

# The MS Center of Saint Louis: A Practice Perspective of the Impacts of High Cost Sharing

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There have been enormous gains in effective treatment for multiple sclerosis (MS) in the last 2 decades, but it has become increasingly expensive for patients. Changes in the healthcare system have led to insurance companies raising cost-sharing responsibilities for consumers, and the “new normal” is that consumers with chronic illness can expect to carry debt. This case study will follow a fictitious patient, Maxine, who encounters common cost-related barriers to treatment we have seen at the MS Center of Saint Louis. The interrelated impacts that these challenges have on Maxine, her caregivers, providers, and nonprofits in her community will be discussed. Solutions that we have implemented at our Center, as well as the potential for policies that create sustainable change, will be addressed.

### The Impacts of High Cost Sharing on Patients

Maxine Parker is a 45-year-old Caucasian, married, female who has been diagnosed with MS. She has recently started Tecfidera, a disease-modifying medication, and like all MS drugs, this is an expensive treatment. Maxine will need yearly magnetic resonance imaging (MRIs) and blood work every 3 months to monitor for a potentially lethal infection that has been known to occur in patients on this medication. She is still working full time and has private health insurance, but the medication co-pay is prohibitive without enlisting the help of a patient assistance program, such as the patient drug program from Biogen. Almost all of our patients, regardless of their insurance, rely on assistance from pharmacy companies or third-party foundations to pay for medications. In addition, insurance companies require prior authorizations for specialty medications, and MS medications fall into that category; this drives up the administrative burden and unreimbursed healthcare costs, often causing delays in access to medications.

Maxine’s ever-increasing healthcare costs amount to significant barriers for her in service, starting when she is quoted the out-of-pocket balance she will owe for her baseline

### ABSTRACT

As treatment for multiple sclerosis (MS) has become increasingly expensive, patients have had to shoulder a greater cost-sharing burden. This case study follows a fictitious patient as she encounters the common cost-related barriers to treatment that have been observed by providers at the MS Center of Saint Louis. Medications, tests to monitor patient safety on medications, physical therapy, occupational therapy, medical equipment, mental health counseling, transportation, and modifications to house or vehicles are all common needs of MS patients that increase their cost burden. The MS Center of Saint Louis provides care management and education to help patients budget for expected expenses and navigate resources for assistance. However, this will ultimately be an unsustainable solution without substantial policy change.

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MRI. It is becoming an increasingly common practice for hospitals to quote the patient's estimated cost when they schedule testing and then ask for payment at the time of service. She cancels the test and asks to stop Tecfidera due to the prohibitive expense of the MRI; this is a good example of patients refusing medication therapies based on ancillary treatments that are necessary, and not just the cost of the drug. This lack of compliance of treatment recommendations compromises their health, as MRIs are needed for appropriate oversight with medications and monitoring of their disease progression. Maxine eventually finds financial assistance, but gets MRIs every other year due to the expense. Without yearly MRIs, new lesions develop in her brain, but are not detected quickly; this leads to the progression in Maxine's disease and not only to increased physical disability, but also increased depression—a symptom of MS and often complicated by the stressors that the disease presents to the patient.

Not all patients immediately cancel tests or refuse treatment due to expenses, however. Patients also frequently look for “bargain prices” in getting the tests they need, especially MRIs, and although patients can find centers that provide lower-cost tests, they may produce a lower-quality image. Our Center has also experienced problems in getting comparisons from prior scanning. This presents a challenge from a practice perspective because the neurologist needs to compare MRIs over time to look for disease progression or signs of side effects from certain medications. This is another factor that results in barriers to best treatment.

With increased symptoms, Maxine must eventually leave work. She applies for and is approved for Social Security Disability, but turns to a marketplace insurance plan for coverage to wait out the 2-year window of time until Medicare is fully active. Marketplace plans generally have very high deductibles and co-pays; additionally, if patients do not qualify for Medicaid or tax subsidies with the marketplace, they have to pay out-of-pocket insurance premiums. Maxine and her husband, who is self-employed, have a family income of \$50,000; they use over 20% of their income to pay for healthcare costs. High deductibles and co-pays for tests required for appropriate oversight lead to thousands of dollars in out-of-pocket costs each year, and a deductible of \$5000 to \$10,000 is common for families earning \$50,000 annually. The combination of reduced income and increased expenses for health insurance premiums leads to a downward cycle and increased stress on the patient.

