

BACKGROUND:

For people with multiple sclerosis (MS), disease modifying therapies (DMTs) may change the course of this chronic disease. A growing body of evidence indicates that early and ongoing treatment with a DMT is the best way to modify the disease course, prevent accumulation of disability and protect the brain from damage.

The prices for the MS DMTs have increased annually at rates 5 to 7 times higher than prescription drug inflation and newer DMTs have commonly entered the market priced 25–60% higher than existing DMTs.¹ Between 2004 and 2015, the average price of DMTs increased 300%. While published information is available regarding insurance benefit design and utilization management techniques, information on the impact of the price of DMTs on people with MS is less available. In October 2015, the National MS Society

conducted an electronic survey on pricing impact to inform the Society's priorities and strategies to improve the lives of people with MS.

OBJECTIVES:

To understand the perceptions and experiences of people with MS related to the price of the MS DMTs and to compare the results to the perceptions and experiences of the general U.S. population surveyed by the Kaiser Health Foundation and Consumer Reports.

METHODS:

An electronic survey, adapted from Kaiser Health and Consumer Report surveys released in summer 2015, was disseminated to 1.3 million constituents in the Society's database; 124,453 of whom self-identify as living with MS. The survey queried all recipients about their perceptions of the MS medications and queried only people with MS about their experiences with the price and cost of MS DMTs.

The survey had some limitations including a reliance on individuals self-identifying as living with MS, a limited number of questions due to its electronic format, and no questions about the type of MS or insurance status of the individual living with MS.

RESULTS:

11,194 people responded to the survey, 8,778 of whom identified as living with MS. 5.3% of individuals living with MS who received the survey invitation took action, compared to 1.1% industry average action rate (M+R 2016 Benchmarks Study). The information in this poster focuses on the responses of people with MS.

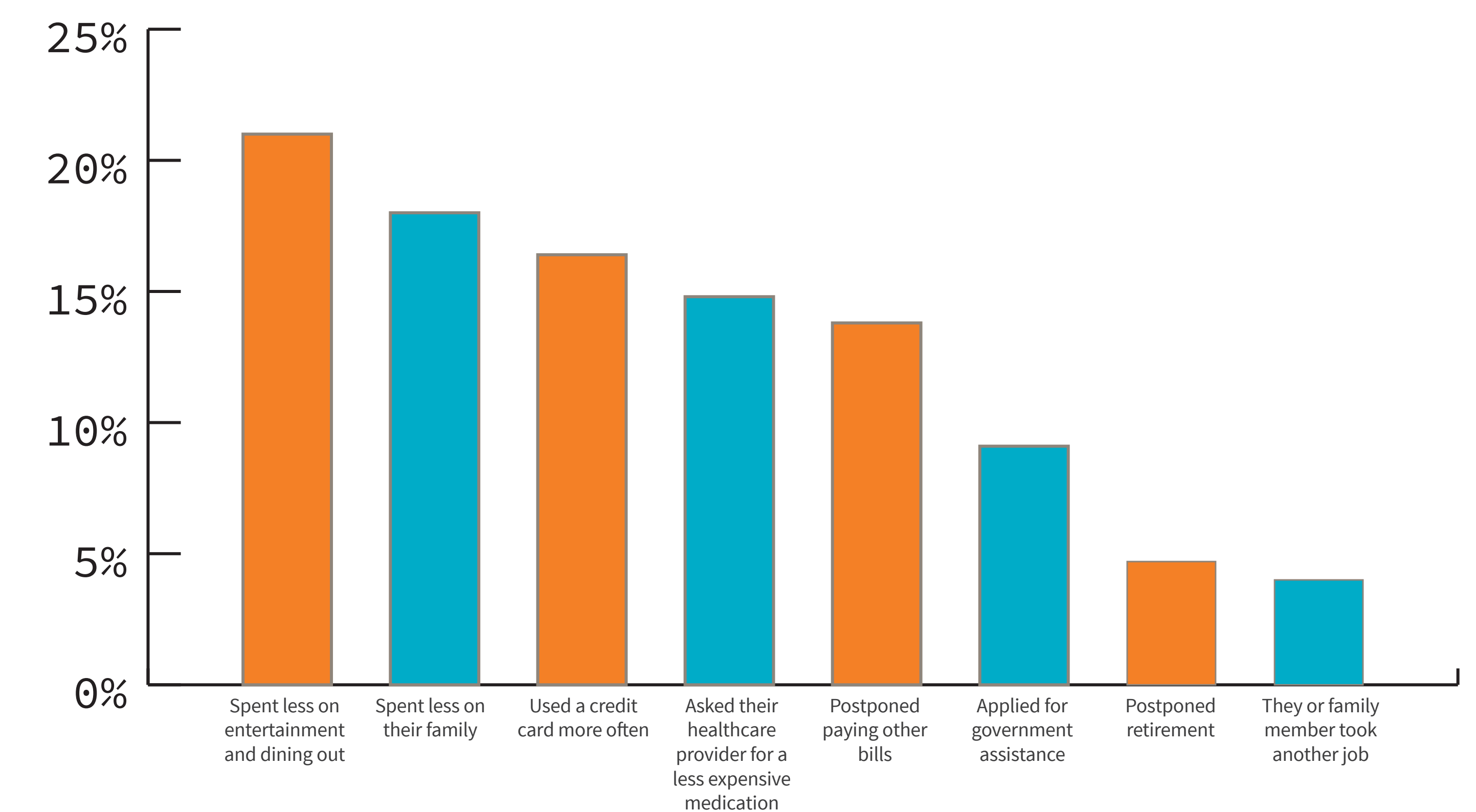
"I have had to choose what medications I have been prescribed for me as to what I can afford, not what is actually best for me."

