



**National
Multiple Sclerosis
Society**

Quantifying the Impact of the High Cost of DMTs

Supplemental Market Research Report
Detailing Findings Among African American
and Hispanic People Living with MS

November 2019

Prepared by

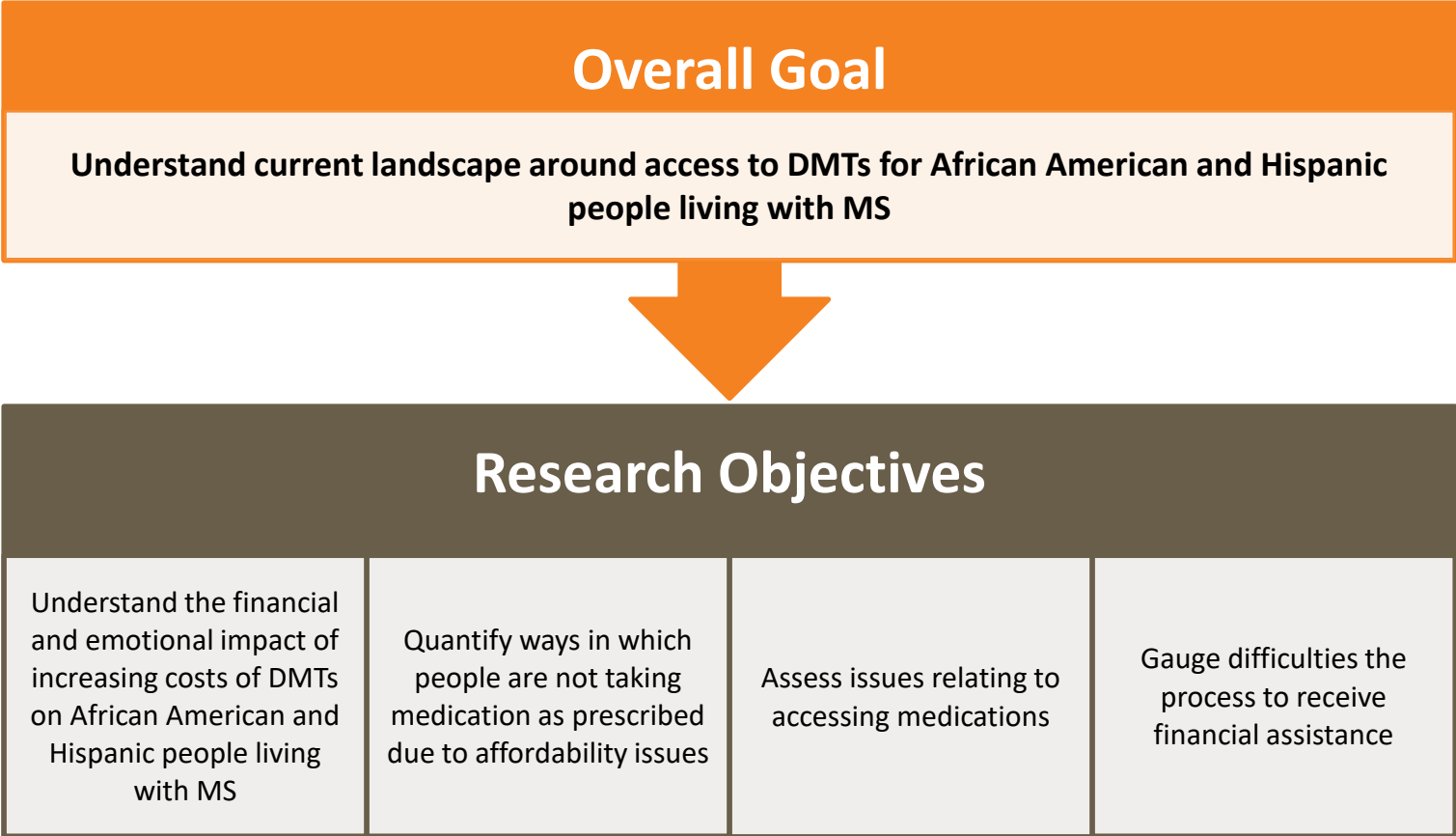
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Study Design

Objectives



Study Specs

- An Online Survey was conducted in July 2019 with 578 People Living with MS, results from which are included in this report for comparison purposes
- As a follow up to this study, we recruited more African American and Hispanic people living with MS to take the survey to get a sufficient sample to analyze findings among these groups
 - Recruited through email invitations to people in National Multiple Sclerosis Society database October 21-29, 2019
- African American and Hispanic respondents from the original survey were combined with those from this new effort for the analysis included in this report
- The purpose of the survey was to assess the impact of increasing costs of DMTs, so 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 details.)
- Statistical significance was tested between groups at a 95% confidence level and differences are noted with A, B or C throughout this report.

Sample Frame

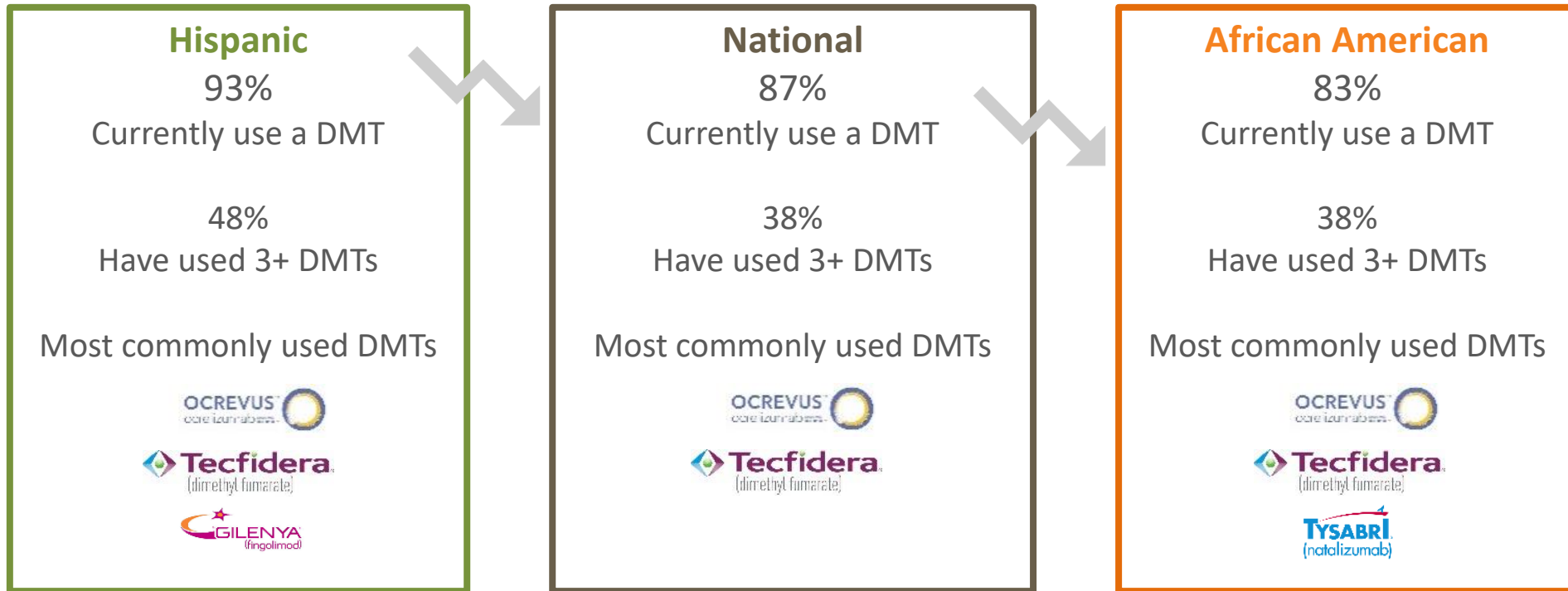
	African American	Hispanic
Original survey July 2019	39	17
Follow up October 2019	81	63
Total	120	80

This report focuses on the differences between African American and Hispanic people living with MS vs. the national population of people living with MS

