



**National  
Multiple Sclerosis  
Society**

# **Quantifying the Effect of the High Cost of DMTs**

**Market Research Report**

August 2019

Prepared by

**ROSCOW**  
MARKET RESEARCH

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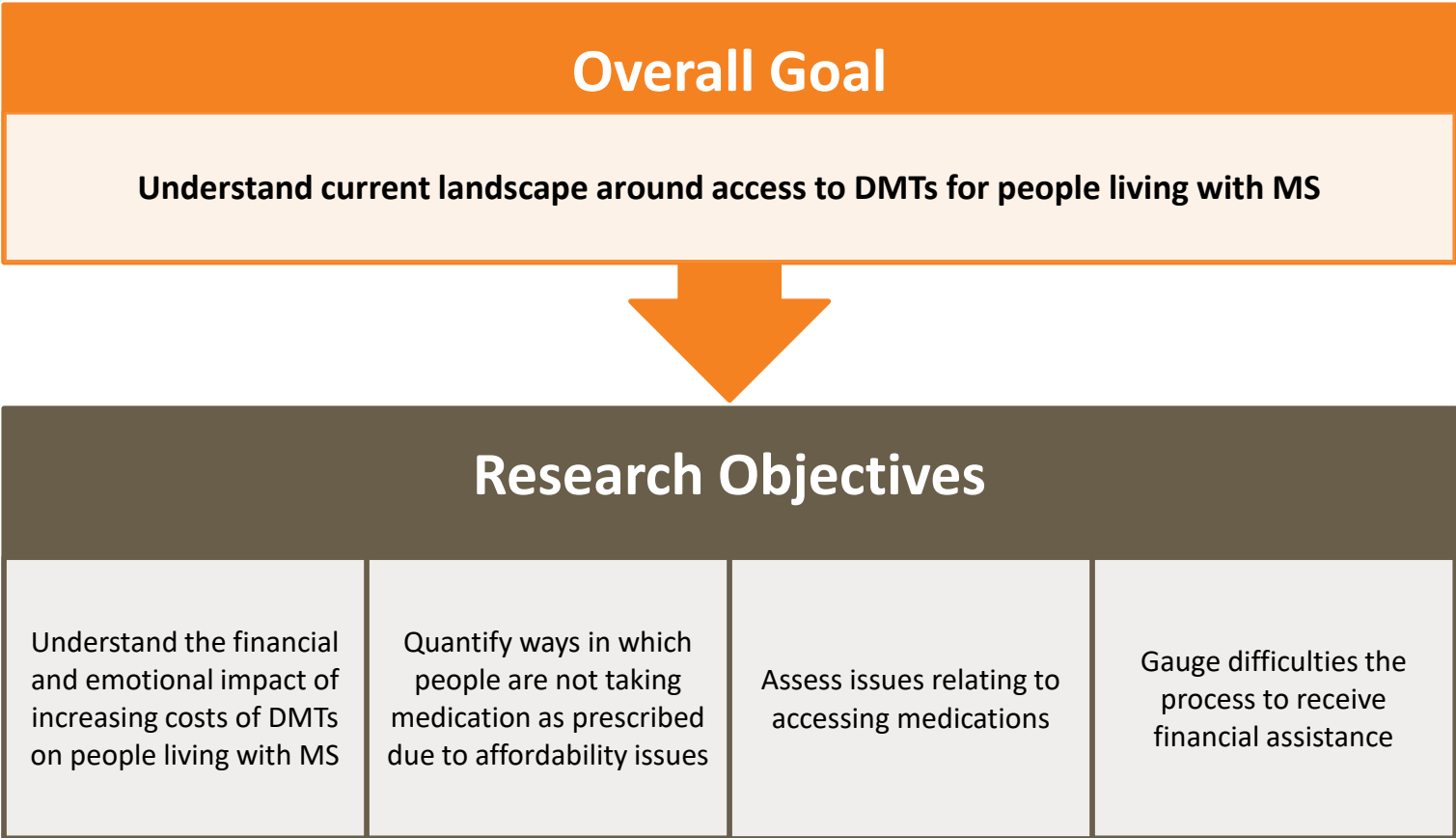
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# Study Design

# Objectives

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# Two Phases of Research

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Phase 1:  
Quantitative Online  
Survey



Phase 2:  
Qualitative Telephone  
Depth Interviews

Quantify the impact of  
increasing costs of DMTs on  
people living with MS

Gain deeper understanding of  
why and how people living with  
MS make decisions and  
sacrifices when affordability of  
DMTs is an issue

# Phase 1: Quantitative Survey

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## Online Survey with 578 People Living with MS

- Recruited through email invitations to people in National Multiple Sclerosis Society database
- 12,000 emails were sent and 578 completed the survey, for a 5% response rate
- Survey fielded July 9-13, 2019
  
- Among all people living with MS who started the survey...
  - 96% had ever used a Disease-Modifying Therapy (DMT)
  - 80% are currently using a DMT
- Since the purpose of the survey was to assess the impact of increasing costs of DMTs, only those who had ever used a DMT were included in the sample
  
- The sample was weighted based on gender and region to reflect the actual proportion of people living with MS in the United States. (See appendix for weighting details.)

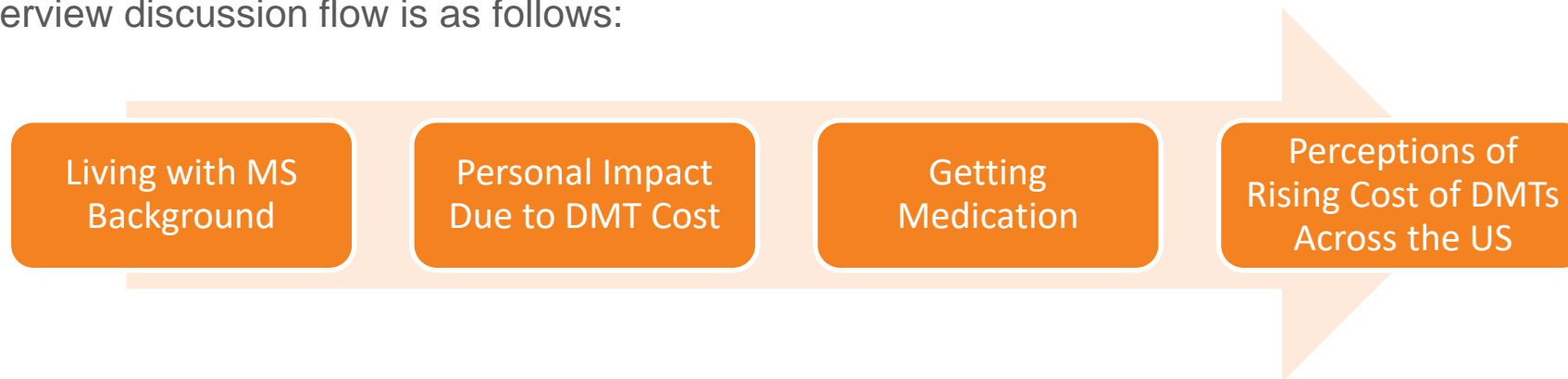


## Phase 2: Qualitative Interviews

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### Telephone Interviews with 15 People Living with MS

- Interviews fielded August 1-8
- Recruited from people who took the survey
- Selected based on indicating one or more of the following in the survey:
  - ✓ Out-of-pocket cost of DMT is somewhat or extreme financial burden
  - ✓ Did not use treatment as prescribed (e.g., stopped using for period of time, used less, etc.) due to cost
  - ✓ Received financial assistance from a pharmaceutical company or charitable organization
- The interview discussion flow is as follows:



# In This Report

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**This report includes findings from both the online survey and the follow-up qualitative interviews.**

- Each slide is labeled on the top right corner indicating the phase of research from which the findings on that slide came.

SURVEY

QUALITATIVE INTERVIEWS



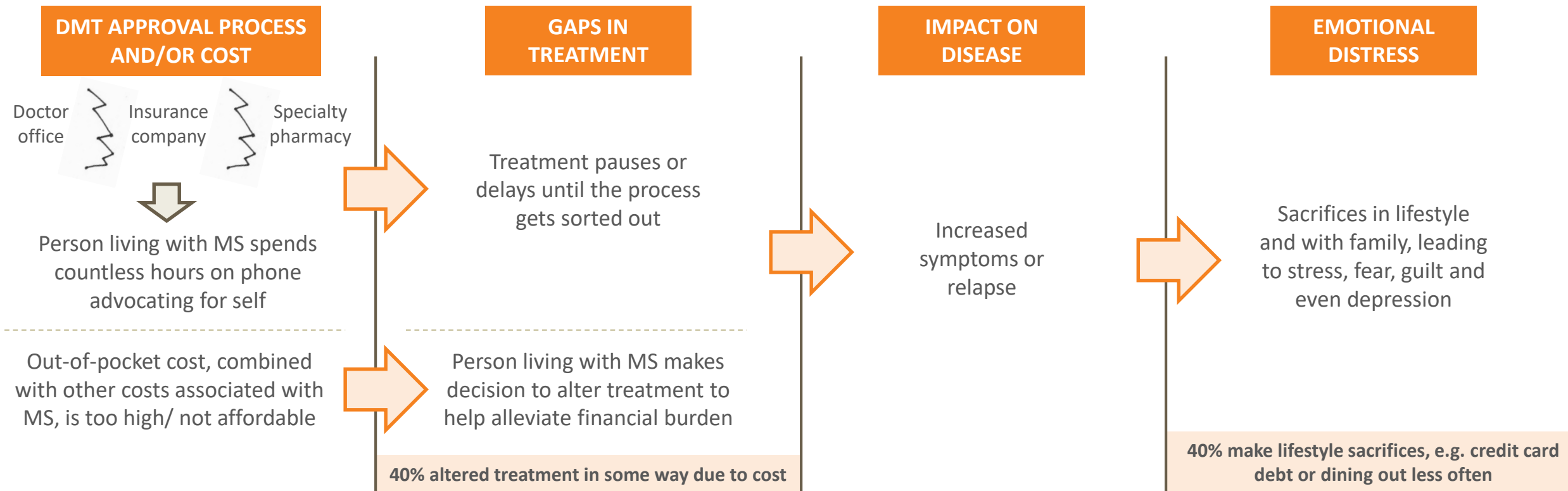


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## Summary of Key Findings

# Cost and Insurance Approvals Cause Greatest Challenge

- The high cost of DMTs and process required for insurance approvals contribute to increased symptoms and emotional distress for people living with MS.



