What People With Multiple Sclerosis Are Saying About Day-to-Day Life With MS, Disability Progression, and What Matters to Them

QL06

Terrie Livingston, PharmD,[1] Monica Fay, PharmD, MBA,[2] Eric Peacock, MBA,[3] Heather Lapidus Glassner[4]

[1]Biogen, Weston, MA, USA; [2]Biogen, Cambridge, MA, USA; [3]MyHealthTeams, San Francisco, CA; [4]MyHealthTeams, San Francisco, CA

Conclusions

Understanding the range of symptoms, the occurance of relapses and the impact of MS on respondents' lives will better allow medical professionals to treat the individual holistically, and not just the disease itself. Additionally, helping patients understand MS progression will allow specialists to set realistic expectations for treating the disease and to help their patients better prepare for the future.

Background

Multiple sclerosis (MS) is a chronic and debilitating disease of the central nervous system that affects more than 570,000 persons in the United States and 2.3 million worldwide.[5] While MS has an increasingly debilitating impact on mobility over time, numerous concomitant symptoms also burden people with MS, from depression and cognitive issues to fatigue. The total impact of these symptoms and progression can lead to significant changes in lifestyle, including early retirement, social withdrawal, and lack of activity that can make living with MS even more profoundly debilitating. There is scant research on how people describe disability progression, how they deal with it and what trade-offs they make in seeking treatment.

Objectives

Leveraging one of the largest MS social networks, we set out to understand what symptoms people with MS experience, the impact of MS and treatment decisions made to minimize MS's impact. We conducted a quantitative patient study that specifically addressed:

1. Impact of MS on day-to-day life
2. Self-reported symptoms of MS
3. Description of disability progression
4. Trade-offs when deciding what DMTs to take
5. What health care providers should know to better manage MS

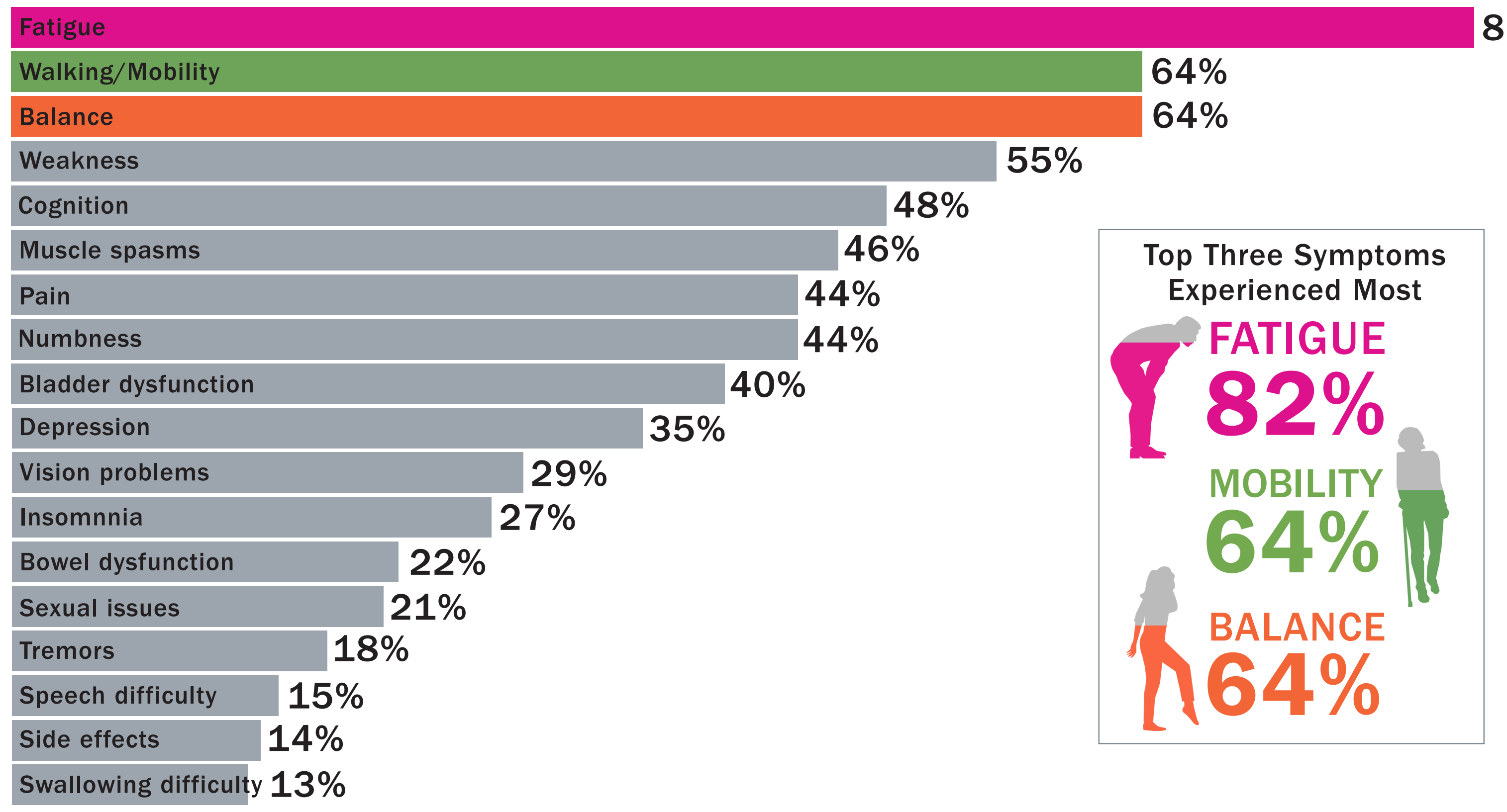
Methods

In November 2014, an email invitation was sent to the entire MyMSTeam community, a social network of ~ 25,000 people (currently > 75,000 people), diagnosed with MS. From Nov 2nd to Nov 29th, a total of 1,107 members responded to a 17 question survey.