Summary of Key Findings

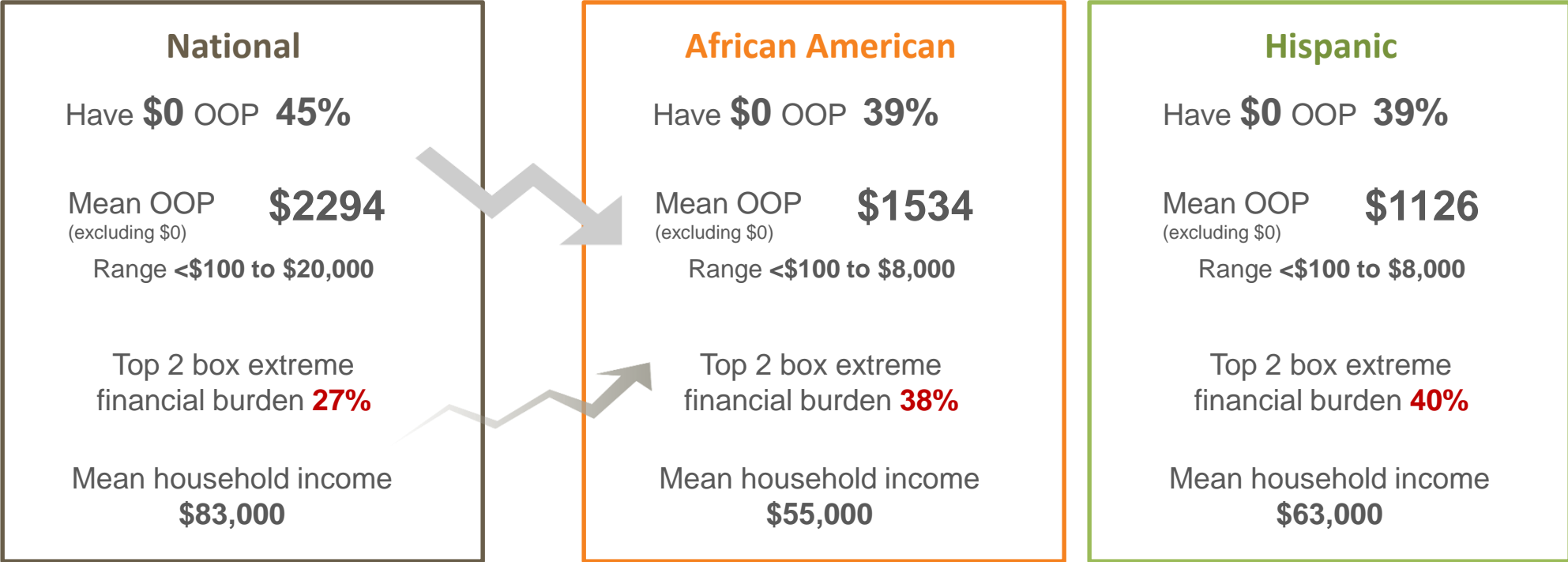
Use of DMTs

- **Hispanic** people living with MS are somewhat more likely to currently use a DMT and to have used more DMTs over time. Contrarily, **African Americans** are somewhat less likely.
- **Hispanics** are more likely to use Gilenya and **African Americans** are more likely to use Tysabri.



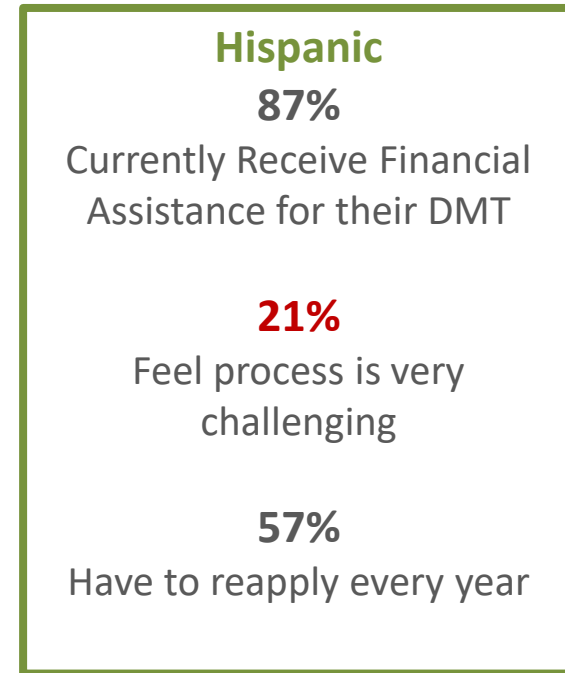
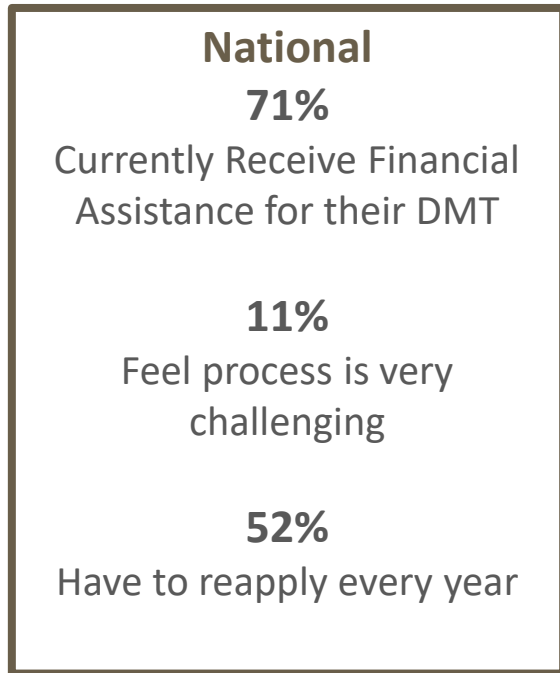
Out-of-pocket Cost of DMT

➤ Compared to the national population, a slightly lower proportion of **African American** and **Hispanic** people living with MS have \$0 OOP costs for their DMT. Those who have OOP costs report a lower annual amount, however are more likely to feel it is a significant financial burden – probably due to lower household income.



Financial Assistance

- **Hispanic** people living with MS are more likely to receive financial assistance for their DMT.
- **African American** and **Hispanic** people living with MS find the process to get financial assistance much more challenging vs. the national population and **African Americans** are more likely to have to reapply every year.



Impact and Accountability

SACRIFICES

- Overall, compared to the national population, **African American** and **Hispanic** people living with MS are making similar sacrifices with their medication (skip, delay, etc.) and/or lifestyle (spend less, save less, etc.).
 - However, **Hispanics** are more likely to feel their MS symptoms make it even harder to get the DMT they need, and more likely to say they can't get the treatment their doctor recommends.

EMOTIONAL IMPACT

- While the emotional impact of the high cost of DMT on people living with MS is similar regardless of race/ethnicity, the emotional impact on family is greatest for **Hispanics** – possibly due to cultural differences.

RESPONSIBILITY

- **African American** people living with MS are less likely to know who to hold responsible for the increasing costs of DMTs. Compared to the national population, they are more likely to feel the government is responsible – but like the national population, the majority feel pharmaceutical companies should be held accountable.

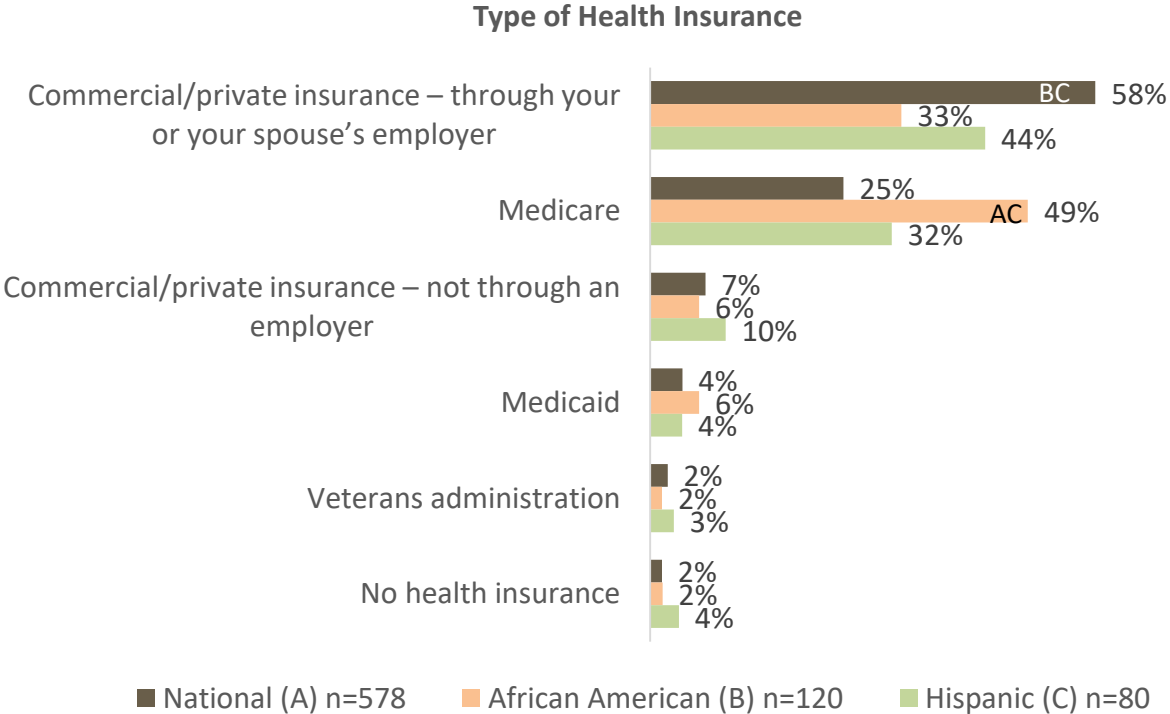


Detailed Findings

– Respondent Profile

Health Insurance

➤ African Americans are more likely to be on Medicare and less likely to have private insurance. (And, they do *not* have more 65+ in the research sample vs. the national sample.)

