

Patient Experiences with the Impacts of Multiple Sclerosis & Disease-Modifying Therapies

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Purpose: Disease-modifying therapies (DMTs) are vital for managing multiple sclerosis (MS), but research using administrative data often excludes patient preferences and factors clinicians consider in treatment decisions. Patient experience data are crucial to understand and improve MS treatment initiation, adherence, and outcomes.

Methods: A cross-sectional survey of US adults with MS or clinically isolated syndrome was conducted online from December 2022 to January 2023 by the MS Coalition. A mixed methods analysis was conducted: logistic regression for quantitative data and thematic analysis of qualitative data.

Results: Among 1,323 participants (median age 55; 78% female), 80% expressed concerns about loss of independence, 65% about financial impacts, 64% about emotional impacts, 57% about relationships, and 42% about careers. Emotional tolls included identity loss, stress from navigating healthcare, and financial strain on families. Concerns varied by age, sex, and disability status. Nearly all participants (97%) reported DMT experience, with 73% having used two or more DMTs. Key factors in initiating DMT included slowing disease progression (92%), preventing relapses (89%), and following medical advice (89%). Financial barriers, such as high out-of-pocket costs, led to treatment delays or discontinuation in 19%. Barriers varied by demographic factors and included stress from medication costs, insurance denials, and fear of losing health coverage. Financial assistance was crucial for many. Half of participants had stopped a DMT due to doctor recommendations, side effects, or insurance issues.

Conclusion: The survey highlights the emotional and financial burdens of living with MS, including concerns about independence and relationships. The findings underscore the need for comprehensive care and provide actionable recommendations for managed care, research, and healthcare providers.

Keywords: multiple sclerosis, disease-modifying therapy, patient experience data survey, treatment initiation, adherence

Background

Multiple sclerosis (MS) is broadly categorized into two subtypes based on disease progression: relapsing forms and progressive forms. Relapsing forms of MS are characterized by episodes of new or worsening symptoms, called relapses, followed by periods of recovery (remissions), during which symptoms may improve or disappear. Progressive forms of MS involve a gradual increase in disability with or without distinct relapses.¹

Disease-modifying therapies (DMTs) are integral to MS management. They are intended to reduce relapses and delay disease progression, although they do not directly alleviate symptoms, which are treated separately.² DMTs are classified as “moderate efficacy” (eg, interferon-beta [IFNβ], glatiramer acetate, dimethyl fumarate, teriflunomide) and “high efficacy” (eg, alemtuzumab, cladribine, fingolimod, natalizumab, ocrelizumab, siponimod, ozanimod, ofatumumab, ublituximab).^{3–7} Given the progressive, lifelong nature of MS, therapy switching is common.^{8,9} Failure to tailor treatment to disease activity may result in worsened clinical outcomes and increased disability.⁶

Clinical practice guidelines direct healthcare providers to consider patient preferences related to safety, route of administration, lifestyle, efficacy, common adverse effects, and tolerability when discussing DMTs during shared

decision-making with patients.^{2,10} In addition, providers and patients must consider treatment sequencing (ie, initiating one therapy can affect the safety and efficacy of subsequent therapies), rapidly evolving evidence regarding effectiveness, heterogeneity of treatment effect, and a rapidly expanding treatment armamentarium.^{7,11,12} Insurance coverage and out-of-pocket costs further impact the selection of therapies, as providers and patients seek to balance high-quality care with affordability.^{13–15}

Studies indicate that a substantial proportion of people with MS in the United States experience financial hardships due to high out-of-pocket costs associated with their treatment regimens despite having insurance.^{16,17} Health insurance policies often require patients to pay copayments, a fixed amount per prescription, or co-insurance, which ties patient payments to a percentage of the medication's list price before discounts or rebates.^{18,19}

A 2019 market research study among people with MS showed that high out-of-pocket costs and the complex insurance approval process are linked to worsened symptoms and increased emotional distress.²⁰ A Medicare claims analysis, which examines data from the US federal health insurance program primarily covering people aged 65 and older or with certain disabilities, found that beneficiaries not subject to traditional cost-sharing are likelier to initiate a DMT following diagnosis.²¹ This is important as evidence supports that early initiation, especially of high-efficacy therapies, allows for people with MS to receive the maximum possible benefit from their DMT.^{5,22} Across conditions, evidence demonstrates that utilization management is associated with worse medication adherence and clinical outcomes.^{19,23–25} People with MS who are adherent to their DMT have a longer time to their first relapse, a lower annualized relapse rate, and a longer period before needing a cane, walker, or wheelchair.²⁶

People with MS not only face financial difficulties due to utilization management strategies but also experience higher levels of absenteeism and productivity losses compared to people without MS.^{16,27–29} Additional factors such as early retirement and the need for informal care contribute to substantial indirect costs.³⁰

Research on treatment patterns and adherence often uses administrative data, which provides information about patient touchpoints within the health system.^{31,32} These data are helpful in identifying population-level trends but lack detailed information on many factors clinicians and patients must consider in shared decision making. While out-of-pocket and non-medical costs are known barriers to care, these data are often missing from administrative datasets. Thus, context regarding *why* patients delay treatment or do not adhere to care plans is often absent.^{33,34}