# Out-of-Pocket Expense Can Be High

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**45%**  
of people living with MS pay  
**no OOP costs**  
for their DMT

Among those with OOP costs,  
the estimated  
**mean annual OOP cost is**  
**\$2300**  
with a range of  
**<\$100 to \$20,000**



This is with **71% receiving financial assistance** –  
mostly from pharmaceutical  
companies

The majority say **without financial assistance, OOP cost would be a significant financial burden**

# It Starts with High Cost of Medication

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# Working Towards a Better Future

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- **People living with MS want the National Multiple Sclerosis Society to find ways to help navigating the administrative process of accessing DMTs.** By reducing the barriers and challenges in getting insurance and financial assistance approvals, and thereby shortening the time frame...
  - ✓ Gaps in treatment could be avoided
  - ✓ People living with MS can focus on work and/or healthy activities, vs. spending hours on the phone navigating between insurance companies, doctors' offices and pharmaceutical companies
  - ✓ Emotional stress can be decreased
- **Out-of-pocket costs associated with DMTs is only one piece of the financial picture for people living with MS, and can not be isolated.** People endure copays for other medications, treatments and diagnostic tests, high health insurance premiums and deductibles, and lost income due to not being able to work full-time or at all.
  - ✓ NMSS should find ways to offer support for all facets contributing to the financial burden for people living with MS.
  - ✓ Ensuring continuous supply of financial assistance programs is critically important as long as drug costs and copays continue to be high.



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## Detailed Findings

### – Respondent Profile

# Demographic Summary

## Female



74%

## Mean Age



35.4

## Married



64%

## Live with Spouse/ Significant Other



70%

## Live Alone



14%

## Have Kids



64%

## Have Pet



25%

## Area of Living



Urban 23% Suburban 55% Rural 22%

## Race/Ethnicity



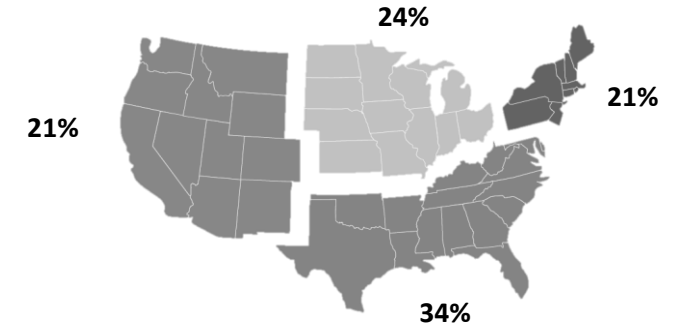
White 89% Hispanic 3%  
African American 7%

## Mean Household Income



\$83,070

## Region



## Graduated College or Higher



64%

## Work Full-Time



40%

## Don't Work Because of MS



39%

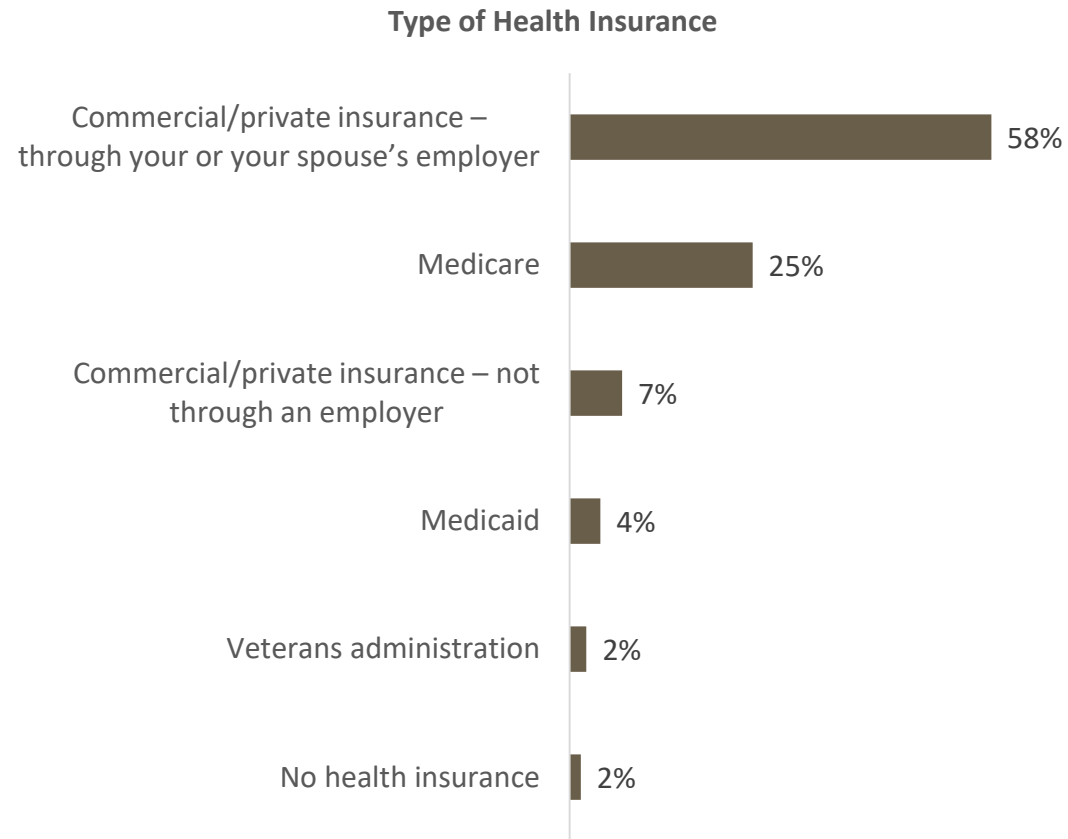
## On Disability



32%

# Health Insurance

- 65% of respondents have commercial insurance, the majority through an employer. One-quarter are on Medicare.

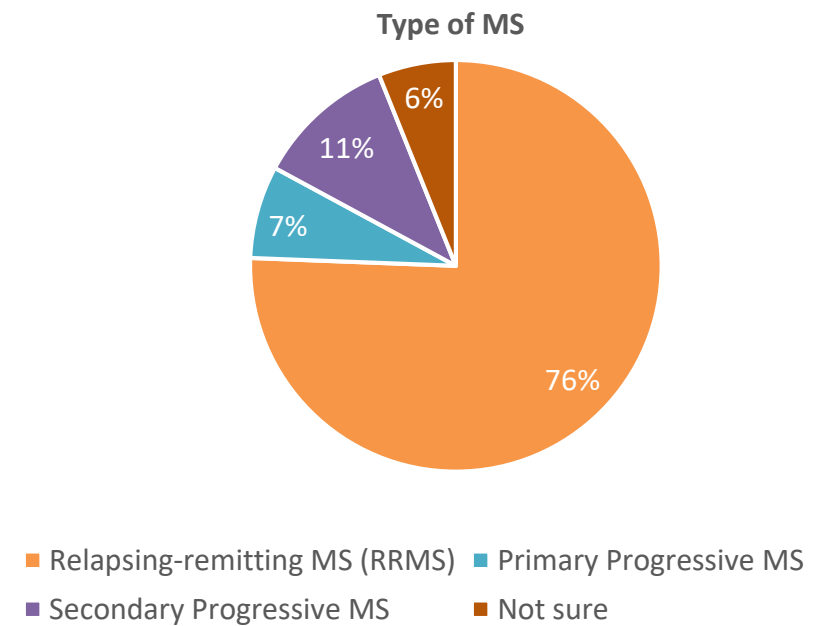
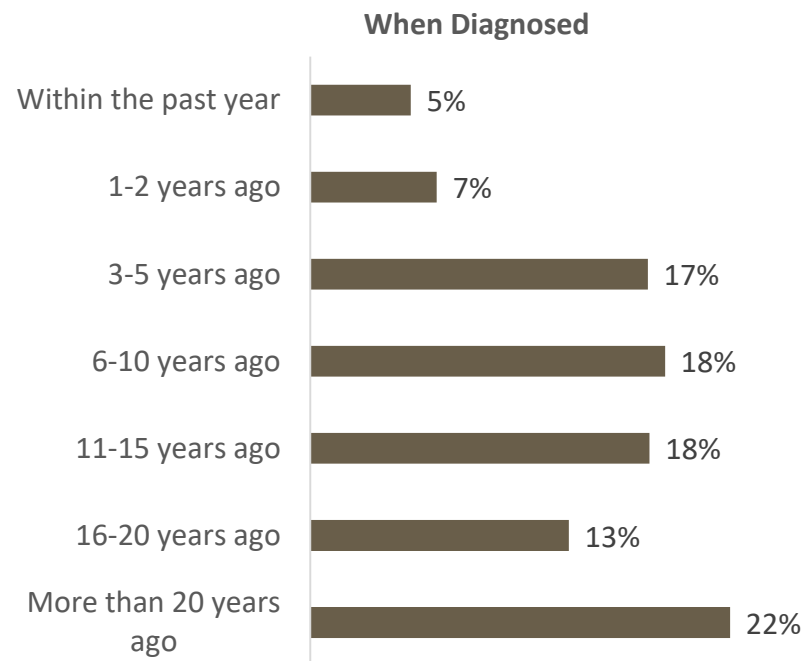


Q11. What is your primary type of health insurance? (n=578) Q36. Are you on disability? (n=578)



# MS Diagnosis

- Three-quarters of respondents have RRMS. Just over half (53%) were diagnosed more than 10 years ago.

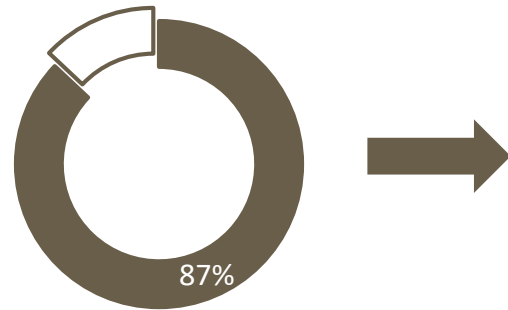


Q4. How long ago were you diagnosed with MS? (n=578) Q5. Do you currently have....? (n=578)

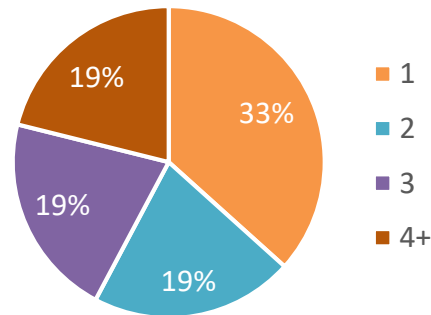
# Use of Disease-Modifying Therapy

- Nearly 90% of respondents are currently using a DMT and two-thirds have tried 2+ DMTs over the years.
- Ocrevus is the most prevalent DMT, used by 23% of respondents, followed by Tecfidera at 17% and Copaxone at 13%.