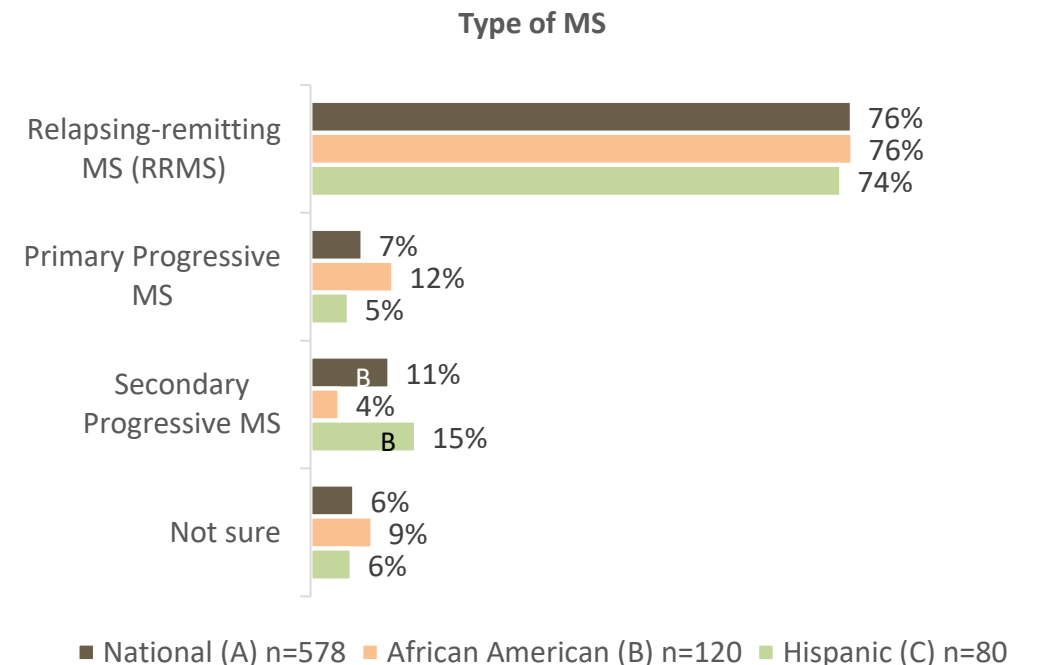
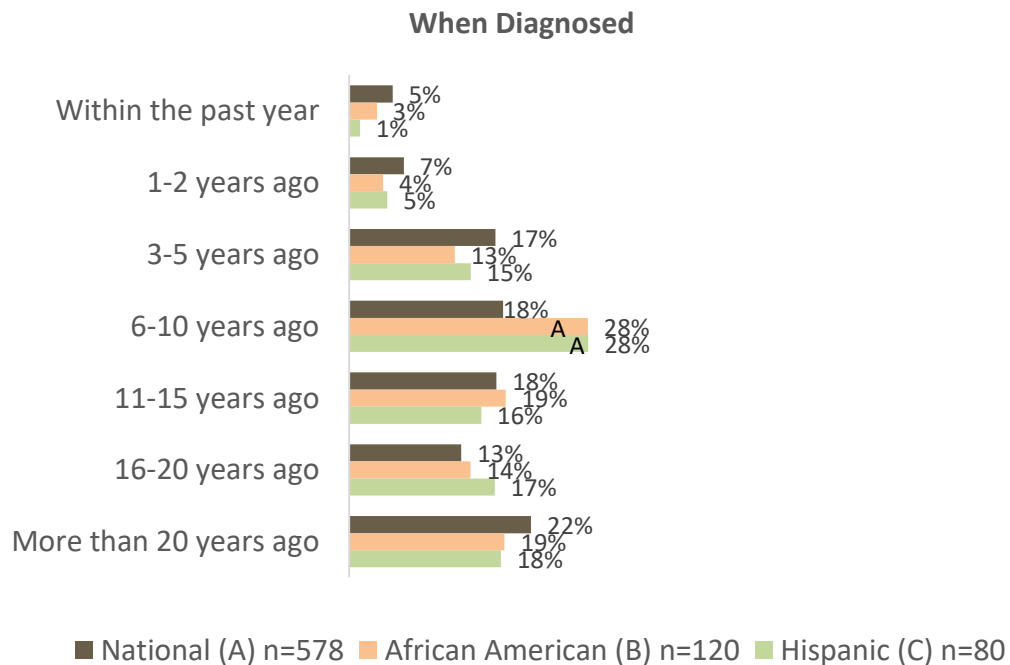


Q11. What is your primary type of health insurance?



MS Diagnosis

- Regardless of race/ethnicity, three-quarters of respondents have RRMS, and just over half were diagnosed more than 10 years ago.

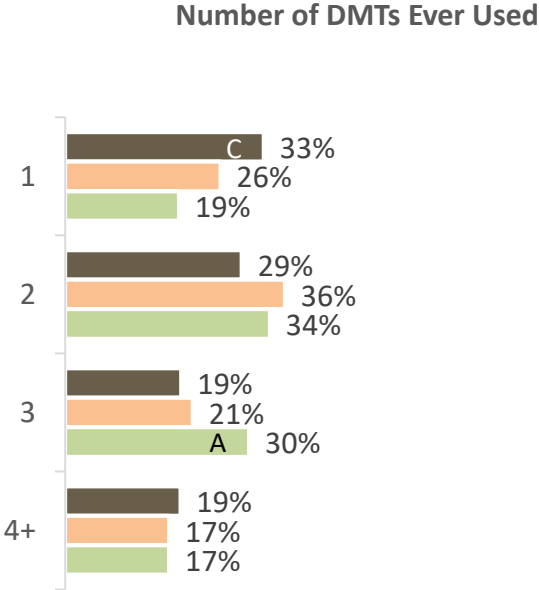
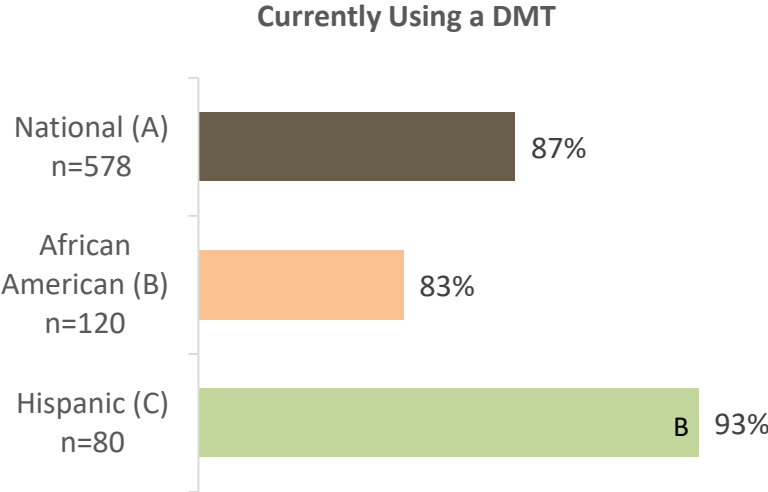


Q4. How long ago were you diagnosed with MS? Q5. Do you currently have....?



Use of Disease-Modifying Therapy

➤ Hispanic people are more likely to have used more DMTs and to be currently using one vs. African Americans.



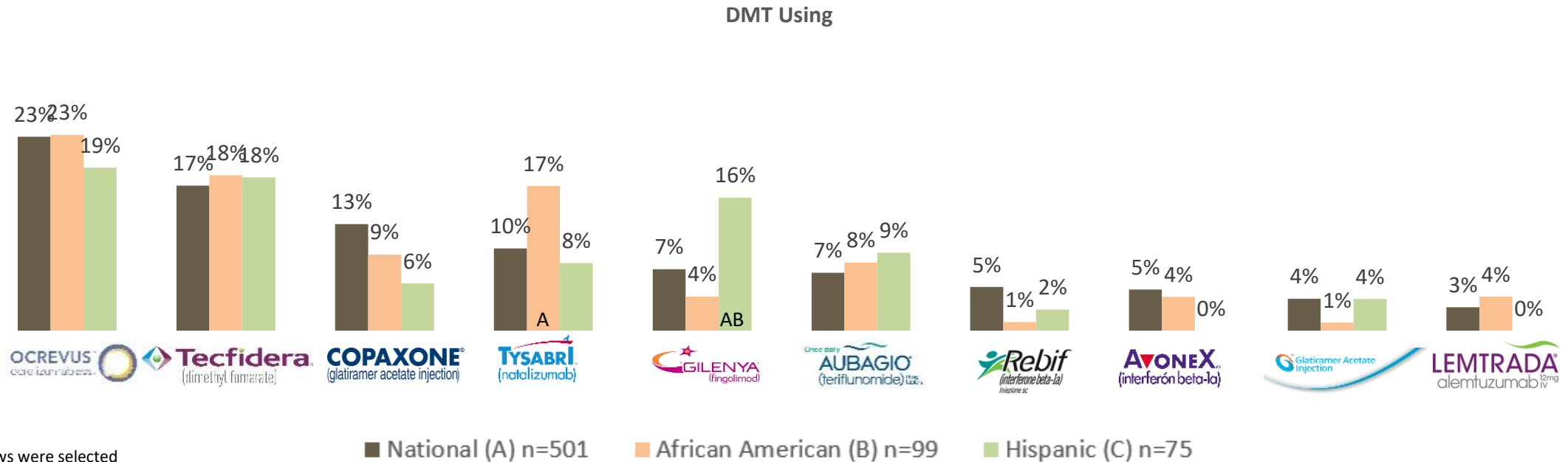
■ National (A) n=578 ■ African American (B) n=120 ■ Hispanic (C) n=80

Q6. Are you currently using a disease-modifying therapy for MS? Q8. How many MS disease modifying therapies have you tried?