Other types of quantitative research could also benefit from additional qualitative information directly from people with MS. For example, a systematic review of stated preference studies in people with MS highlighted that most attributes were based on prior research or clinicians. The authors highlighted the importance of qualitative methods to guide attribute and level selection in future studies since people's experiences with MS are diverse, and without engaging people with MS, key factors in decision-making are likely to be omitted.³⁴

This study collected patient experience data that are not routinely collected in real-world datasets but are critical for understanding and improving patients' experiences, adherence, and outcomes with DMTs. These include the impacts of MS on daily living, emotional health, and financial well-being; the experiences and topics important to patients when deciding among DMTs during shared decision-making; factors associated with high-efficacy treatment initiation; as well as financial and non-financial barriers and side effects impacting adherence.

Methods

Study Design

This study utilized a cross-sectional survey design targeting adults (or their caregivers) who self-reported a diagnosis of MS or clinically isolated syndrome (CIS). A working group from the Multiple Sclerosis Coalition (MSC), a network of nine independent organizations providing essential MS programs and services, crafted and refined the survey items.

Participants were eligible if they agreed to participate in the survey, identified as a person with MS/CIS or their caregiver or friend responding on their behalf, indicated living and receiving care inside the United States, and provided complete demographic information. The survey was initially developed in English, translated, and culturally adapted to US Spanish, and then programmed onto the Jotform™ online platform. Both versions underwent native speaker review and were pilot tested before field administration. Participants were recruited through Email and social media

communications facilitated by MSC member organizations (Accelerated Cure Project for MS, Can Do MS, Consortium of Multiple Sclerosis Centers, the International Organization of Multiple Sclerosis Nurses, Multiple Sclerosis Association of America, Multiple Sclerosis Foundation, MS Views & News, the National Multiple Sclerosis Society, and the United Spinal Association). Data collection spanned December 2022 through January 2023. Advarra's Institutional Review Board reviewed and deemed the study exempt from continuing review (Pro00068288) according to "Exemption 2: Surveys, Interviews, Educational Tests, Observations of Public Behavior." All procedures comply with ethical principles outlined in the Declaration of Helsinki. All participants provided informed consent, which included the publication of anonymized responses/direct quotes.

The survey captured participants' demographic and clinical characteristics and self-assessed disease status using the Patient Determined Disease Steps (PDDS) provided by the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry.³⁵ DMTs reported were categorized as high or moderate efficacy.³⁻⁶

Analysis

We conducted a mixed methods analysis.

Quantitative data

Participant characteristics were summarized using descriptive statistics. Continuous variables were reported as means with standard deviations or medians with interquartile ranges. Categorical variables were presented as frequencies and percentages. Logistic regression models were constructed to assess both unadjusted and adjusted relationships between age, sex, race, and PDDS covariates and the following outcomes of interest:

1. Receipt of initial high efficacy (HE) DMT, among those reporting being on their first DMT.
2. Concern over the impacts of MS (independence, emotional, financial, relationships, career).
3. Financial barriers to accessing DMT (out-of-pocket costs causing delay, DMT coverage rejection, copay assistance, affordability without copay assistance).

Odds ratios (ORs) with 95% confidence intervals (CIs) were reported. Statistical significance was set at a two-sided threshold of 0.05. Analyses were conducted using Stata 14.2. We did not aim to establish causal relationships.

Qualitative Data

Our survey consisted predominantly of quantitative questions; however, participants were also provided opportunities to contribute qualitative information through optional free-text responses to offer additional context. Two researchers thematically coded these free text responses using Atlas.ti. The thematic coding process was structured to align with the specific sections of the survey to ensure contextually relevant analysis.

Results

Population

The survey included 1,323 eligible participants, of whom 99% were people with multiple sclerosis (MS) and 1% were caregivers (see [Table 1](#)). A total of 786 participants offered free text responses in addition to answering quantitative questions.

The median age was 55, and the median age at diagnosis was 38. Most participants were female (78%), and about half received their MS care from a specialized MS clinic or center (49%), while 35% were treated at a general neurology office or clinic. Most participants were insured by commercial insurance rather than public options (Medicare, Medicaid), or other options (58%, 35%, 4%, and 3% respectively). Most participants (73%) had taken 2 or more DMTs since diagnosis.

Table 1 Survey Participant Characteristics

	Total N=1,323
Age today, years (Mean, SD)	54.8 (12.2)
Median (IQR)	55 (46–64)
Age at MS diagnosis, years (Mean, SD)	38.3 (10.8)
Median (IQR)	38 (30–46)
Time since MS diagnosis, years (Mean, SD)	16.5 (10.6)
Median (IQR)	15 (8–23)
Currently on a DMT	82% (1,079)
Currently on first DMT	16% (215)
Total number of DMTs (Mean, SD)	2.7 (1.6)
Median (IQR)	2 (2–4)
Total number of DMTs (Category)	
None	44 (3%)
1	267 (20%)
2	360 (27%)
3	284 (21%)
4 or more	368 (29%)
Sex at birth	
Female	78% (1,037)
Male	21% (283)
Prefer not to say	<1% (3)
Race	
Black or African American	5% (68)
Other (incl. multiple)	7% (94)
White or Caucasian	88% (1,159)
Type of MS	
Clinically Isolated Syndrome (CIS)	1% (12)
Primary-Progressive MS (PPMS)	9% (120)
Relapsing-Remitting MS (RRMS)	75% (988)
Secondary-Progressive MS (SPMS)	15% (203)
Patient Determined Disease Step	
Normal	24% (317)
Mild Disability	18% (235)
Moderate Disability	11% (146)

(Continued)

Table 1 (Continued).