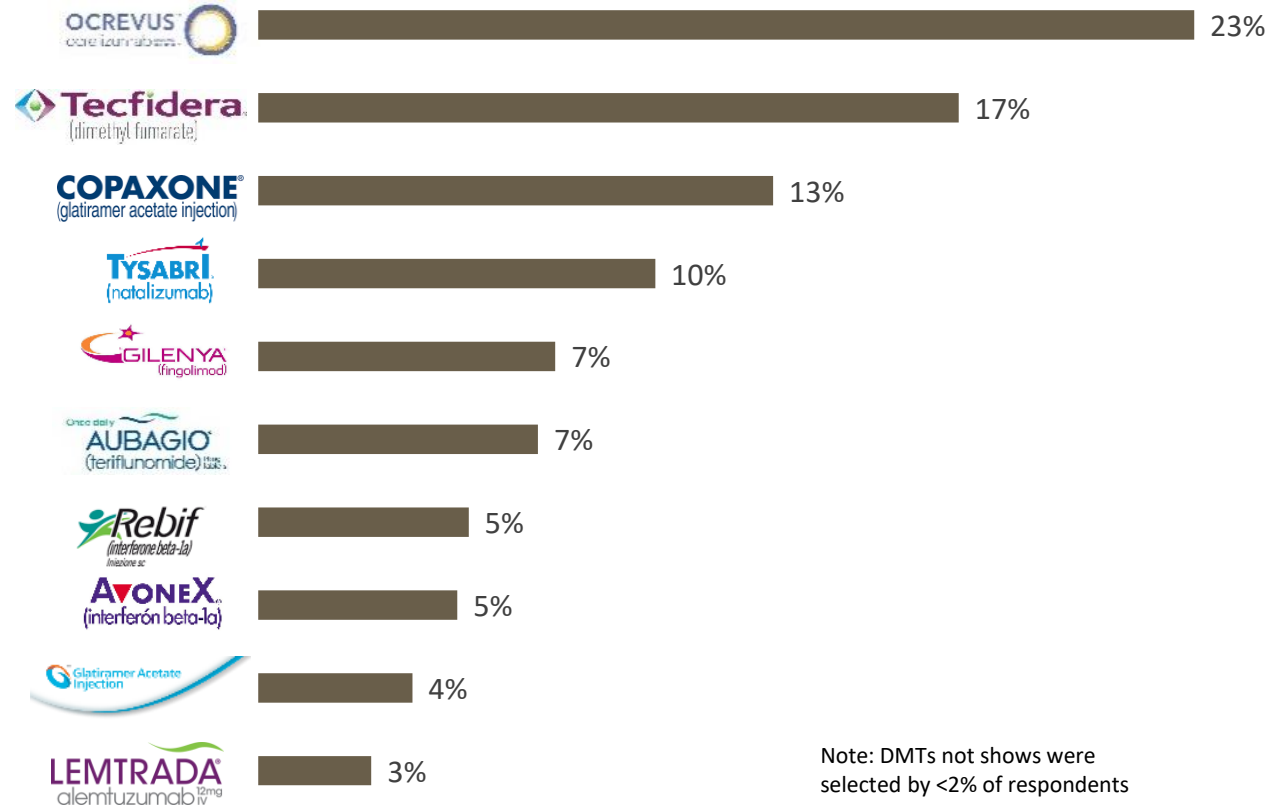
Currently Using a DMT



Number of DMTs Ever Used



DMT Using



Note: DMTs not shown were selected by <2% of respondents

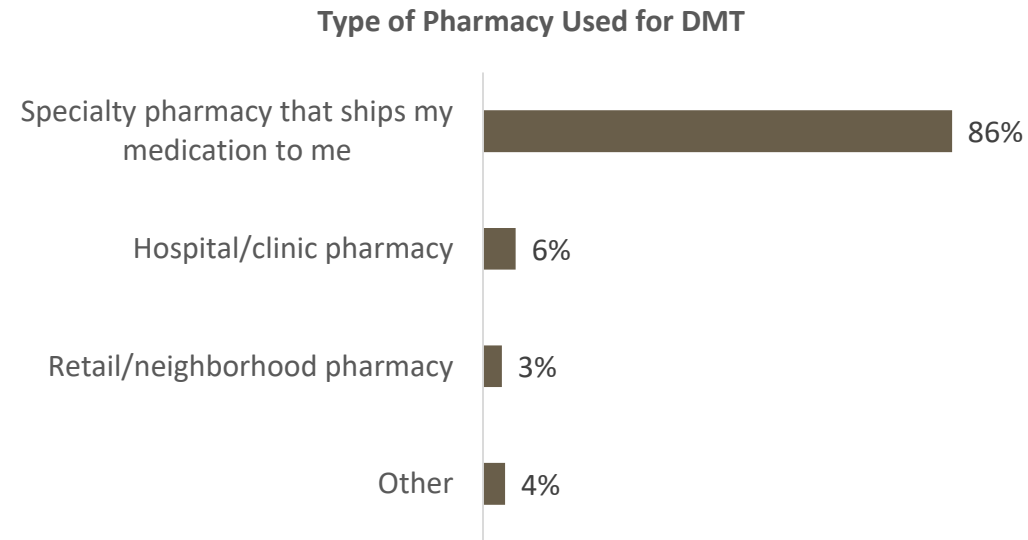
Q6. Are you currently using a disease-modifying therapy for MS? (n=578) Q7. Which of the following disease-modifying therapies are you currently using to treat MS? (n=501) Q8. How many MS disease modifying therapies have you tried? (n=578)



# Type of Pharmacy Used

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- The vast majority of respondents get their DMT from a specialty pharmacy.



Q9. What type of pharmacy do you use to get your disease modifying therapies? (n=325)

# Interview Respondent Overview

➤ 15 People Living with MS participated in qualitative interviews.

## Gender

- 10 Female
- 5 male

## Age

- 9 are 29-39 years old
- 6 are 40+ years old

## Race

- 12 White
- 2 Hispanic
- 1 African American

## Diagnosis

- 13 RRMS
- 2 SPMS

## Health Insurance

- 12 Commercial insurance through employer
- 3 Medicare

## Financial Assistance

- 12 receive pharmaceutical company copay assistance
- 1 received small stipend from charitable organization years ago
- 3 do not receive financial assistance

## Disease Modifying Therapies

- 1 uses injectable DMT
- 6 use oral DMT
- 8 go to infusion center or hospital for IV DMT

# Challenges Living with MS

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## Physical Challenges

- Numbness
- Weakness on one or both sides
- Vision issues
- Balance issues
- Fatigue and stamina
- Walking with cane
- Wheelchair

## Cognitive Challenges

- Feel groggy
- Can't find words
- Slur words
- Short term memory loss
- Headaches and migraines

## Emotional Challenges

- Feel overwhelmed
- Feel isolated
- Feel guilt from reliance on family for support
- Depression
- Live in fear of what is to come

## Financial Challenges

- Copay for DMT and other medications
- Copay for doctor visits
- Out-of-pocket costs for MRIs and other testing
- Cost of health care plan
- High deductibles

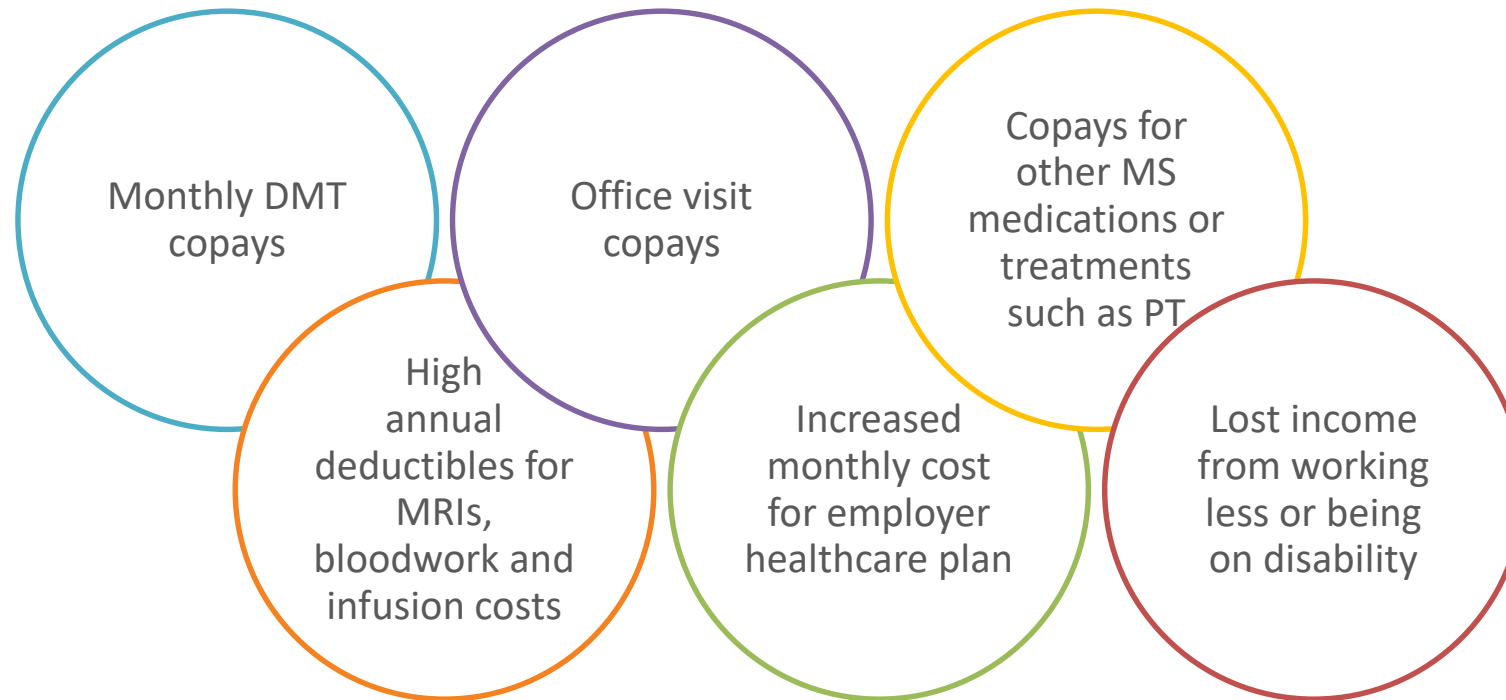
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## Detailed Findings