After receiving disability benefits for 2 years, Maxine has access to Medicare; however, she is responsible for

20% coinsurance for medical services and pays the premium for Part B. She also has to buy a Medicare Part D plan to cover medications—as discussed earlier, she has been receiving assistance for Tecfidera. Patients are no longer eligible for pharmaceutical patient assistance programs when they receive Medicare or any form of government insurance. They are referred to third-party foundations, which may or may not have funding available, and they routinely require a 30-page application, which is onerous for someone with a cognitive challenge. Fortunately, Maxine is able to continue using assistance from Patient Access Network under her new insurance status, but her disease progression necessitates other services that have only limited coverage under Medicare.

As Maxine's MS progresses, comprehensive treatment involves more than the tests needed for appropriate oversight while on Tecfidera, including mental health services, symptom management medications, physical therapy, occupational therapy, and home health services. These treatments involve additional co-pays or other out-of-pocket costs. As Maxine's disability worsens, she needs a power wheelchair to move about her home without the risk of falling, subsequently necessitating a ramp to the front door of the house. Durable medical equipment is restrictively covered by insurance, but the modifications that increase accessibility to the home and vehicles are out-of-pocket expenses. Patients frequently have to turn to nonprofits for assistance with these costs or take out loans. The Parkers cannot afford the ramp without incurring additional debt.

### Impact on Caregivers

As Maxine is wheelchair bound, her husband needs to help her with transfers in the bathroom, to and from bed, and transportation; however, he also has to continue to work and cannot always be home. Private duty care is not covered by Medicare unless the patient has been recently hospitalized. Unable to pay \$20 per hour for a care aide, Maxine's care relies on her husband and their 16-year-old daughter, and she is left alone for some hours during the day, especially when other family members have to be at work or school. Maxine's husband drives her to most appointments, but must take time off work to do so.

Poor access to transportation eventually impacts Maxine's ability to get to treatment. Although her husband is able to help, there are some days he has business conflicts. Maxine finds ADA-compliant public transportation prohibitive, as this type of transportation service requires her to be away from a restroom; she has incontinence, which leads to skin breakdown when there is chronic moisture on the skin. Maxine cancels some of her follow-up visits

when she is not able to get to the office. Due to increased disability and depression, she is referred to counseling; however, she does not go due to challenges in meeting the co-pay and the difficulty in finding transportation for regular sessions.

The effects of these cost-related barriers to services form interrelated consequences for patients, caregivers, and providers lead to a negative cycle. We have seen how this has impacted Maxine, as she is inconsistently compliant with recommended treatment and has experienced worsening disease progression that results in worsening disability. In addition to reduced income, Maxine is increasingly isolated, as she has stopped social activities due to physical restraints. Her quality of life deteriorates further, as she stops engaging in social activities, such as support groups, group exercise, or outings with friends. Most of her time is spent in her wheelchair in front of the TV.

As Maxine's stress and isolation increases, she becomes more agitated and combative with her husband, which in turn places more stress on him as a caregiver. Maxine's caregiving needs continue to increase, however, so not only does this provide a situation ripe for caregiver burnout, but the increased time her husband has to take off from his business negatively impacts his income as well. The combination of increased patient isolation and increased caregiver stress can set the stage for abuse. Although the situation does not escalate to this level in the Parker household, the health of Maxine's husband becomes compromised. Their teenage daughter also finds that there are limits on the extracurricular activities she is able to do at school due to needing to help in the care of her mother.

### Impact on Providers

The impact on patients and families discussed above have resulting consequences that also impact providers and hospitals. Organizations find that services sometimes go unpaid, as patients are increasingly unable to keep up with the out-of-pocket expenses. Providers cannot continue to provide services that they are not reimbursed for, so they may refuse to schedule appointments with patients until services are paid. Returning to the example of Maxine, she is referred for bladder Botox injections, a treatment often recommended for incontinence in MS patients. She begins these injections every 6 months while still on private insurance; however, after 1 injection, she is left with a higher bill than anticipated. She cannot schedule another appointment until it is paid, but as the cost is prohibitive, she opts not to schedule another appointment. This leads to bladder dysfunction and additional health risks.