	Total N=1,323
Gait Disability	14% (183)
Early Cane	11% (148)
Late Cane	7% (89)
Bilateral Support	9% (122)
Wheelchair / Scooter	6% (79)
Bedridden	<1% (4)
Primary location for MS care	
MS Clinic or Center (Hospital or University Medical Center)	49% (649)
General Neurology Office or Clinic	35% (468)
Private MS Clinic (not associated with a Hospital or University)	10% (136)
Primary Care or Internal Medicine Office	3% (35)
I don't receive treatment for my MS	1% (18)
Other	1% (17)
Treatment or steps taken to manage MS	
Prescription medicine	90% (1,190)
Exercise or physical therapy	67% (882)
Supplements	57% (749)
Diet	39% (513)
Alternative therapies	15% (197)
Current insurance type	
Commercial	58% (761)
Medicare	35% (458)
Medicaid	4% (55)
Other	3% (40)
None	1% (9)

Impact of MS on Daily Life, Finances, and Emotional Well-Being

Participants reported significant impacts of MS on activities of daily living, emotional health, and finances. Participants stated they were “concerned” or “very concerned” about the loss of independence (n=1,054; 80%), financial impacts on families (n=848; 65%), emotional impacts (n=835; 64%), impacts on relationships (n=741; 57%) and impacts on careers (n=548; 42%). In the adjusted logistic models, age, sex, and PDDS were associated with different levels of concern across the impacts. Older participants were less likely to report concern with financial impacts on family, emotional impacts, impact on relationships, and impacts on career relative to younger participants. Men were less likely to be concerned with loss of independence and the emotional impact of MS relative to women. Respondents reporting any

Table 2 Factors Associated with Participants Reporting Being “Concerned” or “Very Concerned” Over Impacts of MS

	Loss of Independence			Financial impact on my family			Emotional Impact			Impact on Relationships			Impact on my Career		
	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P
Age today, years	0.992	[0.980–1.003]	0.166	0.972	[0.963–0.982]	<0.001	0.973	[0.962–0.983]	<0.001	0.972	[0.962–0.983]	<0.001	0.942	[0.930–0.953]	<0.001
Sex															
Female	REFERENCE CATEGORY														
Male	0.699	[0.509–0.960]	0.027	0.775	[0.583–1.031]	0.080	0.629	[0.450–0.877]	0.006	0.889	[0.651–1.214]	0.460	0.849	[0.601–1.201]	0.355
Race															
Black or African American	0.865	[0.468–1.601]	0.645	1.091	[0.656–1.813]	0.738	1.003	[0.575–1.752]	0.990	0.845	[0.476–1.502]	0.566	1.358	[0.778–2.370]	0.281
Other	1.305	[0.733–2.323]	0.366	1.417	[0.923–2.173]	0.111	1.255	0.792–1.989	0.333	1.082	[0.679–1.725]	0.737	1.493	[0.931–2.392]	0.096
White or Caucasian	REFERENCE CATEGORY														
PDDS*															
Reported “normal”	REFERENCE CATEGORY														
Reported disability	1.922	[1.415–2.612]	<0.001	1.321	[1.002–1.743]	0.049	1.738	[1.261–2.396]	0.001	1.723	[1.254–2.369]	0.001	1.454	[1.046–2.024]	0.026

Abbreviation: *PDDS: Patient Determined Disease Steps provided by the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry.