- Challenges Due to Cost

# Financial Burden of Living with MS

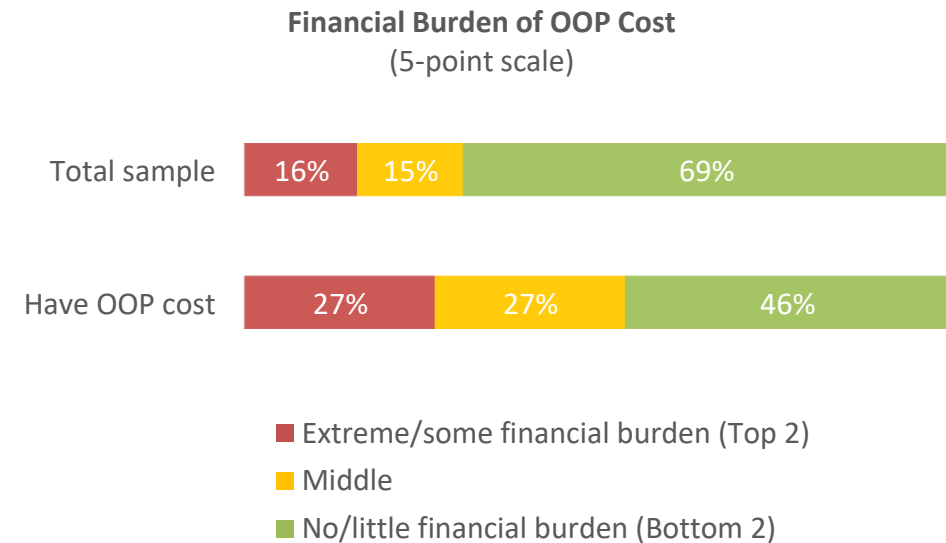
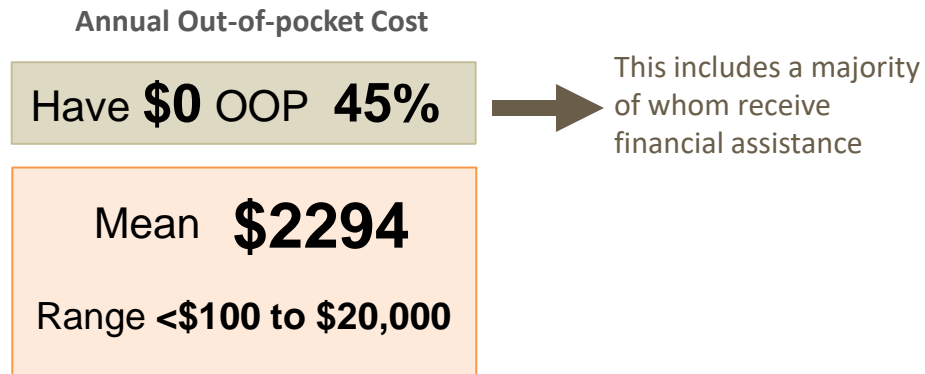
- The combined associated costs of living with MS has an extreme financial burden on people living with MS.



*"I very quickly met my annual deductible which is \$6000 between office visits, all of my medications, various testing and an ER visit. I am paying the hospital in monthly installments."*

# Out-of-pocket Expense

- 45% of people living with MS do not pay anything out-of-pocket for their DMT. However, the average annual OOP cost among those who do pay is nearly \$2300.
- 31% of people living with MS feel at least some financial burden because of their OOP cost. This goes up to 54% among those who have an OOP cost.



Q12. Approximately how much do you pay out-of-pocket on an annual basis for your MS disease-modifying therapy? Out-of-pocket cost is the amount YOU pay, not what is covered by insurance or financial assistance. (n=578) Q15. How much of a financial burden is the amount you pay out-of-pocket for your MS disease-modifying therapy? (n=578)

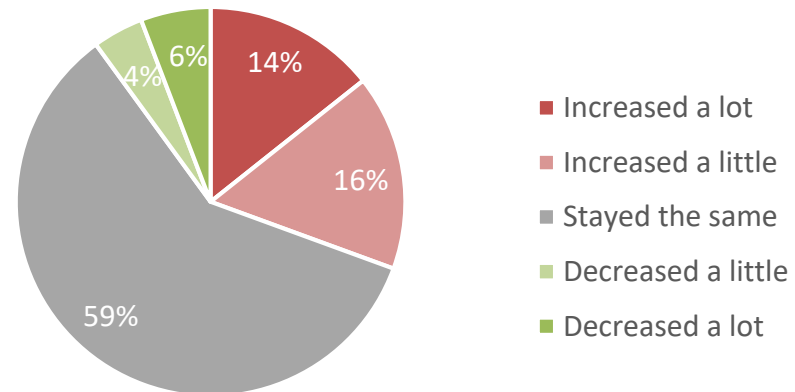


# Out-of-pocket Expense

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- 30% of people living with MS say their OOP cost has increased over the past few years.

Change in OOP Cost Over Past Few Years



Q14. Over the past few years, has your out-of-pocket expense for MS disease-modifying therapy increased, decreased or stayed the same? (n=578)

# Cost of DMT: List Price, Out of Pocket and Overall Cost

## List Price of DMT

Most respondents are very aware of the list price of their DMT, stating amounts of \$60,000 to over \$100,000 annually.

## Out-of-pocket Cost of DMT with Insurance

Out-of-pocket cost of medication with insurance coverage varies from \$600 to over \$12,000 per year. Many have high deductibles that include part of the cost of the DMT

## Out-of-Pocket Cost of DMT with Financial Assistance

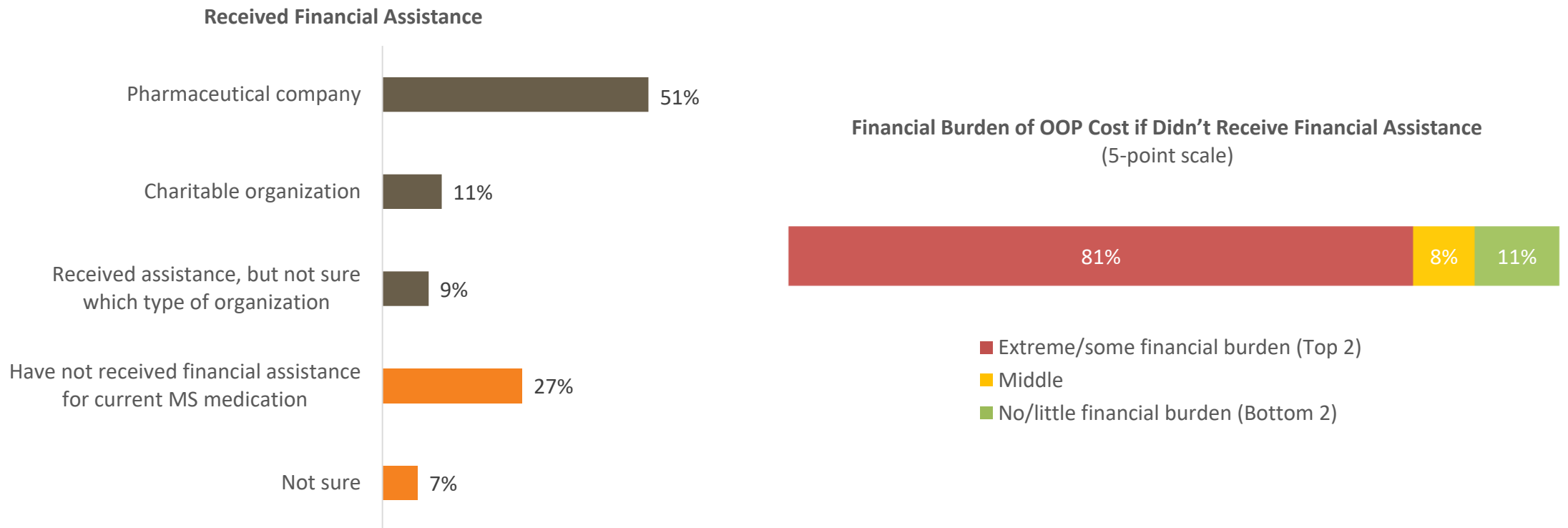
Pharmaceutical assistance programs bring costs down to close to \$0 copay for the DMT, but the DMT cost is only one part of the financial burden

## Overall Costs Associated with Treatment of MS

High deductibles coupled with lost income and other non-insurance covered costs cause significant financial challenges for people living with MS.

# Financial Assistance

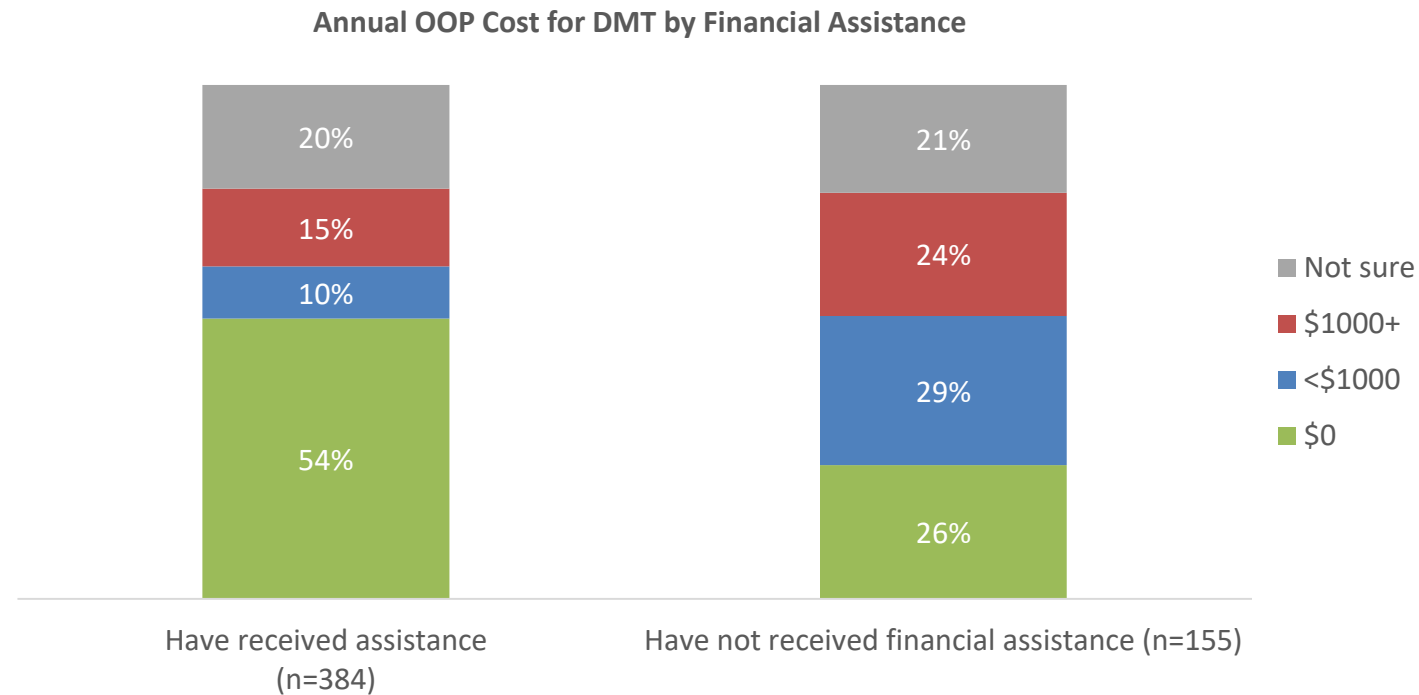
- More than 70% of people living with MS have received financial assistance for the DMT they are currently using, the vast majority of whom say the financial burden would be great without assistance.



Q21. From what types of organizations have you received financial assistance for the MS disease-modifying therapy you are currently using? (n=578) Q24. How much of a financial burden would the out-of-pocket cost of your MS disease-modifying therapy be if you did not receive financial assistance? (n=384)

# OOP Expense Based on Financial Assistance

- Those who have not received financial assistance are much more likely to have an OOP cost for their DMT, and it's more likely that it is higher.



Q21. From what types of organizations have you received financial assistance for the MS disease-modifying therapy you are currently using? Q12. Approximately how much do you pay out-of-pocket on an annual basis for your MS disease-modifying therapy? Out-of-pocket cost is the amount YOU pay, not what is covered by insurance or financial assistance.

