in the majority of those surveyed. Calcium supplementation was not prescribed in 59% of women and 75% of men surveyed. In spite of the role of vitamin D in calcium absorption and the fact that vitamin D deficiency has been postulated as a potential factor in premature osteoporosis for people with MS, vitamin D supplementation was not ordered in the overwhelming majority (81–82%) of members surveyed.

Additionally, DEXA screening was not routinely prescribed. The survey revealed that despite associated osteoporosis risk factors in the overwhelming majority of members including steroid use (75%) and impaired mobility (91%), DEXA screening was not performed in over half the women, 40% of whom were postmenopausal. It was concerning to find that more than one third of members who were screened with a DEXA scan were diagnosed with osteoporosis, but only half of them were being treated. This fragmented care may, in part, be due to issues with continuity of care in hospital clinics.

There was an inadequate focus on the prevention and detection of this serious secondary complication of MS. Neurologists have traditionally considered osteoporosis management as the domain of the primary care physician or the gynaecologist. However, primary care physicians and gynaecologists are often not aware of the risk of premature osteoporosis in the MS population and consequently prevention strategies are neglected until the patient has already sustained a fracture. Neurologists might consider osteoporosis prevention as part of their management of the secondary complications of MS, rather than relying on primary care physicians or gynaecologists. This approach could have a significant impact on this neglected secondary complication.

The main consequence of osteoporosis is fracture, a devastating injury for people who already have physical limitations. The fracture potential is further increased by the risk of falling due to MS-related neurological deficits including balance difficulties, weakness, sensory and visual loss. The majority of members surveyed complained of balance difficulties (84%) and more than half had a history of falling (61%). Therefore, in addition to early osteoporosis screening and treatment, a falls prevention programme is another important component of reducing the risk of fracture in people with MS.

As part of the Performance Improvement project and care management role of ICS, a set of MS care guidelines and interventions has been formally established to address the deficiencies in care revealed in our survey results. These guidelines and interventions focus primarily on education, and are consistent with recommendations noted in the literature.¹⁷ These guidelines and interventions can be replicated at other long-term managed care agencies for members with MS.
Information will be given to all members in English and Spanish regarding immunomodulating drugs and osteoporosis prevention. A series of seminars will be scheduled for members with MS, in English and Spanish, led by an MS specialist, and transportation will be provided. In addition, any member who is not taking calcium and vitamin D and/or has not had the appropriate screening for osteoporosis, will be asked to give an ICS alert letter to their physician. Educating members with MS about their disease and the immunomodulating drugs will hopefully result in improved compliance. Educating members about their risks for osteoporosis will enable them to ask their physicians for the appropriate screening tests, calcium and vitamin D supplements, as well as empower them to pursue healthier lifestyles.

Furthermore, referrals to an MS specialist will be arranged for all members who have never seen an MS specialist. All members with MS who are at risk for falling will be referred for an evaluation by a rehabilitation professional as part of a falls prevention programme. Wheelchair users who transfer independently will also be evaluated for the safety of their transfer technique. Follow-up surveys will be performed throughout the year to confirm that our interventions have been effective.

This strategy to improve MS care for our population is consistent with a disease management approach (MS management) which involves co-ordination of care through a collaboration between the patient, physician and the long-term managed care program. Disease management programmes include evidence-based medical practice guidelines and a set of interventions to enhance patient care. These interventions include patient education, as well as support systems to assist physicians in monitoring patients and assist patients with medication and treatment plan compliance.24

Ultimately, the goal is to create a comprehensive set of care management guidelines for ICS members with MS. Future ICS surveys will focus on evaluating the pain management, urological and mental health services for this population of low income, minorities with MS. Insights gained through this process can be extrapolated to other programmes involved in the long-term care of minority, low-income patients with complex chronic diseases.

References