Table 3 Illustrative Quotes Related to the Impacts of MS

Impact	Illustrative quote
Loss of independence	<p>Losing independence impacts personal identity and self-worth</p> <ul style="list-style-type: none"> “MS turned my life upside down. I lost my ability to drive, to work, to make friends, to have an active social life, to be in a partnership. I have lost my independence, and much of my identity. I do not really know who I am, or what my purpose is, and why am I still here? What for?” - A person with SPMS <p>Emotional toll of losing independence</p> <ul style="list-style-type: none"> “It causes depression when you lose your independence like being able to walk without some type of assistance. Plus I'm 42 years old and had to stop working and that sucks.” – A person with RRMS
Financial impact on my family	<p>High out-of-pocket costs despite insurance</p> <ul style="list-style-type: none"> “Even with insurance, the cost of copays is a very significant part of my family's expenses. There is a constant temptation to skip doses to stretch out the supply of my medication, which could possibly lead to much greater expenses to the insurance company, not to mention the toll on my health and the impact to my family.” – A person with RRMS “We dropped my employer's insurance and my husband found new work just so we could get my medication approved.” – A person with RRMS
Emotional impact	<p>Stress related to navigating the healthcare system</p> <ul style="list-style-type: none"> “It's all just so stressful. Having MS, trying to find financial aid to get your medicine, is insurance going to pay for rehab, what kind of facility will I have to be in, how long will they pay for.” – A person with RRMS “MS has SO MANY symptoms and it's not easy. Right now I am mourning Christmas and all the things I can no longer do, the tree and stringing lights and dropping all the ornaments, cooking, baking, decorating, writing cards. It makes me sad.” – A person with RRMS
Impact on relationships	<p>Caregiver burden and family strain</p> <ul style="list-style-type: none"> It's very expensive having MS. It's also very isolating. My husband is my care giver and I worry about the toll it takes on him, especially since there does not seem to be any compensation for it. – A person with PPMS “Emotional impact on family was HIGH when was at worse. Now divorced and on own with little/no financial security. Meds DMT not covered and must look for assistance yearly If not found will not take meds.” – A person with RRMS “I want to watch my Granddaughter (5) grow up. I was married 25 years and my husband could no longer handle my MS. I didn't sign up for MS. MS has taken so very much from me.” – A person with SPMS
Impact on my career	<p>Cognitive difficulties impact daily life and career</p> <ul style="list-style-type: none"> “I have gone from a confident female who excelled at my job and home life. I can no longer work, as I become lost and forget how to do tasks.” – A person with SPMS <p>Employment decisions shaped by healthcare access</p> <ul style="list-style-type: none"> “The hoops I have to jump thru to get my Rx is demoralizing. The fact that I had to leave a job for other employment due to not being able to afford a \$2K copay is indicative of why this country needs universal care insurance.” – A person with RRMS

level of disability in the PDDS were more likely to report a concern with all five impacts relative to people reporting no disability (see Table 2).

In the free text responses, participants contextualized loss of independence and financial impacts on their families (see Table 3).

I don't have a lot of the problems, like work, money, or family.... because I'm so disabled I'm on Medicaid and Medicare. Sure I don't have to worry about these issues, but it's because I'm constantly on the brink of homelessness and living in poverty and have had no chance to have a career, house, family, or education. MS hit me just when most people are starting their real adult lives. Many people with MS may be in this boat where a few narrow questions make it look like we are doing great, but in reality, we are not. – Person with relapsing-remitting MS (RRMS)

Numerous participants shared personal narratives highlighting the emotional impact of MS, detailing how it disrupts their lives by complicating both short- and long-term planning. They expressed the ongoing challenge of navigating the

uncertainty surrounding disease progression and the severity of daily symptoms. Participants described the difficulties of living with an “invisible” illness:

I look fine on the outside, but am extremely tired, confused, and dizzy all day, every day. No one can see what I feel like on the inside. My lifelong dreams and goals were robbed of me before I could even begin my career. – Person with RRMS

Among these responses, many mentioned that the symptoms of MS are worsened by stress. Stress can be caused by fear of relapses and disease severity. Participants stated their stress is exacerbated by challenges navigating the health system, insurance, and healthcare costs. Patients often face challenges related to insurance coverage, copays, changing medications, and the need for ongoing advocacy for their healthcare needs. They described stress due to managing medical appointments and working with their insurance company to overcome bureaucratic hurdles, such as when medicine coverage is rejected, or they are switched to an alternate DMT instead of the DMT prescribed by their health care provider.

There are so many things that concern you. EVERY TIME something hurts, twitches, tingles; every time you can't think of something, any time anything is difficult, you worry that it is the start of a relapse or a larger problem. It could be because I'm getting older, could be just a hiccup that people get, but it becomes a source for stress and anxiety. – Person with RRMS

The stress of dealing with insurance and medical appointments is a direct trigger for MS symptoms for many of us. We are told to avoid stress at all costs yet managing the US insurance/medical system is a nightmare (and I have good insurance and providers). – Person with RRMS

Participants also expressed concerns regarding MS symptoms, whether they had experienced them or not. These included walking or other mobility problems (n=919; 69%), fatigue (n=770; 58%), difficulties with thinking, learning, and planning (n=683; 52%), muscle spasms, stiffness, weakness (n=557; 42%), and bladder problems (n=525; 40%). These were contextualized in free-text responses; two examples are below.

Even though I don't have persistent physical disability (like issues with mobility), the uncertainty of the disease is very wearing. Also, because I can be fatigued in the morning and fine after resting for a few hours it's hard not to feel like people think you're more lazy than sick. Cognitive issues can be scary, too, because it's hard to tell if it's something to worry about or not. Am I just getting old? Or is it something more? Will I be able to be independent for a long time or will I suddenly need more assistance? It can get pretty dark if you let yourself get consumed by anxiety. – Person with RRMS

[I] must always remain aware of environment - heat, steps, holes in walkway. Big impact on travel choices and outdoor excursions. Limits hiking, biking, climbing, camping, water sports. Fatigue affects time with my children, grandchildren, and ability to attend events. Balance impacts choice of seating in stadiums and music performances. It is ever-present in my life. I am so thankful I am able to control it with the medications available. - Person with SPMS

Experiences and Topics Important to Patients When Deciding Among DMTs During Shared Decision-Making

Nearly all participants reported DMT treatment experience (n=1,279; 97%), with most receiving two or more DMTs since diagnosis (n=1,012; 73%). The factors participants most often reported as “important” or “very important” when deciding to start a DMT include slowing MS progression (n=1,217; 92%), preventing relapses (n=1,177; 89%), following their doctor’s advice (n=1,177; 89%), achieving life goals (n=1,005; 76%), long term risks (n=979; 74%) and side effects (n=961; 73%).