# Financial Assistance Process

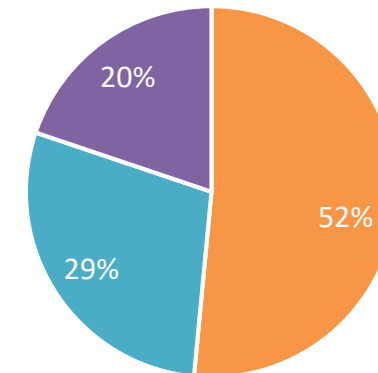
- For the majority of those who receive financial assistance, the process to apply and receive it is easy. But, for 30% the process is at least somewhat challenging. Half have to reapply/renew every year.

Financial Assistance Process  
(5-point scale)



- Very challenging/ Challenging (Top 2)
- Middle
- Very easy/ Easy (Bottom 2)

Renewal of Assistance



- I have to renew/reapply
- It continues automatically
- Not sure

Q22. How easy was the process of getting financial assistance for your current MS disease-modifying therapy? (n=384) Q23. Do you have to renew or reapply for financial assistance every year, or does it continue automatically? (n=384)

# Process of Getting Financial Assistance



**For some, applying and receiving financial assistance is easy**

Same day as office visit, told about the pharmaceutical assistance program

Person living with MS calls into program and shares financial status, some programs may request fax of W2 or paystub

Doctor's office or pharmaceutical company provides samples while waiting for approval

Approval is considered quick and easy, receive approval and medication within 1-2 weeks

Annual reapplication is also seen as easy process



**For others, it is a very stressful process**

Doctor's office may inform about program or learns on their own through seminar or support group

Feels like excessive amount of paperwork to get approval

Delays in receiving approval requiring multiple calls to doctors office, insurance company, and assistance program

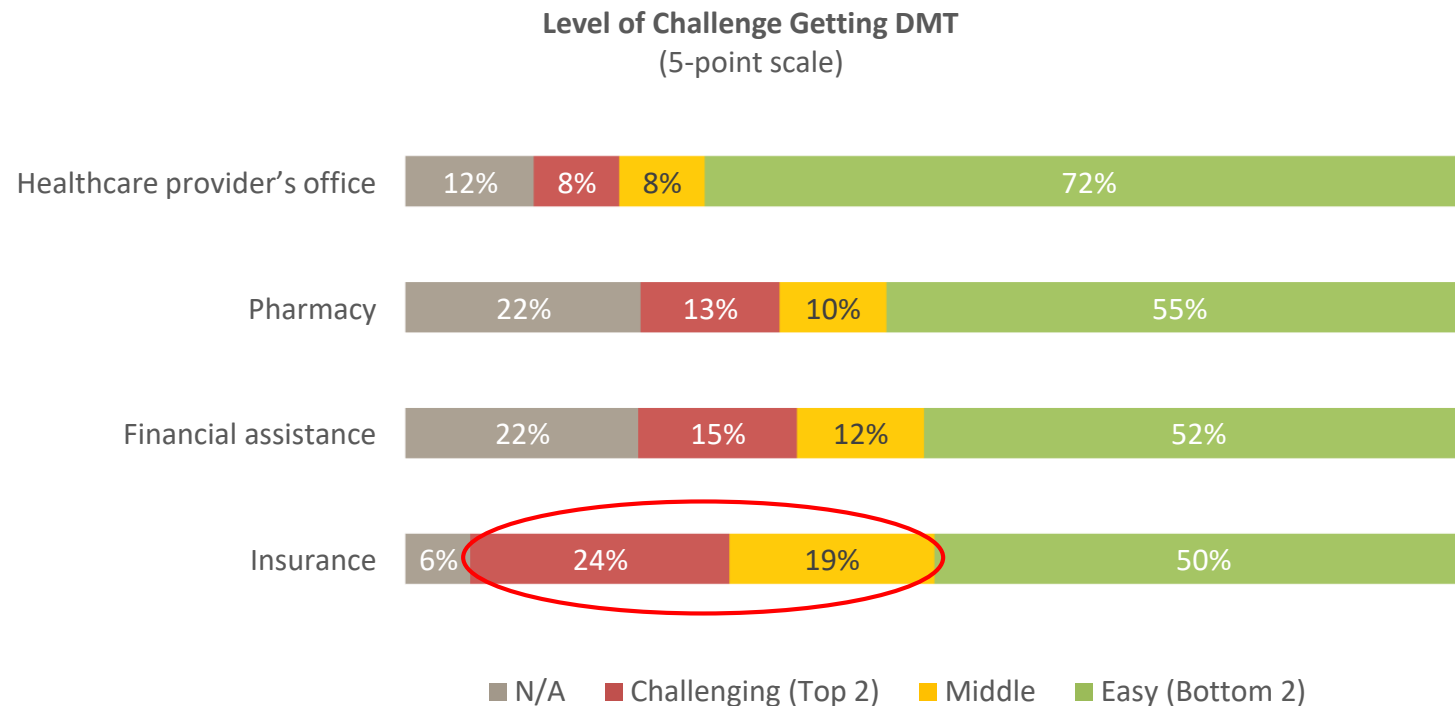
Unable to get infusion or delivery until approval, which causes delays in treatment

Changes or gaps in health insurance cause delay in treatment because having health insurance is required to be part of program

Annual reapplication requires entire process again, causing stress and often gaps in treatment

# Challenge Accessing DMT

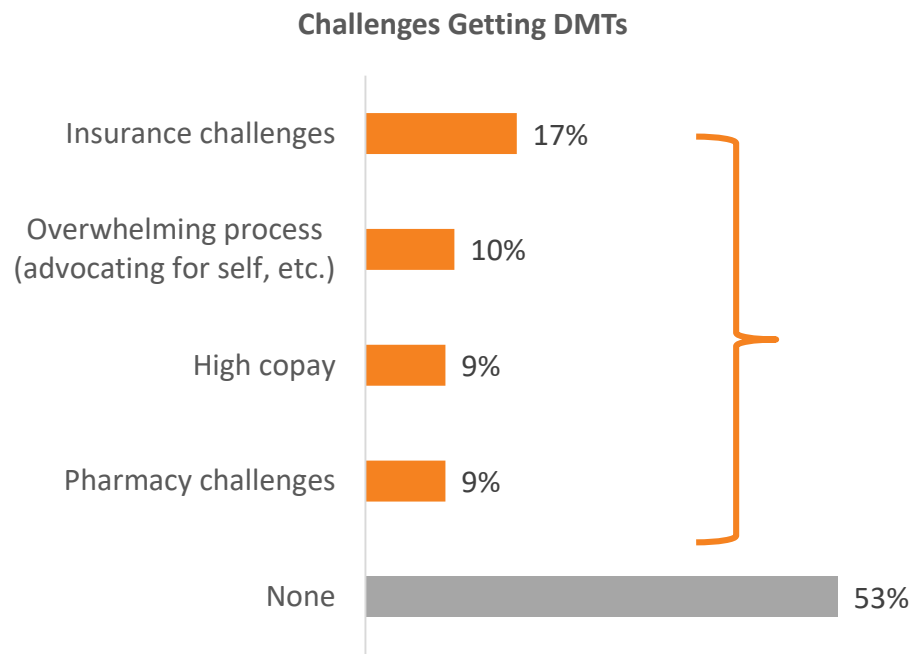
- The greatest challenge in getting DMTs comes from insurance companies.



Q10. How easy was the process to get your current MS disease modifying therapy in the following areas? (n=578)

# Open-Ended Challenges Faced

➤ Survey respondents were asked about their challenges getting DMTs. About half had challenges to write about – and the most prevalent topic mentioned is insurance and process related problems. Here is a summary of what they told us.



“Having to re-apply every year and waiting to hear back is very stressful.”

“The costs are continuing to grow.”

“Getting up every day and making it to work is a challenge. Without treatment I don’t know where I would be.”

“I had a real problem getting my last prescription through the insurance hurdles. I was out of meds for months.”

“My greatest issue has always been insurance coverage.”

“Drug (Tecfidera) initially wasn't on my insurance formulary and I had to appeal. It is on the approved drug list now, however I am considering switching drugs, and the two drugs I'm considering are not included, so I'm expecting to have to go through the appeals process again. Not sure of what the outcome will be. The stress of not knowing if something will change with my insurance is very intense. I would definitely not be able to afford the drug if it wasn't covered by insurance or I didn't get financial aid.”

“My doctor wrote a conflicting prescription which I didn’t find out until it was processed through my insurance, so I had to totally restart the process. I must have made 20 phone calls to get the medicine.”

“I have been on disability and delayed getting my infusion due to transitioning jobs due to stress and MS and symptoms like migraines, which affected my daily life.”

Q25. Please tell us your personal story about any challenges you’ve had getting the MS disease-modifying therapy you need. Please be as detailed as possible about what happened and how it affected you or your family. Your story will not be used for any purposes without your consent. If you haven’t experienced any challenges getting MS disease-modifying therapy, please type None.





# Challenges in Getting DMT

- People living with MS are faced with the challenge of maneuvering the complex world of understanding their healthcare plan, ensuring their medications are covered and arrive on time – all while dealing with fatigue, depression and cognitive issues.

Prior authorizations are challenging for people living with MS. There is a disconnect between the doctor's office, insurance company and specialty pharmacy, which leaves some people frustrated and unsure what to do or who to call.

Many health plans require people living with MS call the specialty pharmacy monthly to ensure delivery of their DMT. This adds stress because they have experienced delays in receiving their medication in the past.

When health insurance requires in-network specialists and infusion centers, people living with MS have experienced situations where they were unaware they were out of network and were responsible for large bills that have caused financial challenges.

Most people living with MS rely on their doctor's office to handle administrative approvals for treatment but get upset when there are delays in approval and treatment. Generally, most feel their doctor's office is doing their best, at times the stress has caused tension between them and their doctor.



A few are contacted by an insurance company nurse on a regular basis to discuss treatment, but most feel they do not have support from their insurance company and that the insurance company does not care if they have gaps in treatment.

“I take my DMT regularly but every month it's always down to the hour receiving it. If you don't take that pill regularly, it destroys your bowel. It's frustrating that I have to ensure it's refilled every month. It's very stressful.”

# Access Challenges Affect Disease Symptoms

- From the doctor recommending a DMT to actually receiving the medication requires time and effort from people living with MS – and ultimately can lead to treatment gaps and increased symptoms.

## People living with MS must self-advocate

- Most people living with MS report that being a self-advocate in accessing treatment is extremely challenging.
- There is a disconnect between the doctor's office, insurance company and specialty pharmacy. Everyone is blaming someone else.
- Many spend hours making phone calls to get their treatment approved and delivered. This is for initial prescription and either every 6 months or each year depending on insurance company plan

## Gaps in treatment

- Many experience gaps in treatment due to administrative delays in getting approval for treatment or changes in insurance coverage.
- Others make the tough decision to delay treatment to reduce the financial burden of copays, high deductibles, or managing other family expenses.