Use of Disease-Modifying Therapy

- Both groups are likely to use Ocrevus or Tecfidera, but African Americans are more likely to use Tysabri and Hispanics are more likely to use Gilenya.



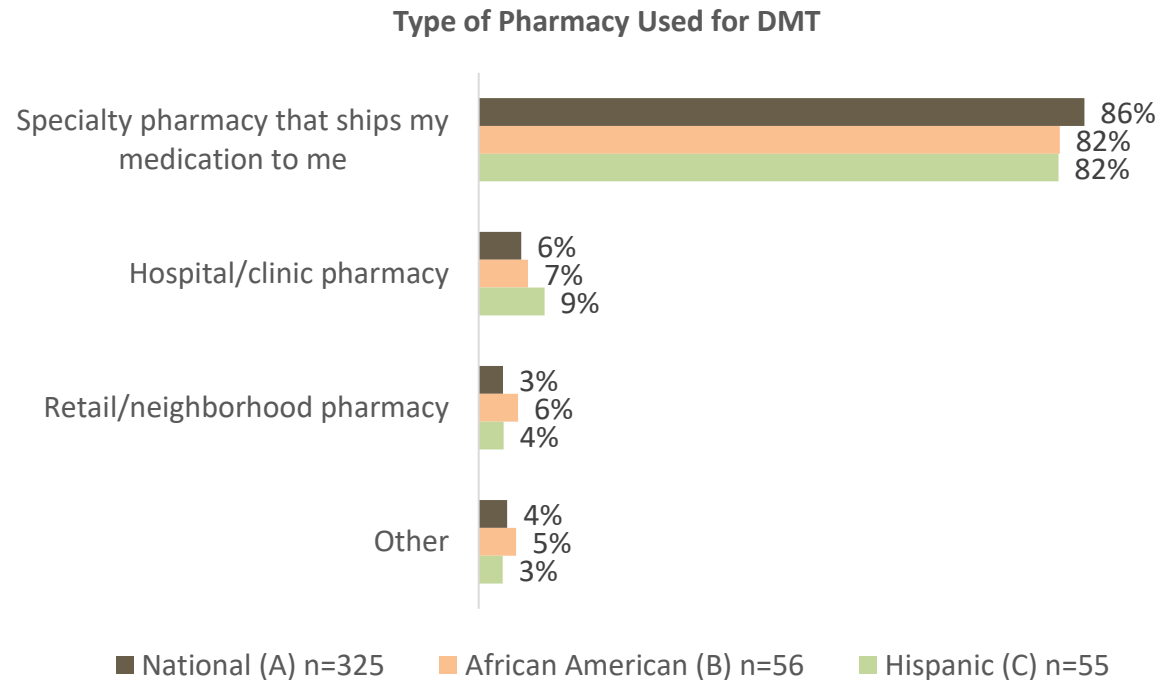
Note: DMTs not shown were selected by <2% of national respondents

Q7. Which of the following disease-modifying therapies are you currently using to treat MS?



Type of Pharmacy Used

- Regardless of race/ethnicity, 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?

Detailed Findings

- Challenges Due to Cost

Out-of-pocket Expense

- Nearly 40% of African American and Hispanic people living with MS do not pay anything out-of-pocket for their DMT – slightly less than the national population. The estimated average annual OOP cost among those who do pay is less than the national average for these two populations.

This data includes a majority of whom receive financial assistance

Annual Out-of-pocket Cost

National	African American	Hispanic
Have \$0 OOP 45%	Have \$0 OOP 39%	Have \$0 OOP 39%
Mean \$2294 (excluding \$0)	Mean \$1534 (excluding \$0)	Mean \$1126 (excluding \$0)
Range <\$100 to \$20,000	Range <\$100 to \$8,000	Range <\$100 to \$8,000

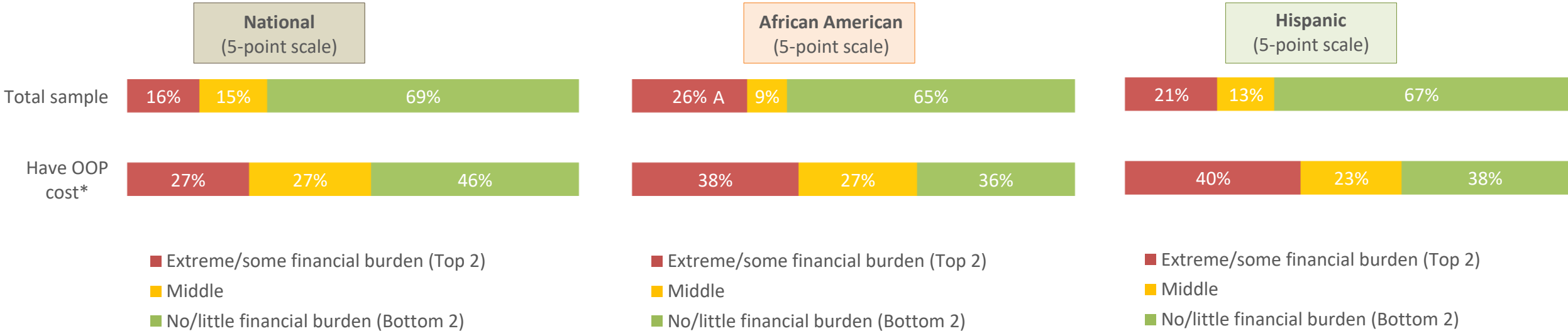
Q12. Approximately how much do you pay out-of-pocket on an annual basis for your MS disease-modifying therapy? Out-of-pocket cost is the amount YOU pay, not what is covered by insurance or financial assistance.



Out-of-pocket Expense

➤ African Americans and Hispanics are likely to have more extreme financial burden because of their OOP cost of their DMT vs. the national population.

Financial Burden of Out-of-pocket Cost

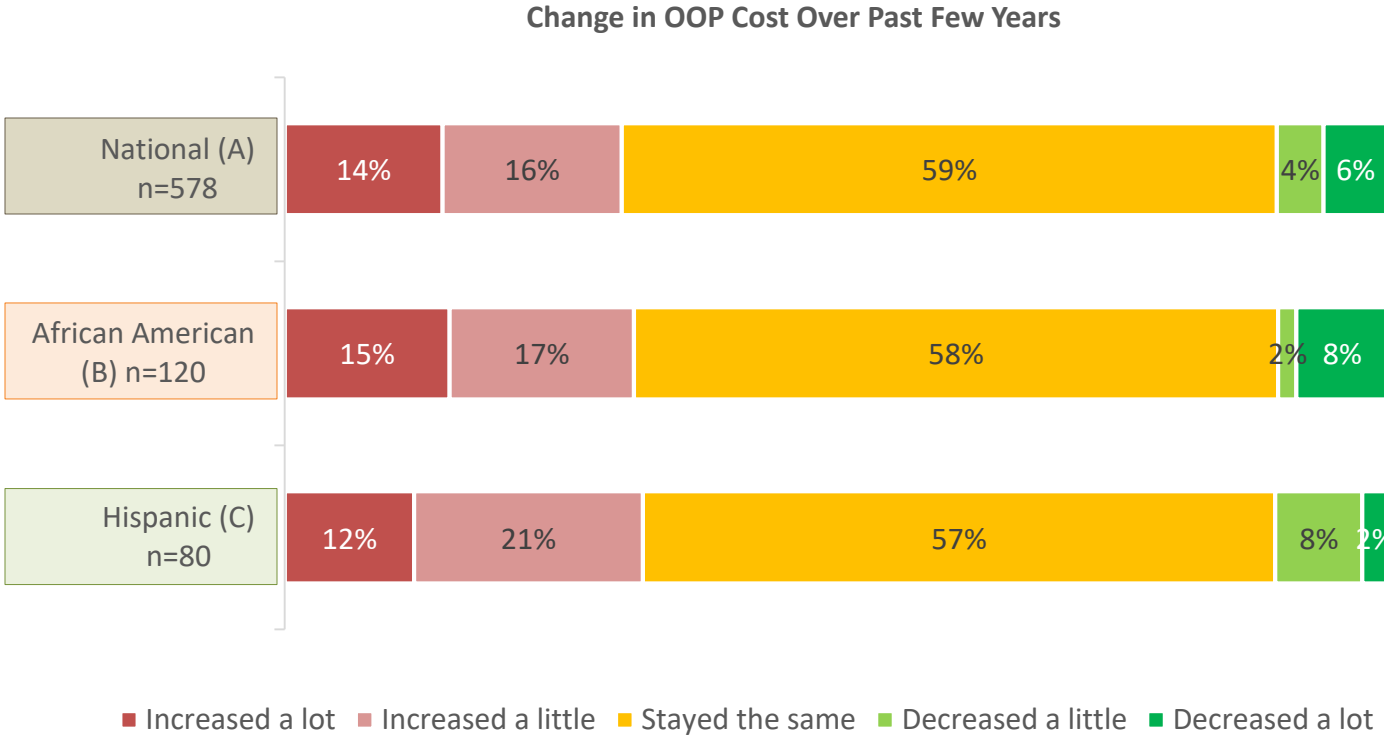


*Very small sample size, interpret with caution
 Q15. How much of a financial burden is the amount you pay out-of-pocket for your MS disease-modifying therapy?