Half of the survey participants (n=647; 50%); believed their personal preferences and/or lifestyles were considered “very much” in the treatment decision-making process, whereas a minority (n=42; 3%) believed their preferences were “not at all” considered.

Availability of a Neurologist experienced in MS makes a huge difference... Many doctors assume disability is inevitable, but with today's drugs, that is not always true. I live a normal life, yet some doctors have told me I should prepare to leave work and

*that symptoms would only get worse. They were wrong. Attitude in MS makes a difference and doctors make a huge difference.-
A person with RRMS*

Factors Impacting Treatment Initiation and Adherence

High-Efficacy and Moderate-Efficacy DMT Initiation

Of the 215 survey respondents currently on their first disease-modifying therapy (DMT), 41% use a high-efficacy DMT, while 59% are on a moderate-efficacy DMT. Age, disability status, and location of MS care were all significantly associated with HE DMT initiation. Older respondents were less likely to initiate high-efficacy therapy relative to younger respondents [OR: 0.918; 95% CI: [0.891–0.946], people reporting any level of disability were more likely to receive an HE therapy relative to people reporting no level of disability [OR: 2.569; 95% CI: [1.240–5.307]. Additionally, the type of healthcare facility played a role in the choice of DMT; patients receiving care at a general neurology office or clinic were less likely to initiate an HE therapy relative to people receiving their treatment at an MS clinic or center affiliated with a hospital or university medical center [OR: 0.371; 95% CI: [0.183–0.751] (see Table 4).

Financial Barriers & Patient Assistance

Nearly one out of every five participants (19%) reported that out-of-pocket costs had caused a delay, pause, or discontinuation of their DMT. About one-third (30%) indicated that an insurer rejected their provider's request for

Table 4 Factors Associated with Receipt of High-Efficacy Therapy Among People on Their Initial DMT (n=215)

	Univariate Analysis			Multivariable Analysis		
	Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P
Sex						
Female	REFERENCE CATEGORY			REFERENCE CATEGORY		
Male	0.674	[0.364–1.249]	0.210	0.589	[0.288–1.203]	0.146
Age today, year	0.932	[0.909–0.957]	<0.001	0.918	[0.891–0.946]	<0.001
Race						
Black or African American	2.548	[0.886–7.324]	0.083	1.252	[0.377–4.161]	0.714
Other	0.873	[0.348–2.191]	0.773	0.925	[0.336–2.541]	
White or Caucasian	REFERENCE CATEGORY			REFERENCE CATEGORY		
PDDS*						
Reported “normal”	REFERENCE CATEGORY			REFERENCE CATEGORY		
Reported some level of disability	1.302	[0.733–2.312]	0.368	2.569	[1.240–5.307]	0.011
Primary location for MS care						
MS Clinic or Center (Hospital or University Medical Center)	REFERENCE CATEGORY			REFERENCE CATEGORY		
General Neurology Office or Clinic	0.399	[0.215–0.742]	0.004	0.371	[0.183–0.751]	0.006
Private MS Clinic (not associated with a Hospital or University)	1.691	[0.645–4.435]	0.285	1.415	[0.466–4.301]	0.540
Primary Care or Internal Medicine Office	0.781	[0.166–3.668]	0.754	1.427	[0.245–8.302]	0.692

Abbreviation: *PDDS: Patient Determined Disease Steps provided by the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry.

DMT coverage at some point. Nearly two-thirds (64%) have received copayment assistance or other financial support for their DMT. Of those receiving financial assistance, 65% stated they could not afford their DMT without this support.

Men, people identifying as “Black or African American”, and people reporting no disability were less likely to report that out-of-pocket costs had caused a delay, pause, or discontinuation of their DMT. Older people and men less frequently described that an insurer had ever rejected a provider’s request for DMT coverage. Older people less frequently described receiving copay assistance or other financial support for their DMT, which is likely due to fewer financial assistance options being available for people on Medicare or other public programs.³⁶ Among people receiving financial assistance, younger participants, men, and people identifying as “White or Caucasian” were more likely to describe that they would not be able to afford a DMT without assistance (see Table 5).

In addition to costs associated with DMTs, participants provided free text responses describing their difficulties affording supportive care and non-medical costs (see Table 6). Examples include costs for home modifications, paid caregivers,

I wish insurance paid for home modifications to increase/maintain our independence! I strongly wish/beg for insurance to pay for private duty health aides (aside from homecare), to relieve our caregivers, as well as maintaining our independence! We have to pay privately for this which is over \$40 an hour! On a disability check that doesn't go very far. – Person with SPMS

DMT Side Effects

Among people currently taking a DMT (n=1,079), 556 (52%) reported experiencing side effects. The most common side effects participants experienced included blushing or flushing (n=13%), hair loss (n=117; 11%), and flu-like symptoms (n=93, 9%). Approximately half (n=523; 48%) of people currently on a DMT reported experiencing no side effects. Additionally, 56 participants discussed side effects in their free text responses. They described a variety of experiences: some continued using a DMT despite significant side effects that affected their daily lives, others had severe side effects but were able to switch to a more tolerable DMT.