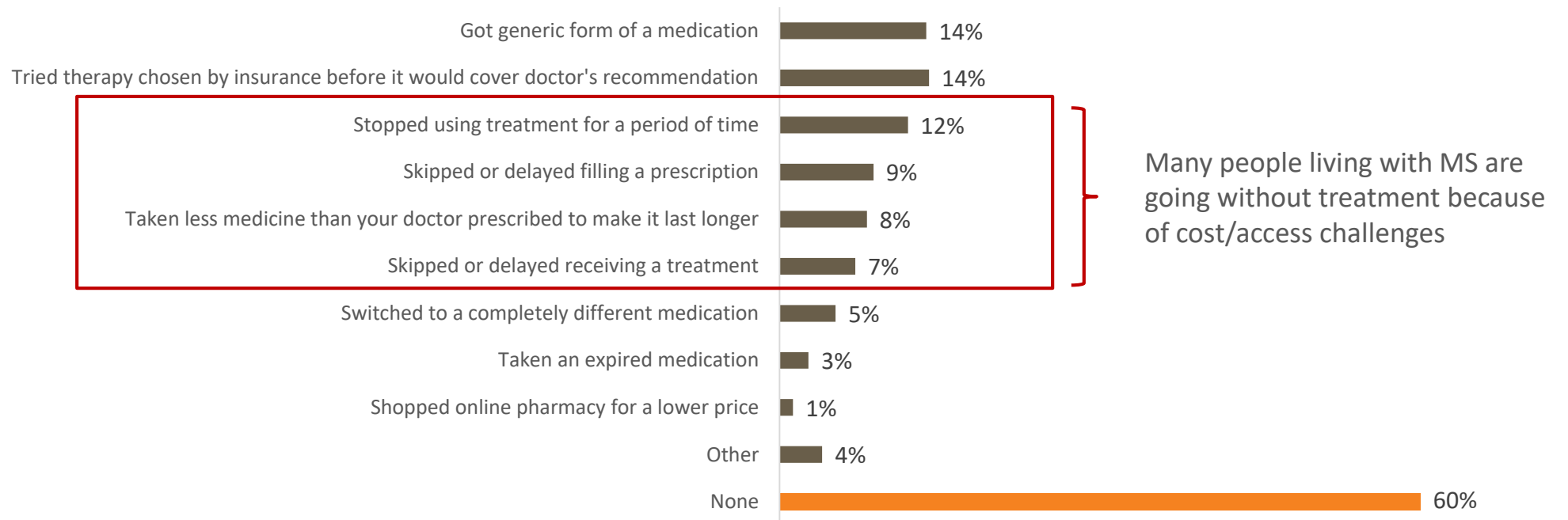
## Relapse in disease or increased symptoms

- Some people living with MS can draw a direct causal relationship to gaps in treatment and relapse.
- Others feel it is hard to draw a direct connection between gaps in treatment and increased symptoms but suspect it plays a role.

# Effect of Out-of-pocket Cost on Therapy

- 40% of people living with MS have altered the use of their DMT because of costs.

## Actions Relating to Therapy Because OOP Cost is Too High



Q19. Which of the following have you ever done because the out-of-pocket cost of a disease-modifying therapy was too high? (n=578) Q16. Have you ever had to try a disease-modifying therapy chosen by your insurance company before the plan would cover the medication that your doctor recommended? (n=578)

# Delays in Medication

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*“There were times I had to wait for pay day to order my monthly medication to cover the copay, so would have to wait a day or two to take it or take half dose.”*

*“On my current program, I had to wait over a month to get approval through pharma company. They wouldn’t give the infusion until we got approval. I was not on medication for 10 weeks at that point because of a severe allergic reaction to my previous treatment. I was in contact with my doctor’s office regularly. They were working with the insurance company. It was very stressful.”*

*“I was pre-approved for the infusion, but I would have to meet my deductible. That’s a lot out of pocket quickly because it’s a \$13,000 cost and I have a \$6000 deductible.”*

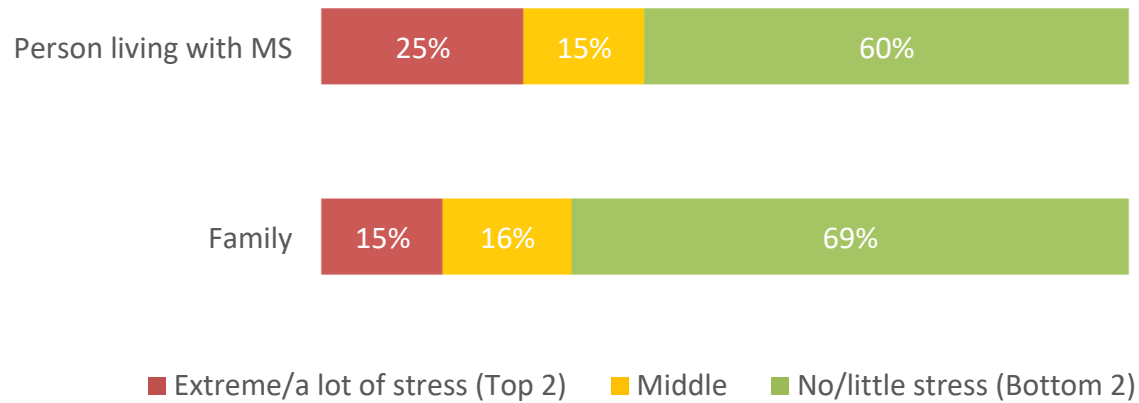
*“I had a refill and didn’t get the medication. I got a new script from the office but there was a disconnect between the doctor’s office, insurance company and pharmacy. They all pointed fingers at each other. For about one week I couldn’t get the medicine.”*

*“I have had gaps in treatments getting prior authorizations approved – a week and even sometimes a month. It happens about once a year and I wish someone else could help me deal with the administrative stuff. I don’t feel anything immediately, but two different times I had a relapse within the next two months. Its hard to make linear decision of cause-effect. It takes hours each time . I have had to utilize my mom to make some of the calls for me . The last time I spent five hours total on the phone and my mom spent three hours.”*

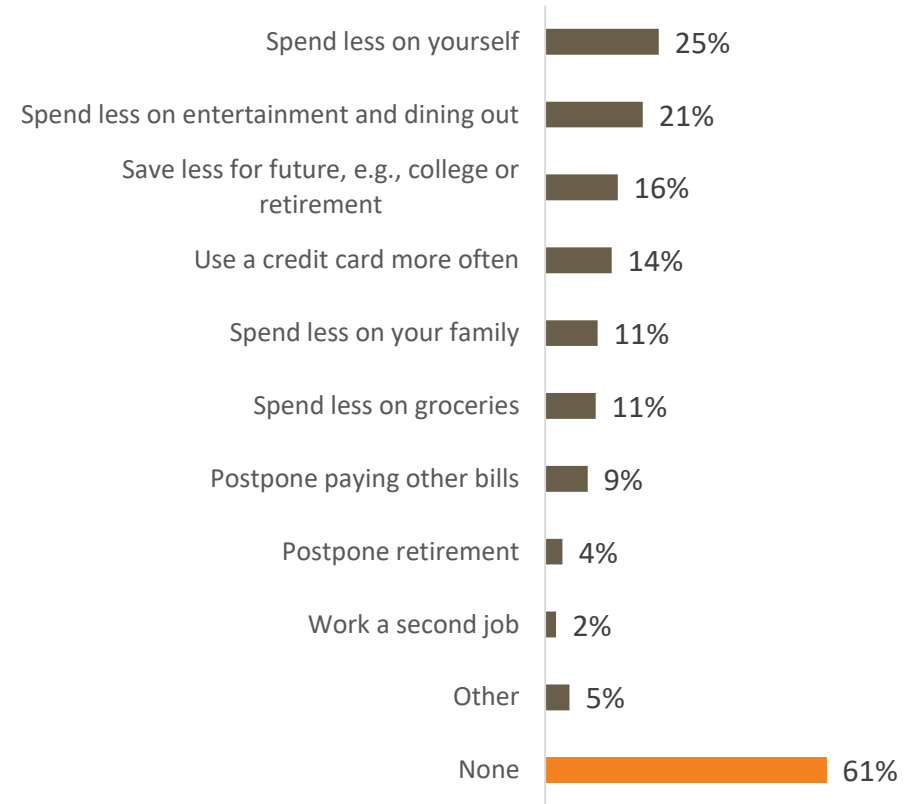
# Effect of OOP Cost on Personal & Family Life

➤ 40% of people living with MS have at least some stress or emotional impact due to their high OOP costs and have made some type of sacrifice on their spending to cope.

Level of Emotional Stress Due to High OOP Cost  
(5-point scale)



Actions Relating to Lifestyle Because OOP Cost is Too High



Q20. How much does the cost of your MS disease-modifying therapy cause stress or affect you or your family emotionally? (n=578) Q18. In the past year, which of the following have you or your family done to afford the cost of your MS disease-modifying therapy? (n=578)



# Emotional Impact of Living with MS

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## Stress

Financial burden on family

Self-advocating

Navigating through the medical landscape



## Fear

The future, what is to come

Having a relapse



## Guilt

Cost of treatment and living with MS

Sacrifices family has to make



## Depression

Managing their own emotions so not to add more burden to family

Feelings of isolation, people just don't understand



*"It's draining on your mental state. I carry a heavy burden of guilt. My last relapse, I was very ill, the steroids made me emotional. I feel like my husband deserves a healthy wife. If I could have actual vacations where I could rest, it would really help."*

# Lifestyle Changes

People living with MS make many sacrifices and feel stress over financial challenges.