Change in Out-of-pocket Expense

➤ Increase/decrease in OOP over the past few years is consistent regardless of race/ethnicity.

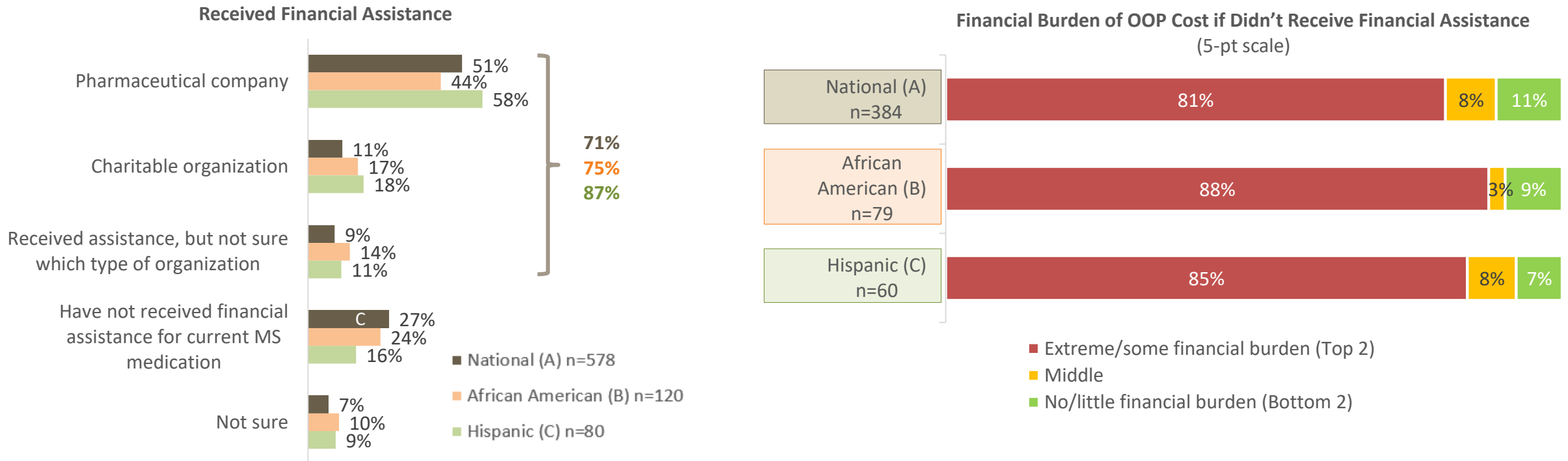


Q14. Over the past few years, has your out-of-pocket expense for MS disease-modifying therapy increased, decreased or stayed the same?



Financial Assistance

- 75% of African Americans and 87% of Hispanics have received financial assistance for the DMT they are currently using (vs. 71% national), the vast majority of whom say the financial burden would be great without assistance.



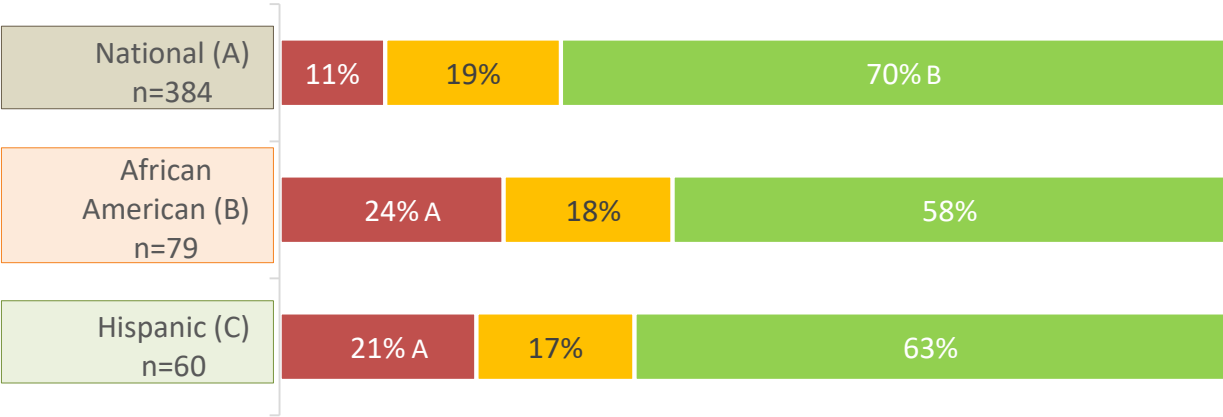
Q21. From what types of organizations have you received financial assistance for the MS disease-modifying therapy you are currently using? Q24. How much of a financial burden would the out-of-pocket cost of your MS disease-modifying therapy be if you did not receive financial assistance?



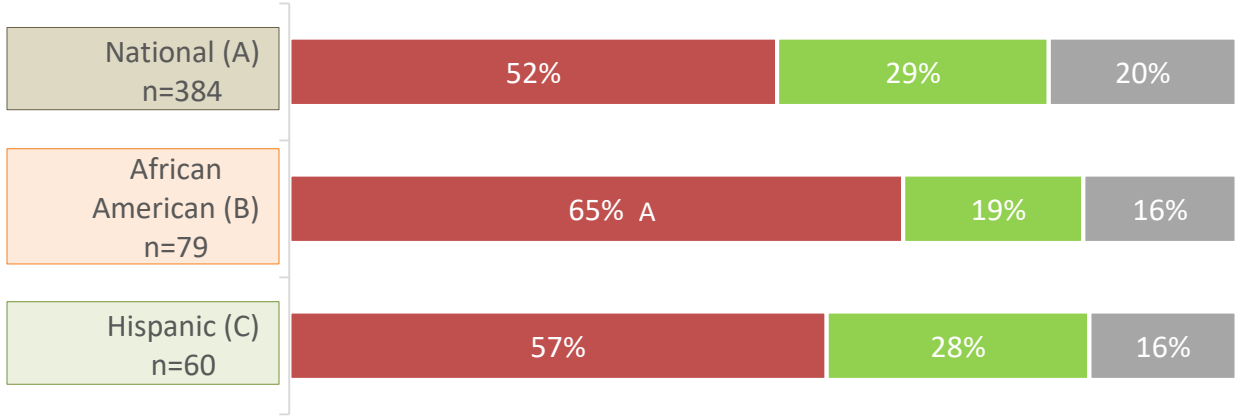
Financial Assistance Process

➤ African Americans and Hispanics are more likely to feel the process of getting financial assistance is challenging vs. the national population of people living with MS. African Americans are more likely to have to renew their assistance every year.

Financial Assistance Process
(5-pt scale)



Renewal of Assistance



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

■ 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? Q23. Do you have to renew or reapply for financial assistance every year, or does it continue automatically?



Challenge Accessing DMT

➤ African Americans report greater challenges with getting financial assistance compared to the national population. But the greatest challenge regardless of race/ethnicity is insurance.