Question	National MS Society Survey Responses — specific to MS medications, only people living with MS	Kaiser Survey Responses — prescription drugs generally
Society: Do you think the cost of prescription MS treatments is reasonable or unreasonable? Kaiser: In general, do you think the cost of prescription drugs is reasonable or unreasonable?	<ul style="list-style-type: none"> 79% – Unreasonable 9% – Reasonable 11% – Don't know 1% – No response 	<ul style="list-style-type: none"> 72% – Unreasonable 24% – Reasonable 4% – Don't know / no response
Society: How easy or difficult is it for you to afford your prescription medicine? Kaiser: In general, how easy or difficult is it for you to afford to pay the cost of your prescription medicine?	<ul style="list-style-type: none"> 17% – Very difficult 22% – Somewhat difficult 17% – Somewhat easy 11% – Very easy 24% – Don't have to pay 6% – No response 3% – Don't know 	<ul style="list-style-type: none"> 8% – Very difficult 16% – Somewhat difficult 27% – Somewhat easy 45% – Very easy 3% – Don't have to pay 1% – No response / don't know

- **30%** of respondents with MS reported no issues in affording their medication.
- **17%** of respondents with MS reported they had skipped doses or stopped treatment due to cost in the year prior to the survey.
- **40%** of respondents with MS reported receiving financial assistance from an MS medication Patient Assistance Program.
 - **53%** of those using a patient assistance program reported it is somewhat or very difficult to afford their medication.

"It took us over a month from the time my MS medication was prescribed to the time it was shipped to me. We had to personally coordinate between the physician's office, the insurance company, the specialty mail order pharmacy our plan requires us to use for this drug, another group our insurance uses to complete prior authorizations, the regular mail order pharmacy for our insurance, and the manufacturer's finance department."

FINANCIAL AND LIFESTYLE IMPACT OF THE COST OF MS DISEASE-MODIFYING THERAPIES



More than 5,000 people with MS responded to an open question about challenges they've had in getting the MS medications they need. People shared that even when they are affordably getting their medication through insurance or a patient assistance program, they are constantly concerned about the future. Comments also focused on the complexities and time-consuming logistics of the process to get medications.

More than 75% of respondents who commented mentioned cost of the medications.

"I am blessed to have a great job with AMAZING medical and drug coverage. It is terrifying to think about the day I will no longer be working there. I always think about my future."

CONCLUSIONS:

- People with MS are negatively impacted by the price of the MS disease modifying therapies.
- People with MS struggle through the complexities of the system to access their medication — including specialty pharmacies, prior authorizations/appeals and patient assistance programs.
- People are making choices that are detrimental to their health and family well-being.
- The challenges of accessing and maintaining access to medications are creating increased stress in the lives of people with MS.

¹Hartung, Bourdette, Ahmed, Whitman. The cost of multiple sclerosis drugs in the US and the pharmaceutical industry: Too big to fail? Neurology. 2015 April 24;84(21):2185-92.