- Physical therapy would be helpful but copay is too expensive
- Massage could be helpful but not possible due to cost
- Using PTO for doctor visits, so not able to take a vacation – yet recognizing their body needs a break
- Can't drive long distances
- Rarely go out to dinner
- Can't afford a decent car
- Never spend money on themselves for items like clothes because they feel guilty, money should go toward family
- Credit card debt to cover medical costs and lost income
- Can't work full-time and/or on disability
- Living paycheck to paycheck
- Still have student loans
- One had to sell house when went on disability

Sacrifices on  
their body

Sacrifices on  
their lifestyle

Sacrifices on  
their finances

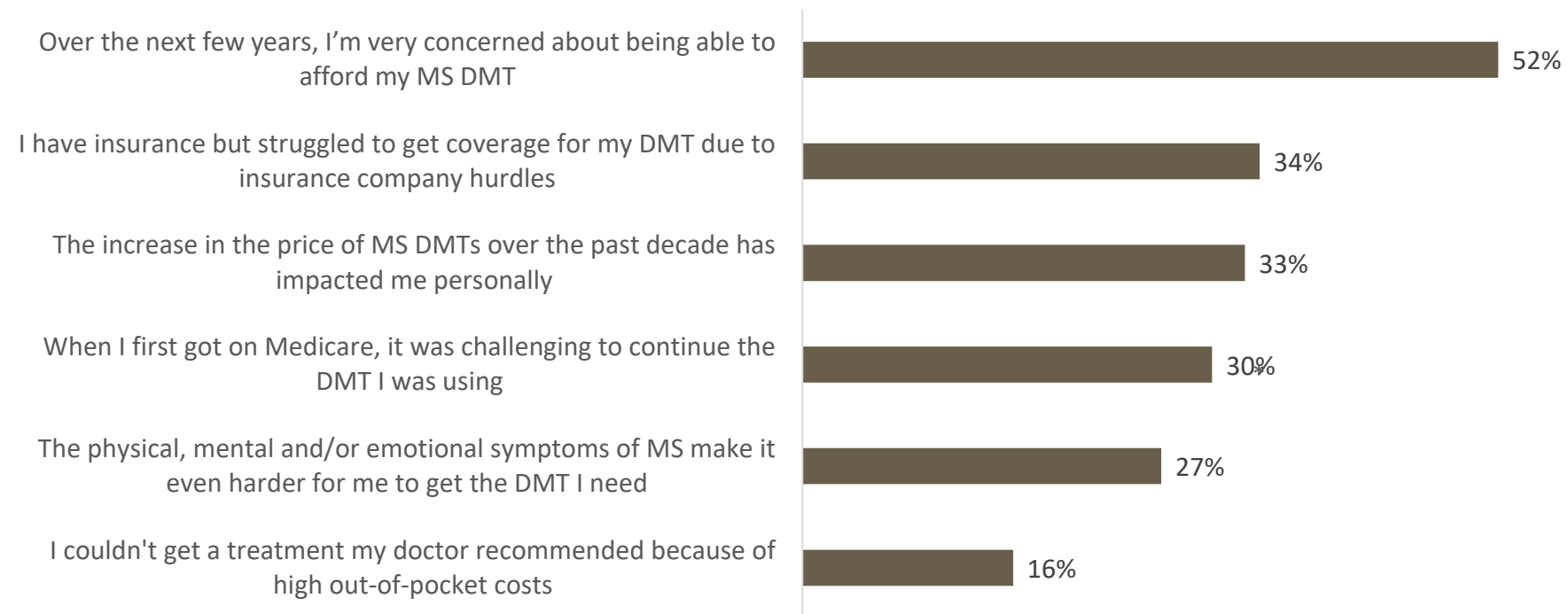


*“The cost of having a chronic illness like MS is horrible. The stress on daily life and ability to feel comfortable with your finances looms over you. I try to not let that loom over my family.”*

# Personal Impact and Concerns

- Half of people living with MS are concerned about being able to afford their DMT over the next few years.

Top-2 Box on a 5-point scale: Agree/ Agree completely



Q26. How much do you agree or disagree with the following statements? (n=578), \*Medicare statement only asked of those on Medicare

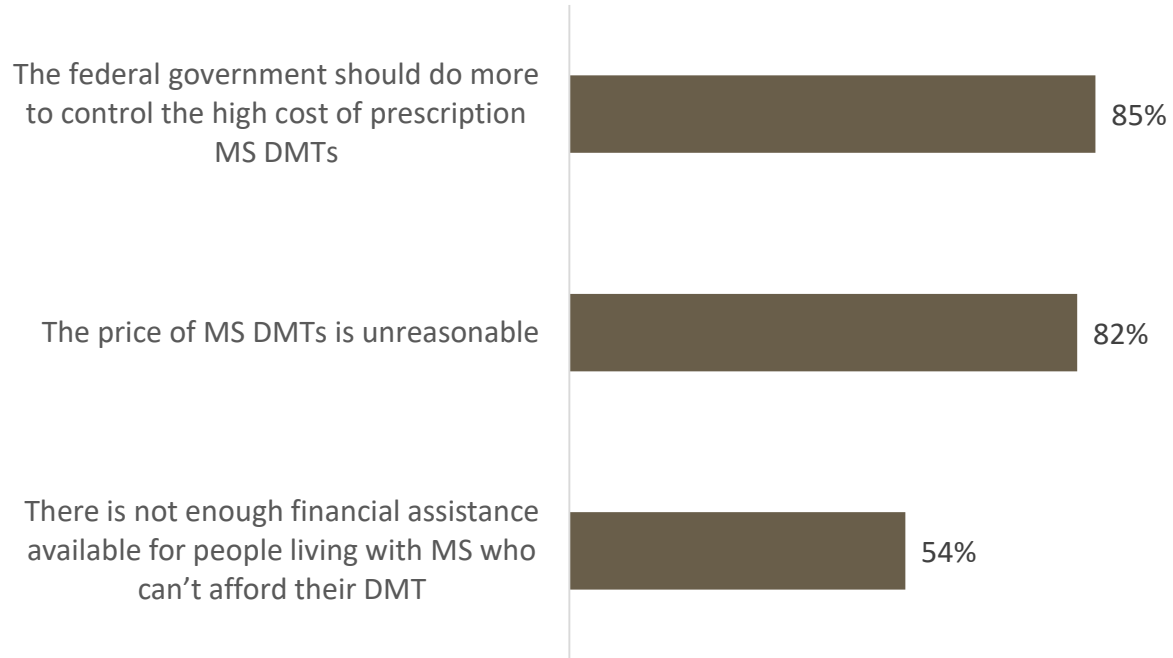




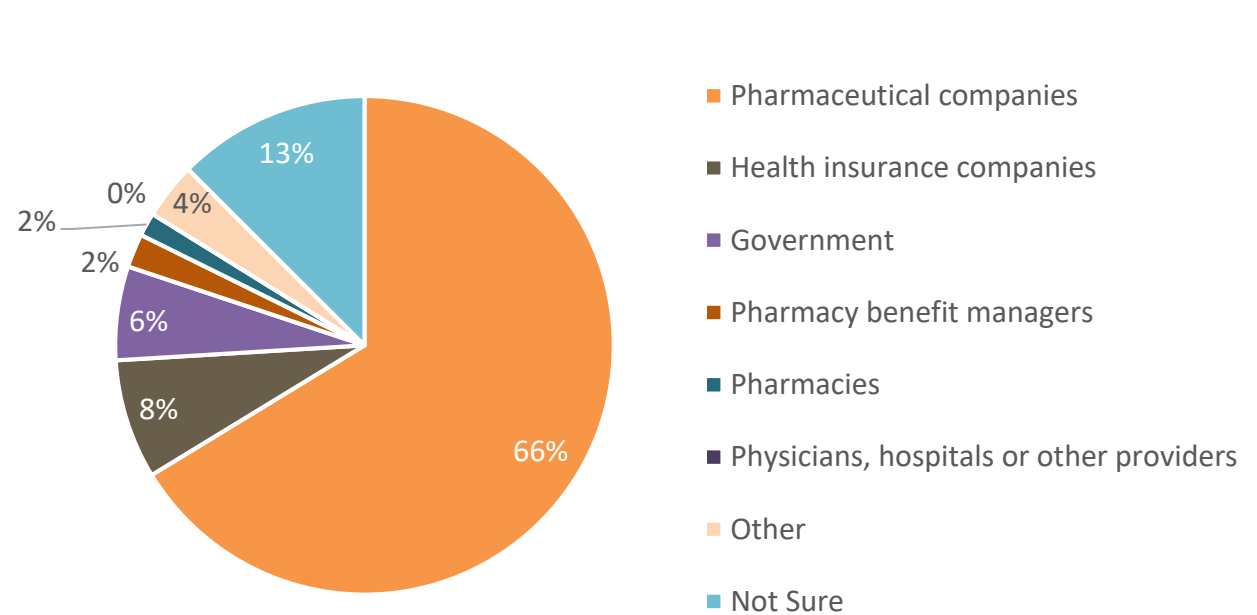
# Perceptions of Increasing Cost at Macro-Level

- Two-thirds of people living with MS hold pharmaceutical companies responsible for the increasing costs of DMTs. However, the vast majority feel the federal government should do more to control the unreasonable costs.

Top-2 Box on a 5-point scale: Agree/ Agree completely



Responsible for Increasing Costs of DMTs



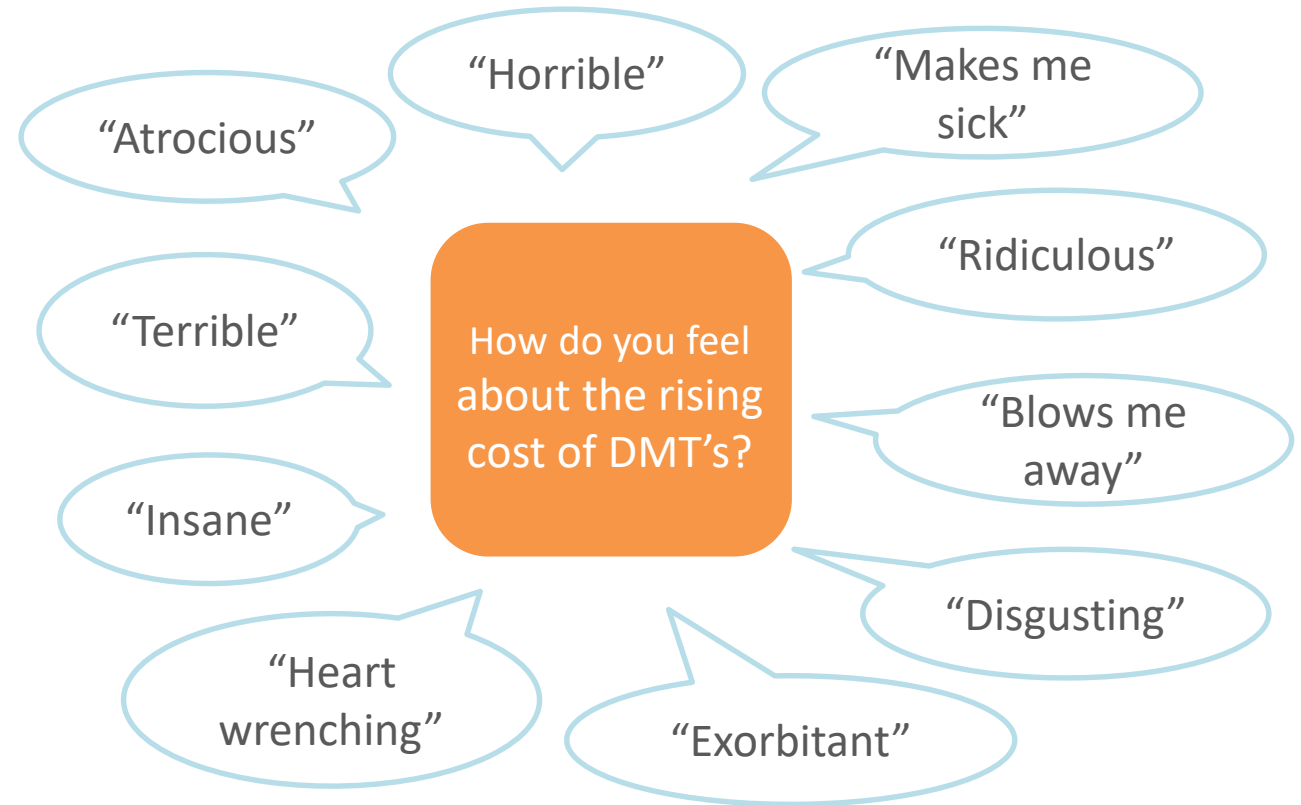
Q26. How much do you agree or disagree with the following statements? (n=578) Q27. In your opinion, who is most responsible for the increasing costs of MS disease-modifying therapy? (n=578)



# Increasing Cost of DMTs at Macro-Level

- People living with MS are very aware of the high and increasing cost of DMTs.
- Although they appreciate the support pharmaceutical companies give to cover the out-of-pocket cost for their DMT copay, they are also resentful because of the high cost of their treatment.
- People also blame insurance companies for making them jump through hoops to get treatment and profiting off the high cost of treatment.