Extremely challenging/ challenging (Top-2 Box on 5-pt scale)

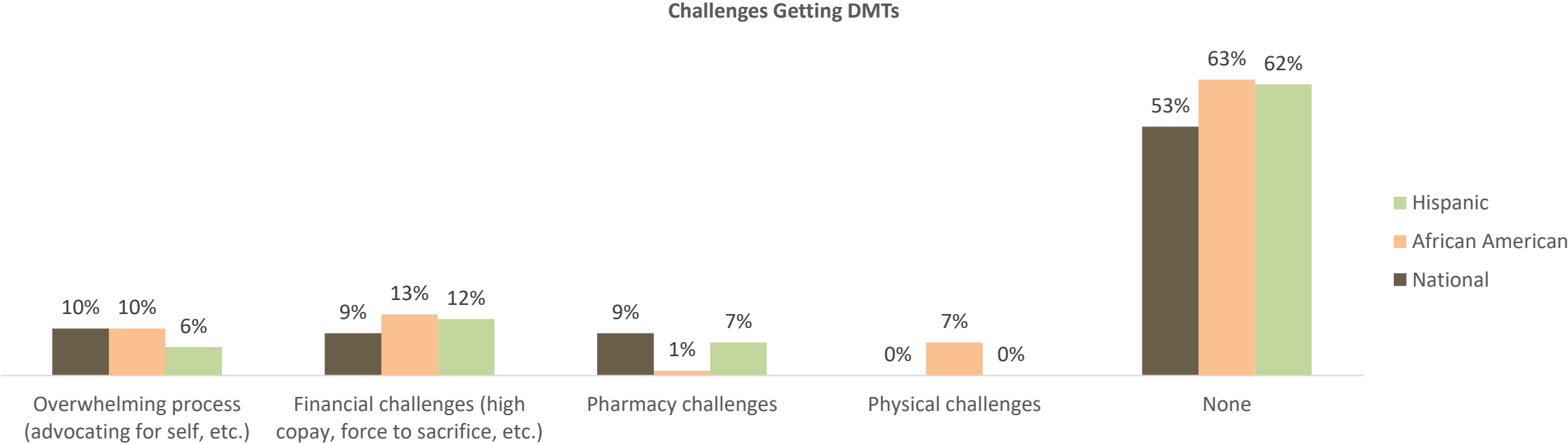
	National (A) n=578	African American (B) n=120	Hispanic (C) n=80
Healthcare provider’s office	8%	11%	13%
Pharmacy	13%	14%	16%
Financial assistance	15%	26% A	18%
Insurance	24%	28%	22%

Q10. How easy was the process to get your current MS disease modifying therapy in the following areas?



Open-Ended Challenges Faced

➤ Survey respondents were asked about their challenges getting DMTs. Compared to the national population, fewer African Americans or Hispanics had challenges to write about. Below summarizes the topics about which respondents wrote.



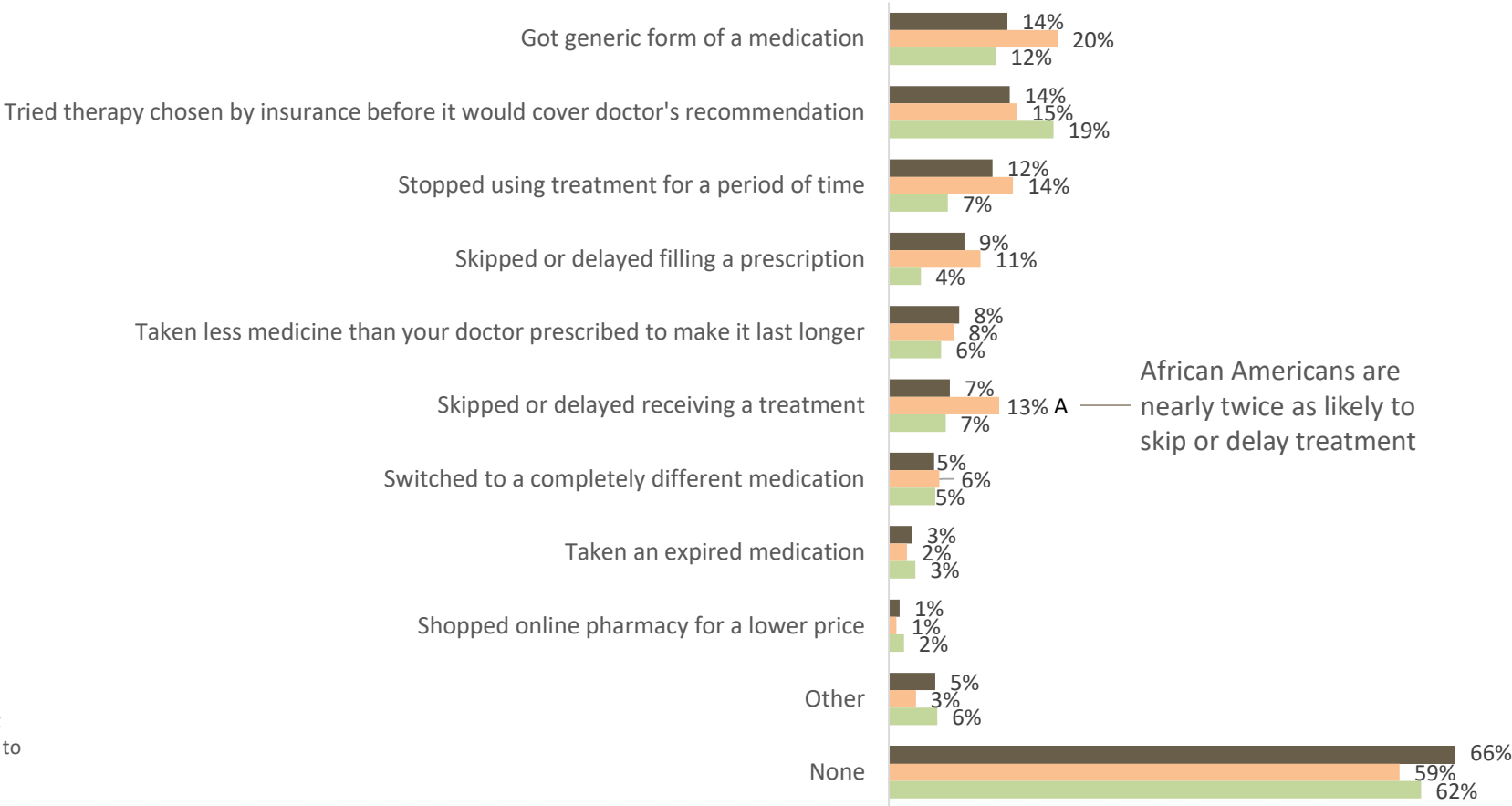
Q25. Please tell us your personal story about any challenges you've had getting the MS disease-modifying therapy you need. Please be as detailed as possible about what happened and how it affected you or your family. Your story will not be used for any purposes without your consent. If you haven't experienced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



Impact of Out-of-pocket Cost on Therapy

➤ Compared to the national population of people living with MS, African Americans and Hispanics are taking similar actions impacting their therapy as a result of high OOP cost of DMTs.

Actions Relating to Therapy Because OOP Cost is Too High



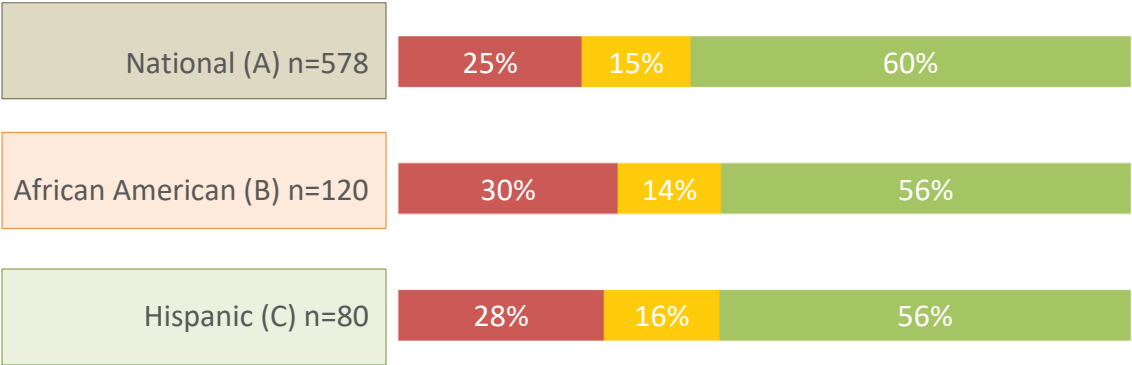
Q19. Which of the following have you ever done because the out-of-pocket cost of a disease-modifying therapy was too high? Q16. Have you ever had to try a disease-modifying therapy chosen by your insurance company before the plan would cover the medication that your doctor recommended?



Impact of OOP Cost on Personal & Family Life

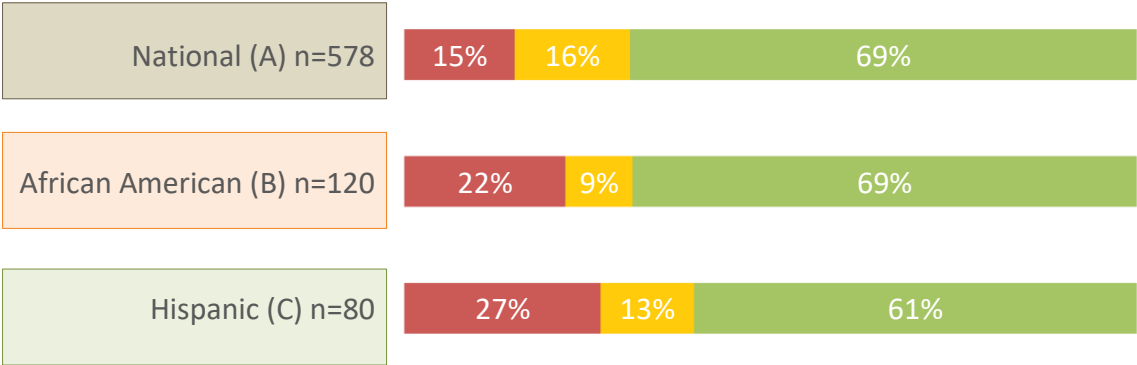
➤ Hispanics report greater emotional stress on their family due to high OOP costs.