When I was first diagnosed, [a moderate-efficacy treatment] had just come out, so I was able to start taking this. Unfortunately, I had liver damage as a result of [the moderate-efficacy treatment], but after a couple of months of stopping, I began taking [different moderate-efficacy treatment], and have been on this about 14 years and have tolerated this well. – Person with RRMS

Additional Barriers to Receiving DMT According to Their Doctor’s Recommendations

Nearly one in five survey participants of the 1,079 currently taking a DMT (n=202; 19%) reported barriers to receiving their DMT according to their doctor’s recommendations. Among the 202 people reporting barriers, the most frequently mentioned were healthcare time commitments for administering treatment, such as infusions (n=83; 41%) or other medical visits, such as MRIs or lab tests (n=51; 25%), missing work (n=82; 41%), transportation to and from their doctor’s office or clinic (n=60; 30%), and requiring assistance from a caregiver, such as a spouse or other family member (n=54; 27%).

Pausing or Discontinuing DMT

Half of participants (n=666; 50%) reported stopping a DMT at some point. Among those who stopped, the most common reasons were recommendations from their doctors (n=202; 30%), dissatisfaction with side effects (n=121; 18%), and insurance-related issues (n=67; 10%). The free text responses provided additional context for stopping treatment:

I have good results from my DMT's. I finished my [high-efficacy] treatment and no longer take a DMT at this time. That is nice – Person with RRMS

I was on [moderate-efficacy treatment] for 20 years before my body turned on it. Then I tried [high-efficacy treatment] and almost went blind, vision is permanently damaged after two months and then tried [moderate-efficacy treatment] and got a rash in my groin and down my thighs. Couldn't sit, walk or have sex or wear pants or underwear. A lot of PAIN... about two months again then stopped and within two weeks completely gone. With my Neurologist agreement we stopped completely eight years ago! Neurologist said a lot of time as we age MS gets better and it has. – Person with RRMS

Table 5 Factors Associated with Financial Barriers to Accessing Disease-Modifying Therapies

	Out -of-Pocket Costs Ever Caused a DMT Delay, Pause, or Stop			Current or Past Insurer Ever Rejected Provider's Request for DMT Coverage			Currently Receive Copay Assistance or Other Financial Support for DMT			Would Not be Able to Afford DMT Without Assistance		
	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P	Adjusted Odds Ratio	95% CI	P
Age today, years	1.002	[0.989–1.014]	0.789	0.979	[0.969–0.989]	<0.001	0.957	[0.947–0.967]	<0.001	0.966	[0.951–0.982]	<0.001
Sex												
Female	REFERENCE CATEGORY											
Male	0.578	[0.394–0.850]	0.005	0.678	[0.499–0.921]	0.013	0.908	[0.691–1.194]	0.489	2.127	[1.417–3.193]	<0.001
Race												
Black or African American	0.258	[0.095–0.720]	0.010	0.671	[0.379–1.187]	0.171	0.906	[0.541–1.516]	0.707	0.674	[0.261–1.733]	0.412
Other	0.882	[0.501–1.552]	0.664	0.786	[0.491–1.260]	0.318	0.648	[0.418–1.001]	0.053	0.229	[0.071–0.746]	0.014
White or Caucasian	REFERENCE CATEGORY											
PDDS*												
Reported "normal"	REFERENCE CATEGORY											
Reported disability	1.847	[1.259–2.709]	0.002	1.214	[0.910–1.619]	0.188	0.861	[0.655–1.131]	0.282	0.637	[0.424–0.958]	0.030

Abbreviation: *PDDS: Patient Determined Disease Steps provided by the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry.

Table 6 Illustrative Quotes Related to Healthcare Costs

Theme	Illustrative Quote
Stress due to the cost of medicines	<ul style="list-style-type: none"> • “Figuring out how to afford such exorbitant costs, even with insurance makes the MS worse due to stress.” – A person with RRMS • “Without my meds, my disease would progress and I’d no longer be a productive member of society. My drugs cost \$10K per month, without insurance I couldn’t afford them at all.” – A person with RRMS
Fear of losing employment and health insurance	<ul style="list-style-type: none"> • “The fear of losing health insurance that is tied to employment is real for people living with chronic illness.” – A person with RRMS
Stress due to denials and utilization management	<ul style="list-style-type: none"> • “The constant fight for meds adds to my stress which flares symptoms. Why do I have to get a formulary exception and preauthorization every year? It’s not as if my tolerance for generic will improve or as if my MS will magically disappear.” – A person with PPMS • “There is an extremely high level of anxiety created when insurers ‘arbitrarily’ remove specific DMTs from formulary.” – A person with CIS • “It is frustrating to have to deal with insurance denials, prior auth. and referrals to see a specialist and to start a new medication. It’s time consuming and sometimes interferes with my health or symptom control.” — A person with SPMS
Important role of copay assistance programs	<ul style="list-style-type: none"> • “The copay assistance programs are a blessing for myself and I am sure many others. Not only does this help with the costs but also reduces stress. Living with MS is scary not knowing what new symptoms may arise at any time. The DMTs make it possible for many to lead active lives.” – A person with RRMS • “The fear of the unknown is there every day. Friends and family try but have difficulty understanding how MS affects me. The cost of the medication is so high, I worry about the assistance running out.” – A person with RRMS
Concern over being moved to a generic treatment due to loss of assistance	<ul style="list-style-type: none"> • “It’s all just so stressful. Having MS, trying to find financial aid to get your medicine, is insurance going to pay for rehab, what kind of facility will I have to be in, how long will they pay for. Everything you need is a fight of some sort and it is exhausting. I take Time us and it is going generic. I currently get my File ha through that manufacturer once I have to get the generic, which is still wickedly expensive, there is no financial aid and I will probably have to stop taking it.” – A person with RRMS