“The cost of my drug makes me sick to my stomach. It’s being paid by my company and I feel guilty. It makes me not want to take the medicine. What else costs that much? I am appreciative of the copay program, but I am also very angry with them for the cost.”



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## **Detailed Findings**

### **– Perceptions of National Multiple Sclerosis Society**

# Perceptions of National Multiple Sclerosis Society

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**Overall, respondents have a positive perception of the National Multiple Sclerosis Society and think it is a good resource**

They like the NMSS website and newsletters

They enjoy participating in local fundraising events



**People living with MS wish NMSS could help more with navigating the administrative process of accessing medications and applying for assistance programs**

Respondents in rural areas feel isolated because they do not have access to local support groups or NMSS events

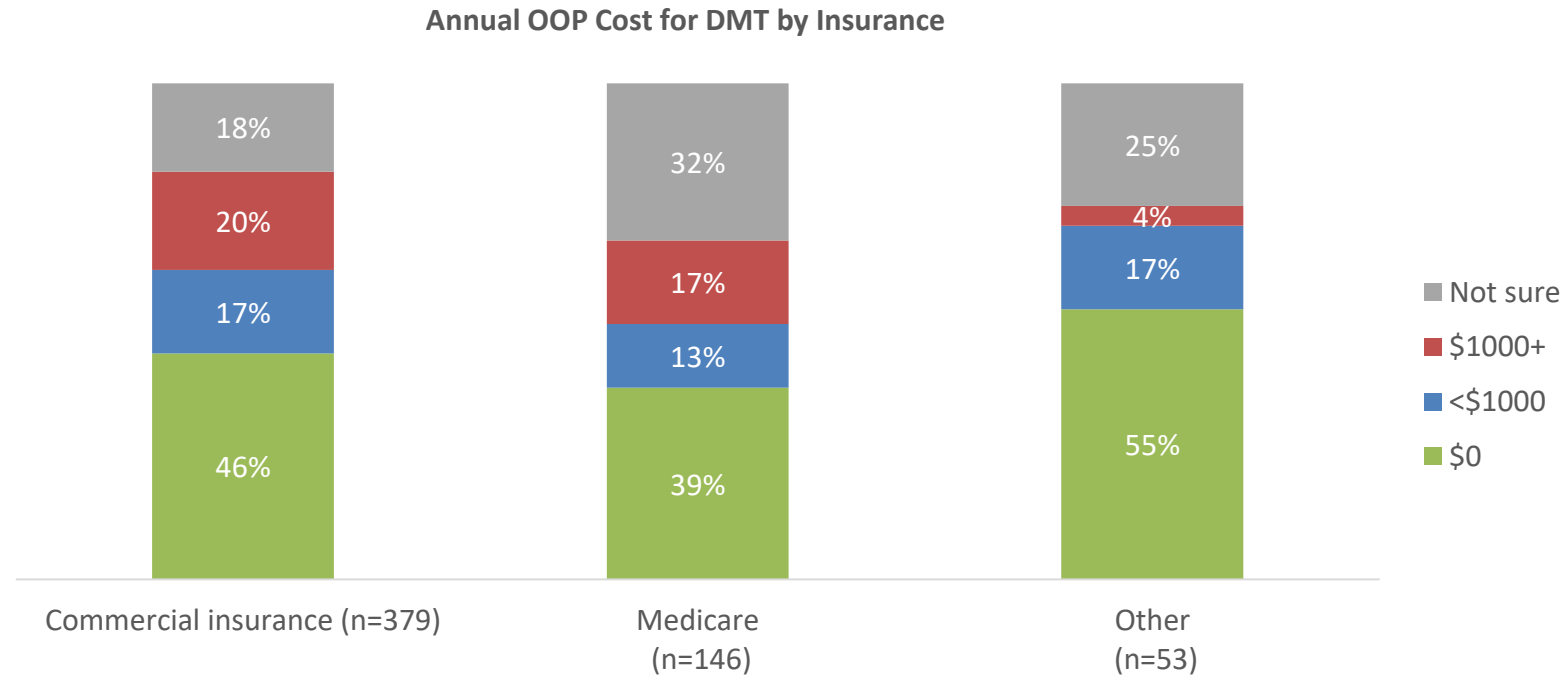


*“It’s so difficult to be sick, to work, and to handle everything. I need an assistant. If there were someone that could help to advocate on my behalf, do some of the intervention, a person who is familiar with me specifically, a resource for me, that would be good.”*

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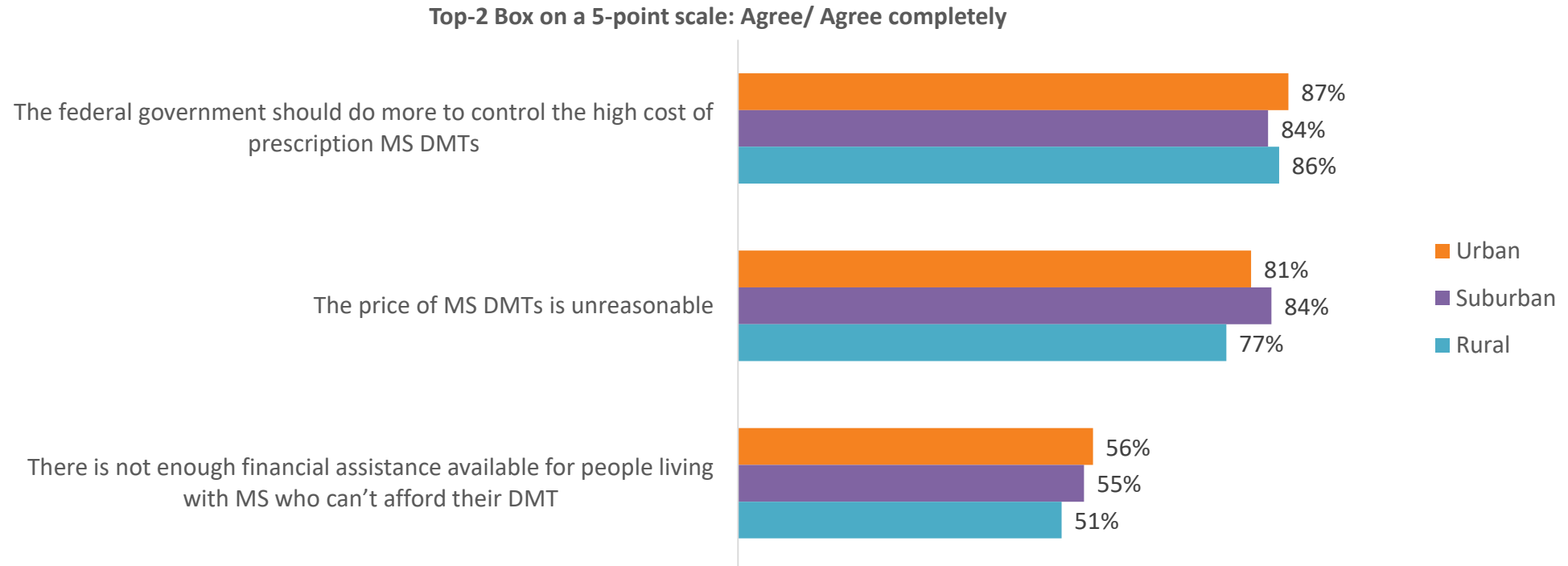
# Appendix

# OOP Expense Based on Insurance



Q11. What is your primary type of health insurance? Q12. Approximately how much do you pay out-of-pocket on an annual basis for your MS disease-modifying therapy? Out-of-pocket cost is the amount YOU pay, not what is covered by insurance or financial assistance.

# Perceptions of Increasing Cost by Type of Living Area



Q26. How much do you agree or disagree with the following statements? (n=578)



# Detailed Demographics

Age		Marital Status		Who Lives in Household		Education Completed		Annual Household Income	
18-29	4%	Single, never married	13%	Spouse/significant other	70%	High school	7%	Less than \$25,000	17%
30-39	16%	Married	64%	Child(ren)	28%	Some college	29%	\$25,000 - \$49,999	19%
40-49	22%	Living with a partner, not married	6%	Pet	25%	4-year college degree	34%	\$50,000 - \$74,999	19%
50-59	30%	Separated/divorced	14%	Parents (or parents-in-law)	7%	Post-graduate degree	30%	\$75,000 - \$99,999	15%
60-69	24%	Widowed	3%	Friend	2%	Work full time	40%	\$100,000 - \$149,999	16%
70-79	5%			Grandchild(ren)	1%	Work part time	10%	\$150,000 - \$199,999	7%
80+	0%			Paid/professional caregiver	<1%	Stay at home/retired/don't work – because of MS	39%	\$200,000+	7%
				Other	4%	Stay at home/retired/don't work – not because of MS	11%		
				I live alone	14%				
Children		Race/Ethnicity							
None	36%	White	89%						
1	16%	Black/African American	7%						
2	29%	Hispanic/Latino/Latina	3%						
3	12%	Native American/American Indian	2%						
4+	6%	Asian/Pacific Islander	1%						
		Other	3%						

Q3. What is your age? (n=578) Q30. How many children do you have? (n=578) Q28. What is your marital status? (n=578) Q37. How do you classify your race? (n=578) Q29. Who lives with you? (n=578) Q34. What is the highest level of education you have completed? (n=578) Q35. What is your employment status? (n=578) Q38. What is your annual household income before taxes? (n=578)





# Sample Weighting

- Weighting was based on the following gender ratios in each region, provided by National Multiple Sclerosis Society:
  - Northeast: F:M ratio = 2.8
  - Midwest: F:M ratio = 3.0
  - South: F:M ratio = 2.7
  - West: F:M ratio = 2.8

	Unweighted Sample	Weighting %	Weighted Sample
Northeast males	29	1.10%	<b>32</b>
Northeast females	82	1.09%	<b>89</b>
Midwest males	38	.91%	<b>35</b>
Midwest females	110	.95%	<b>105</b>
South males	36	1.47%	<b>53</b>
South females	141	1.01%	<b>142</b>
West males	42	.77%	<b>32</b>
West females	100	.90%	<b>90</b>