Emotional Stress on Person Living with MS Due to High OOP Cost
(5-point scale)



■ Extreme/a lot of stress (Top 2) ■ Middle ■ No/little stress (Bottom 2)

Emotional Stress on Family Due to High OOP Cost
(5-point scale)



■ Extreme/a lot of stress (Top 2) ■ Middle ■ No/little stress (Bottom 2)

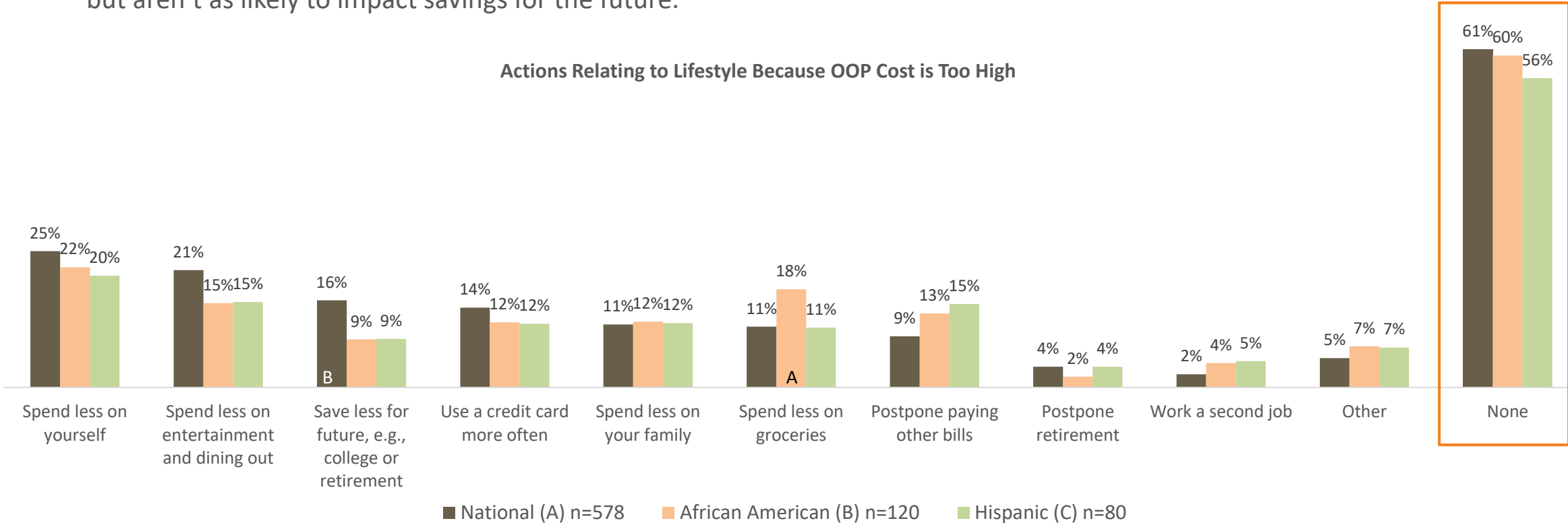
Q20. How much does the cost of your MS disease-modifying therapy cause stress or affect you or your family emotionally?



Impact of OOP Cost on Personal & Family Life

- Overall, a similar proportion of African Americans and Hispanics make lifestyle sacrifices because of high OOP costs.
- Compared to the national population, African Americans and Hispanics are somewhat more likely to postpone paying bills but aren't as likely to impact savings for the future.

Actions Relating to Lifestyle Because OOP Cost is Too High



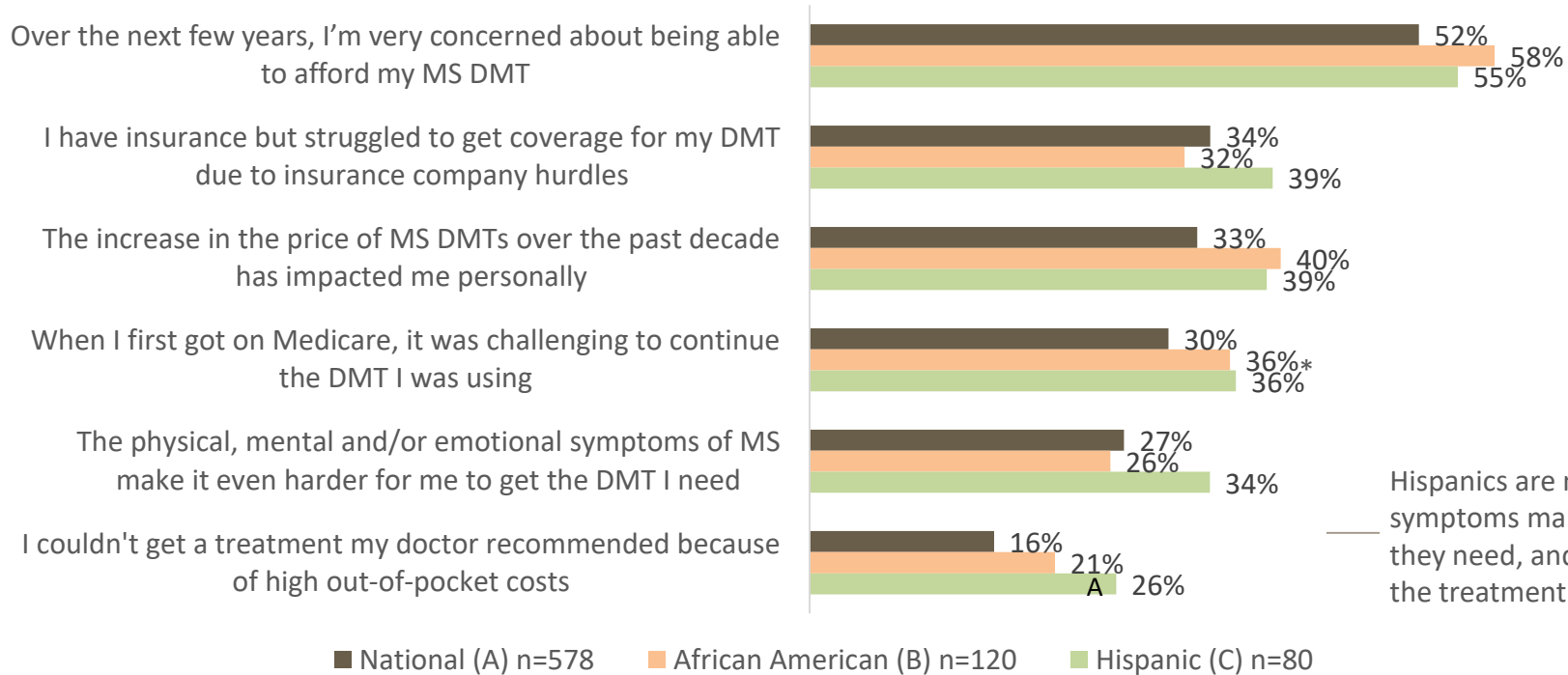
Q18. In the past year, which of the following have you or your family done to afford the cost of your MS disease-modifying therapy?



Personal Impact and Concerns

- Overall, compared to the national population, similar proportions of African Americans and Hispanics have concerns about high costs of DMTs.

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



Hispanics are more likely to feel their MS symptoms make it even harder to get the DMT they need, and more likely to say they can't get the treatment their doctor recommends.