The expensive price for DMT made me decide to discontinue it. I would rather take my chances with how my MS will progress, than to financially burden my family. – Person with RRMS

Among those who stopped their DMT, (n=186; 28%) reported that their symptoms worsened, or they experienced new symptoms during this period, while (n=345; 52% indicated no exacerbation of symptoms from stopping their treatment, and (n=133; 20%) were unsure.

Discussion

We fielded a survey among constituents of the MS Coalition’s member organizations to gather insights into the impacts of MS and its treatment on peoples’ daily lives, as well as the factors influencing their experiences with initiating, switching, and stopping DMTs. Our survey findings describe the impact of MS on different aspects of people’s lives. Participants shared personal accounts of the devastating emotional burden of living with an “invisible” and unpredictable illness. Many detailed how MS significantly alters personal trajectories, affects families, impacts emotional well-being, and strains finances. These findings are relevant to managed care, research, and healthcare provider audiences.

Past research describes obstacles to accessing therapy, including navigating insurance prior authorization requirements and prohibitive out-of-pocket costs.³⁷ This study provides additional insights into the interconnected natures of MS’ impact on daily life, treatment costs, access to financial support, and emotional well-being. Our survey emphasizes the key role of copay assistance programs in helping people pay for their DMT. While these programs are lifelines for

many, participants also highlighted the added stress of managing paperwork and expressed concerns about being switched to generic medications without available assistance.³⁸ These findings align with a critical interpretive synthesis by Eskyte and et.al, which concluded that people with relapsing-remitting MS face significant challenges in treatment decision-making. These challenges stem from the unpredictability of relapses, differing perceptions of DMT efficacy, and the long-term uncertainty associated with MS progression. The study also identified a disconnect between clinical measures of efficacy, such as MRI results and relapse counts, and the lived experiences.³⁹

In addition to DMTs, patients emphasized the important role of comprehensive care, including symptom management, rehabilitation programs, and emotional support for both people with MS and their families. Participants described the added stress of coordinating their own care and navigating health- and cost-related barriers. In the context of MS, managed care organizations can improve the quality of care in a cost-effective manner through a coordinated approach to “preventive, medical, rehabilitative, cognitive, and long-term healthcare services.”⁴⁰ Care coordinators or navigators are important facilitators of comprehensive care. They can assist patients in locating healthcare providers, navigating financial and administrative aspects of care, and connecting people with psychosocial support.⁴¹

In our study, participants shared qualitative insights highlighting the significant emotional, financial, and career challenges that people with MS experience. Similarly, a qualitative study focusing on people with relapsing-remitting MS in the UK found that switching disease-modifying therapies (DMTs) is emotionally challenging due to fears of progressing to secondary progressive MS and uncertainty about DMT effectiveness. These examples highlight unmet needs for psychosocial support among people with MS.⁴²

Many resources are already available to support people with MS, highlighting the importance for healthcare providers and insurers to make patients aware of these resources. Patient advocacy groups and others have numerous support groups and resources to help people with MS and their healthcare providers achieve comprehensive care.^{43–47} Lakin and et.al recently published a narrative review of invisible symptoms (including fatigue, mood disorders, cognitive impairments, pain, bladder/bowel dysfunction, sexual dysfunction, and vision changes) and offered strategies to align clinical knowledge with the patient’s perspective on these symptoms.⁴⁸ There has also been work to link pain, self-efficacy, fatigue, and physical disability to explore broader psychosocial interventions to mitigate the burden of MS-related symptoms.⁴⁹ Past qualitative evidence indicates that patient-physician interactions at the time of diagnosis are particularly important. However, clinical pathways may not allow sufficient time for meaningful, plain-language discussions between patients and providers.⁵⁰

Our findings are relevant to researchers interested in conducting more patient-centered research, including efforts to measure outcomes important to people with MS or develop economic evaluations aligned with patient experiences. Many of the impacts participants in this survey identified as important are included in the Standard Outcome Set for MS recently developed by an international, multidisciplinary team consortium.⁵¹ It is intended for use in health care delivery and to support value-based health care. The core set recommends measures of disease activity, symptoms, functional status, and quality of life.