As patients experience worsening health and more limited resources, they may seek nonemergency services in the emergency department (ED) or they may call an ambulance as a way of getting to the hospital due to barriers to transportation resources. Because she is unable to find other transportation while her husband is working, Maxine is one such patient who calls an ambulance. Further unnecessary utilization of emergency resources occurs when Maxine experiences increased urinary tract infections as a result of reduced treatment compliance. Also, lack of education and the symptoms lead her to go to the ED each time rather than seeking care in an appropriate setting, such as a doctor's office.

Hospitals are negatively impacted by an increasingly crowded ED, and overworked staff must triage an increasing number of patients. Maxine and her husband are left with an ambulance and ED bill, which they will not be able to pay. Hospitals in this situation are left with providing services that are not reimbursed, so administration has the task of finding ways to reduce outstanding debt.

With increasing financial pressures on patients, caregivers, and providers resulting from the factors discussed above, nonprofits are faced with increasing demand for financial aid. As providers working with MS patients, we frequently refer patients like Maxine to the MS Foundation, the MS Association of America, and the National MS Society for help paying for medical equipment and services. It is increasingly common for patients to be unable to obtain assistance, however, as these organizations are also dealing with increasing financial pressure due to high demand. Maxine applied to all of these organizations to get financial help for a wheelchair ramp outside her home, but when the amount she was awarded still left her with a high out-of-pocket cost, she decided not to get the ramp. Funds at such nonprofits often are depleted before the end of the fiscal year, thus increasing patient cost burden.

### Solutions

At the MS Center of Saint Louis, we have education services to help provide solutions to some of the treatment barriers that Maxine encounters. This involves care management and the nurse's line, which are provided at no cost to the patients. Returning to Maxine, she initially refused to go on Tecifidera when she sees she would owe \$2000 toward her deductible for each annual MRI. When she talks to a care coordinator about financial assistance programs available and her ability to request a payment plan, she continues with treatment. As mentioned earlier, however, she does not get MRIs as often as recommended because she cannot afford the remaining expenses she

would owe after financial aid. Patients are also able to call the nurse's line regarding questions about symptoms or medications; getting nurse feedback about symptoms can help patients avoid ED visits when not truly necessary. As the cost-sharing burden on patients increases in a changing healthcare system, patient education needs to be expanded to change patient expectations regarding the expenses involved with MS.

Although patient education and resources is a short-term solution in some cases, it will ultimately not be sustainable as funding dries up due to increasing demand. If government programs were expanded to provide more financial assistance to nonprofits, such organizations could expand the type of financial aid they have available for services like transportation, vehicle/home modifications, and durable medical equipment. Much of the financial burden on Maxine pertains to the need for home health services and transportation services, which are not covered by insurance and rarely have sliding scales available. If these services could be made available to her through the expanded availability of financial assistance, she could have a dramatically better quality of life.

Medicaid expansion will make comprehensive healthcare coverage more accessible to more patients. Patients that do not qualify for, or make too much money to qualify for, Medicaid are often left paying a premium each month on their health insurance in addition to deductibles or out-of-pocket costs. Maxine's household makes too much to qualify for Medicaid; it is not unheard of for couples to divorce so one spouse can qualify for this coverage. In order to save on a monthly premium, she gets a marketplace plan with higher deductibles, which amounts to out-of-pocket costs for testing. This is a good example of how reduced access to Medicaid leaves patients with inadequate coverage.

Although the federal introduction of marketplace insurance policies begins to address the problem of health-

care costs, it is minimally effective for patients like Maxine who have MS. Potential long-term solutions to this problem include federal regulations that would cap profits for insurance companies, which would thereby provide incentives for coverage providers to lower their contracted rates and deductibles. Such regulations could include less restrictive prior authorization procedures, reducing administrative burden and cutting delays in patients getting access to their medications.

## Conclusions

The rising cost of healthcare leaves MS patients, such as Maxine, with thousands of dollars in out-of-pocket expenses. This is currently mitigated by financial assistance for selected services, but patients are not prepared for the increased cost-sharing burden, which results in multiple barriers to treatment for patients and increased patient and caregiver stress. Likewise, healthcare organizations and nonprofits are unprepared to provide the amount of financial assistance that patients need in this changing healthcare environment. Patient education in planning effectively and locating resources is a short-term, but ultimately inadequate, solution. Changes in state and federal policies will be needed for sustainable improvements in patients getting comprehensive access to healthcare.

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