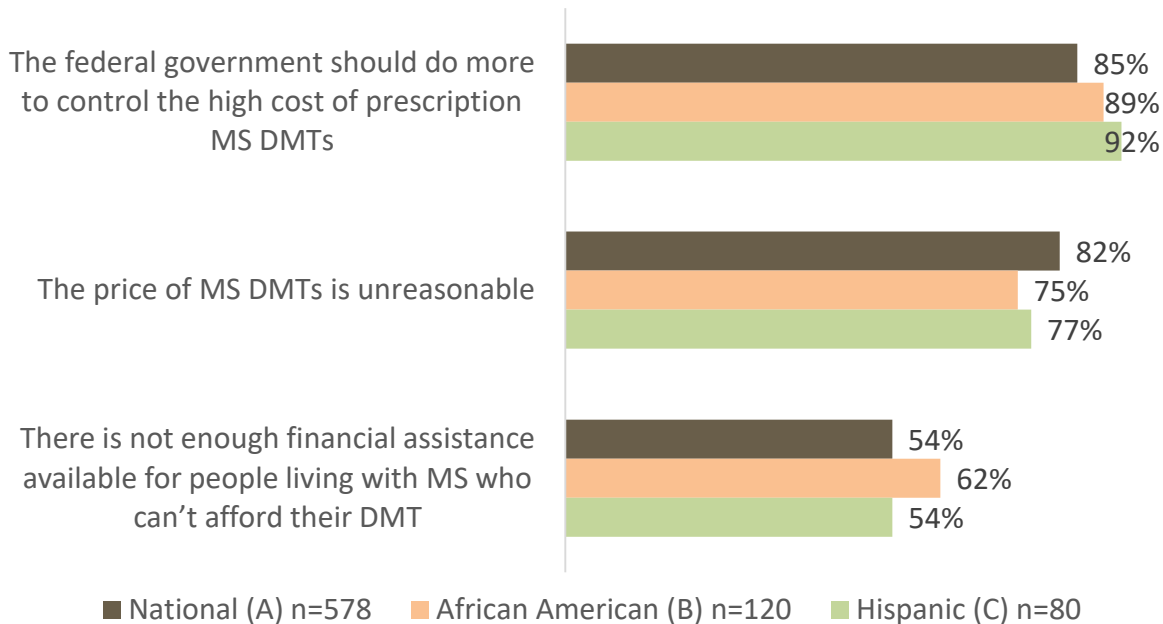
Q26. How much do you agree or disagree with the following statements? (n=578), *Medicare statement only asked of those on Medicare



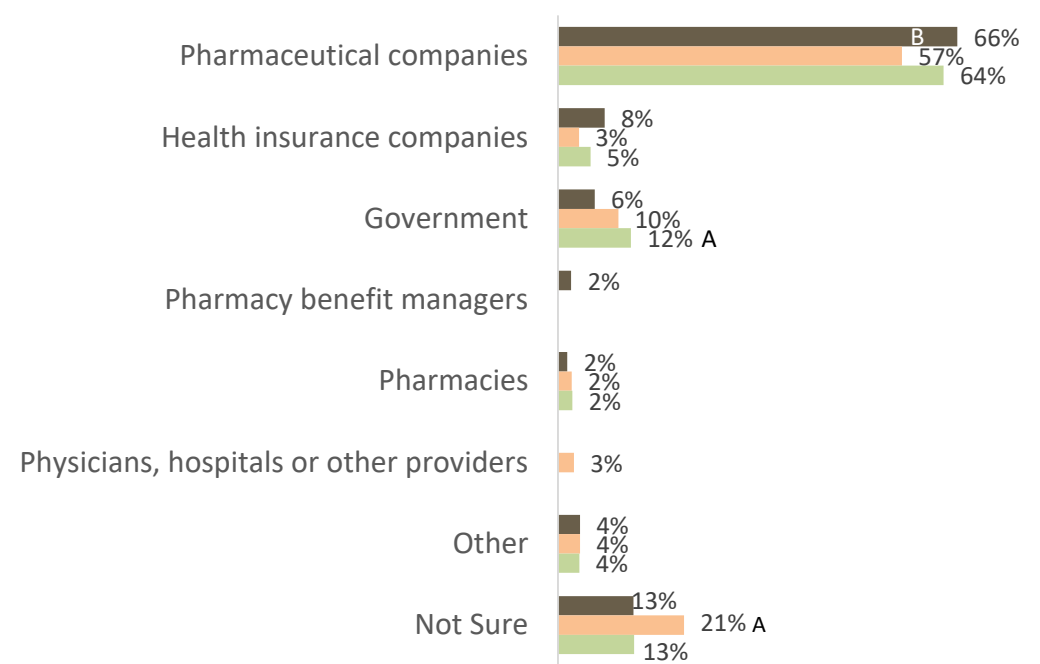
Perceptions of Increasing Cost at Macro-Level

- Regardless of race/ethnicity, pharmaceutical companies are held most responsible for increasing costs of DMTs. Compared to the national population, African Americans and Hispanics are somewhat more likely to hold the Government responsible, and African Americans are less likely to have an opinion about who is responsible.

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? Q27. In your opinion, who is most responsible for the increasing costs of MS disease-modifying therapy?



Appendix

Demographics

Age				Marital Status				Children				Who Lives in Household			
	National (A) n=578	AA (B) n=120	Hispanic (C) n=80		National (A) n=578	AA (B) n=120	Hispanic (C) n=80		National (A) n=578	AA (B) n=120	Hispanic (C) n=80		National (A) n=578	AA (B) n=120	Hispanic (C) n=80
18-29	4%	4%	8%	Single, never married	13%	36% AC	13%	None	36%	26%	36%	Spouse/significant other	70% B	38%	63% B
30-39	16%	14%	12%	Married	64% B	35%	63% B	1	16%	18%	11%	Child(ren)	28%	25%	40% AB
40-49	22%	21%	34% AB	Living with a partner, not married	6%	2%	5%	2	29%	27%	39%	Pet	25% B	12%	21%
50-59	30%	37%	31%	Separated/divorced	14%	23% A	19%	3	12%	12%	12%	Parents (or in-laws)	7%	13% A	15% A
60-69	24%	21%	14%	Widowed	3%	4%	0%	4+	6%	17% AC	3%	Friend	2%	4%	1%
70-79	5%	4%	2%									Grandchild(ren)	1%	4% A	0%
Mean	51	52	48									Professional caregiver	<1%	1%	1%
												Other	4%	6%	6%
												I live alone	14%	28% AC	11%

Q3. What is your age? Q28. What is your marital status? Q30. How many children do you have? Q29. Who lives with you?



Demographics

Education			
	National (A) n=578	AA (B) n=120	Hispanic (C) n=80
High school	7%	19% A	16% A
Some college	29%	31%	30%
4-year college degree	34%	31%	35%
Post-graduate degree	30% BC	19%	19%

Employment			
	National (A) n=578	AA (B) n=120	Hispanic (C) n=80
Work full time	40% B	21%	32%
Work part time	10%	5%	11%
Stay at home/retired/don't work – because of MS	39%	67% AC	46%
Stay at home/retired/don't work – not because of MS	11%	7%	11%

Household Income			
	National (A) n=578	AA (B) n=120	Hispanic (C) n=80
Less than \$25,000	17%	38% AC	21%
\$25,000 - \$49,999	19%	24%	32% A
\$50,000 - \$74,999	19%	16%	17%
\$75,000 - \$99,999	15%	11%	13%
\$100,000 - \$149,999	16% B	7%	15%
\$150,000 - \$199,999	7% BC	2%	2%
\$200,000+	7% BC	2%	1%
Mean	\$83K	\$55K	\$63K

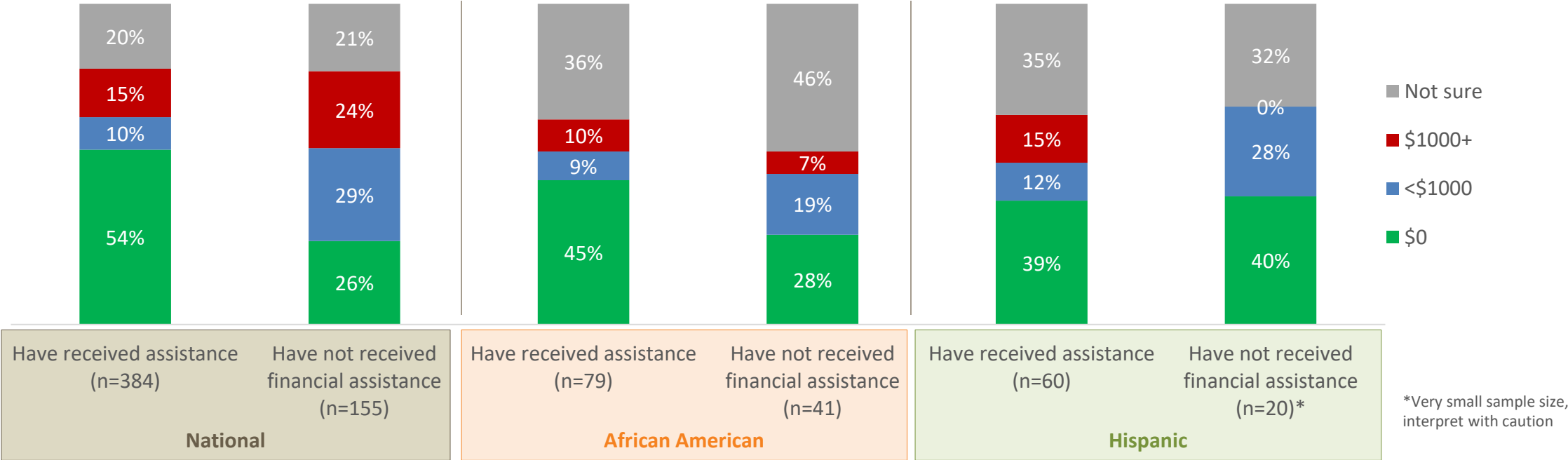
Q34. What is the highest level of education you have completed? Q35. What is your employment status? Q38. What is your annual household income before taxes?



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.

Annual OOP Cost for DMT by Financial Assistance



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.



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