Financial or economic impacts should also be consistently assessed in MS-related studies, at least those conducted in a US setting.⁵¹ Many participants felt stressed about the costs of care, even with health insurance, and some described making tradeoffs between adhering to medical treatments and paying for basic living expenses. Participants submitted free text responses describing how they made employment decisions based on health insurance coverage offered by different employers. This is supported by an analysis of the economic burden of MS in the US for 2019, which estimated the average indirect and nonmedical costs as more than \$18,000 annually for people with MS and more than \$22,000 when accounting for caregiver costs.⁵²

In addition to informing the costs included in economic evaluations, researchers can develop more precise models by understanding and modeling patients’ real-world experiences rather than relying only on randomized trial evidence for point estimates and assumptions. For example, most participants in our sample had taken two or more DMTs and cited numerous reasons for treatment discontinuation, including their doctor’s recommendation, side effects, and costs. Nonetheless, these pathways leading to discontinuation are important to model given that discontinuing DMTs, even with a switch to other medications, increases the risk of relapse.^{12,53} Our findings regarding treatment discontinuation are also consistent with Hua et al, who noted that 29.7% of older patients (60

+) discontinued MS treatment because of stabilized disease, comorbidities, and cost.⁵⁴ This has implications for both people with MS and payers, as discontinuation can be associated with lower per-patient costs alongside a higher proportion of relapses, indicating there is no “one-size-fits-all” strategy.⁵³ While there is evidence that stopping disease-modifying therapies in older (55+) people with MS who have stable disease is a “reasonable option”, the same study also found that there is some benefit for patients without disease activity. This supports a continued shared decision-making approach regardless of age.⁵⁵ Real-world factors influencing treatment decisions are typically absent from controlled trials, which commonly involve younger populations with mean ages generally in the mid-30s or early 40s.⁵⁶

The Institute for Clinical and Economic Review (ICER) recently conducted a value assessment of DMTs. While this report and other studies intended to guide access decisions around DMTs consider clinical trial evidence and, to a certain extent, real-world evidence, they frequently overlook the difficulties encountered by people with MS as they navigate the healthcare system and make decisions regarding the initiation, discontinuation, or switching of DMTs. To overcome this gap, we recommend researchers interested in developing economic evaluations reflecting people with MS’ real-world experiences, priorities, and needs consider methodological recommendations from Hernandez and et. al. These recommendations aim to develop models that better reflect patients’ lived experiences by incorporating disease progression, treatment sequencing, treatment discontinuation, and other health outcomes (eg, relapses avoided).⁵⁷

Finally, researchers should further evaluate trends in outcomes and the initiation of a high-efficacy treatment early after diagnosis. Recent consensus recommendations suggest that this approach can be more effective than an escalation strategy.²² Among our survey participants on their first DMT, less than half of new patients received a high-efficacy treatment. Although this is a topic of interest to the patient community, our survey did not capture a DMT start date. Thus, while this study provides an indicator regarding the initiation of high-efficacy DMTs, a study using a more robust healthcare database would provide more conclusive evidence regarding the extent to which this recommendation is being adopted by prescribers in US healthcare settings.

Strengths & Limitations

This survey collected patient experience data on topics of interest to the MS patient community. All topics and response options were developed and refined by members of the MS patient and clinical communities. The survey was distributed by the nine member organizations comprising the MS Coalition. English and Spanish versions were developed and pilot-tested by native speakers from the MS patient community; however, it was not forward- and backward-translated.

Participants learned about the survey through one of the MS Coalition member organizations, suggesting a potential bias towards more engaged people than those not affiliated with MS organizations. Due to the unique structure of the US healthcare market, our findings may not be generalizable to healthcare systems in other countries. Furthermore, we relied upon the participants’ self-reporting for adverse events, diagnosis and medication history. Self-reports are considered reasonably accurate relative to healthcare provider data but could introduce bias that could affect the accuracy and interpretation of our findings.⁵⁸ Additionally, most participants were non-Hispanic white, and their responses, including barriers to care and health system experience, may not be generalizable to the broader American population. However, our sampling approach and eligibility criteria were not restricted to any insurance coverage or clinical and demographic characteristics, thereby enhancing the diversity and inclusivity of our study population.

Conclusion

The study provides qualitative and quantitative patient experience data about the impact of MS and the needed treatments and management strategies on personal finances, daily life and emotional well-being. Participants shared the emotional burden of living with an “invisible” illness and emphasized the need for comprehensive care. People with MS are very concerned about the loss of independence, the financial impacts on families, the emotional impacts, and the impacts on relationships. Personal anecdotes from open-ended survey responses illustrate the profound challenges of these impacts. Factors important to people when initiating a DMT include slowing MS progression, preventing relapses, following their doctor’s recommendation, and achieving life goals. Copay assistance programs are key in helping people pay for their

DMTs. While these programs are lifelines for many, participants also highlighted the added stress of managing paper-work and expressed concerns about being switched to generic medications without available assistance. Incorporating patient perspectives and patient experience data in multiple sclerosis (MS) care and decision-making is essential for developing personalized treatment strategies that align with patients' values, preferences, and real-world challenges. This approach enhances shared decision-making, can improve adherence to disease-modifying therapies, and ultimately lead to better health outcomes and quality of life for people living with MS. We recommend ways by which managed care, research, and healthcare provider audiences can apply the patient experience data collected in this study to guide their work.

Disclosure

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