Results

Research results highlighted the far-reaching impact MS has on quality of life. People with MS most often experienced symptoms of fatigue, lack of mobility/walking, and balance. Other symptoms commonly experienced were weakness, cognitive issues, and depression.

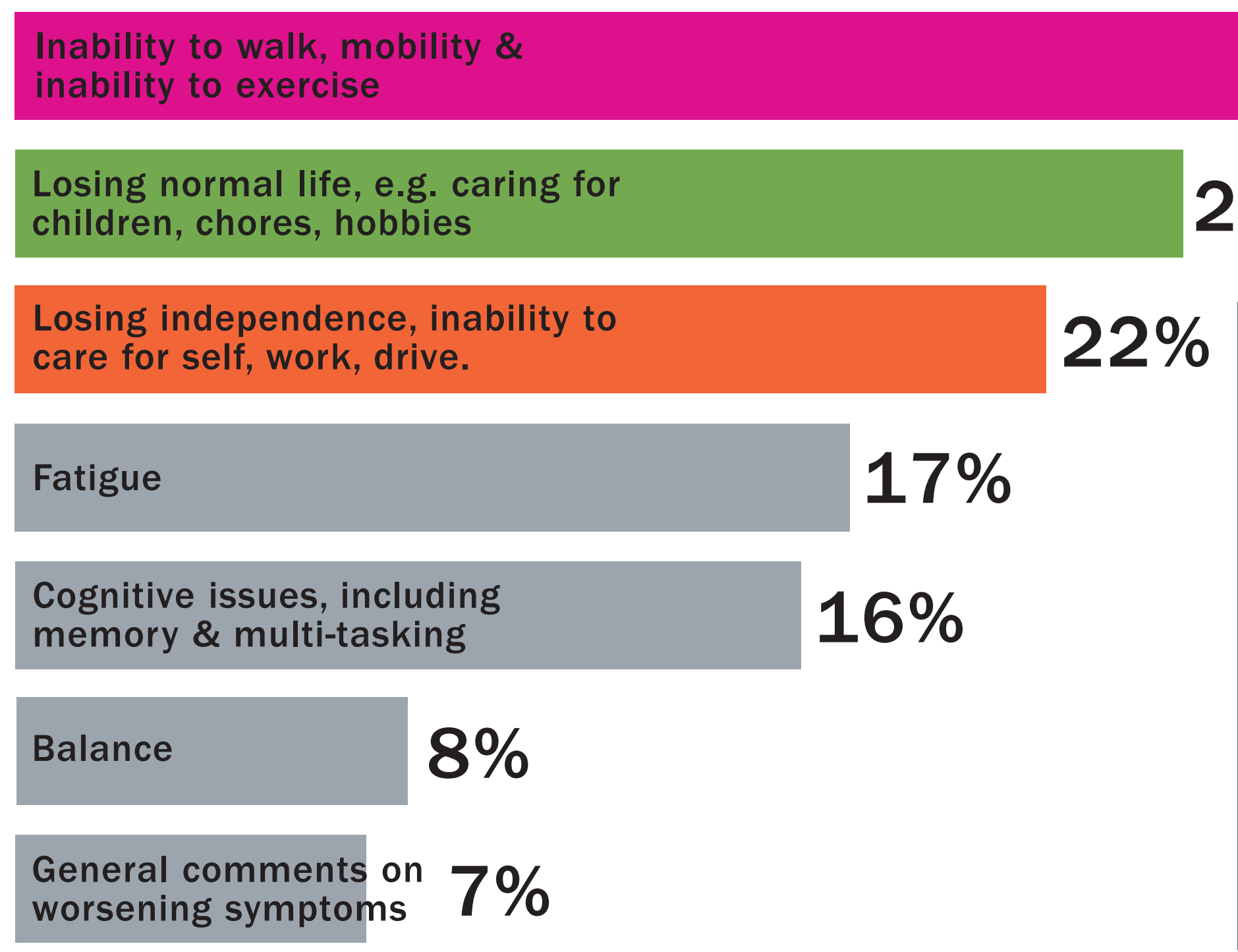
Symptoms Experienced Among All Respondents (n=1,075)



Q5 Which of your MS symptoms are most limiting to your day to day activities or have the biggest impact on your life? (Check all that apply)

People with MS defined "disability progression" as 1) increased limitations on their ability to get around, 2) sacrificing "normal" daily activities, and 3) losing their ability to be independent.

Respondents Defined Disability Progression as… Coded Open End Responses Among All Respondents* (n=965)



What Disability Progression Means

42%	Losing the ability to walk, move or exercise independently
25%	Losing normal life, e.g. ability to care for children, do chores or participate in hobbies
22%	Losing independence, their ability to care for themselves, to work or to drive

"My ability to be independent is very important to me. I have never had to rely on other people. Disability progression would mean that I would need assistance from another individual to carry on with daily activities."

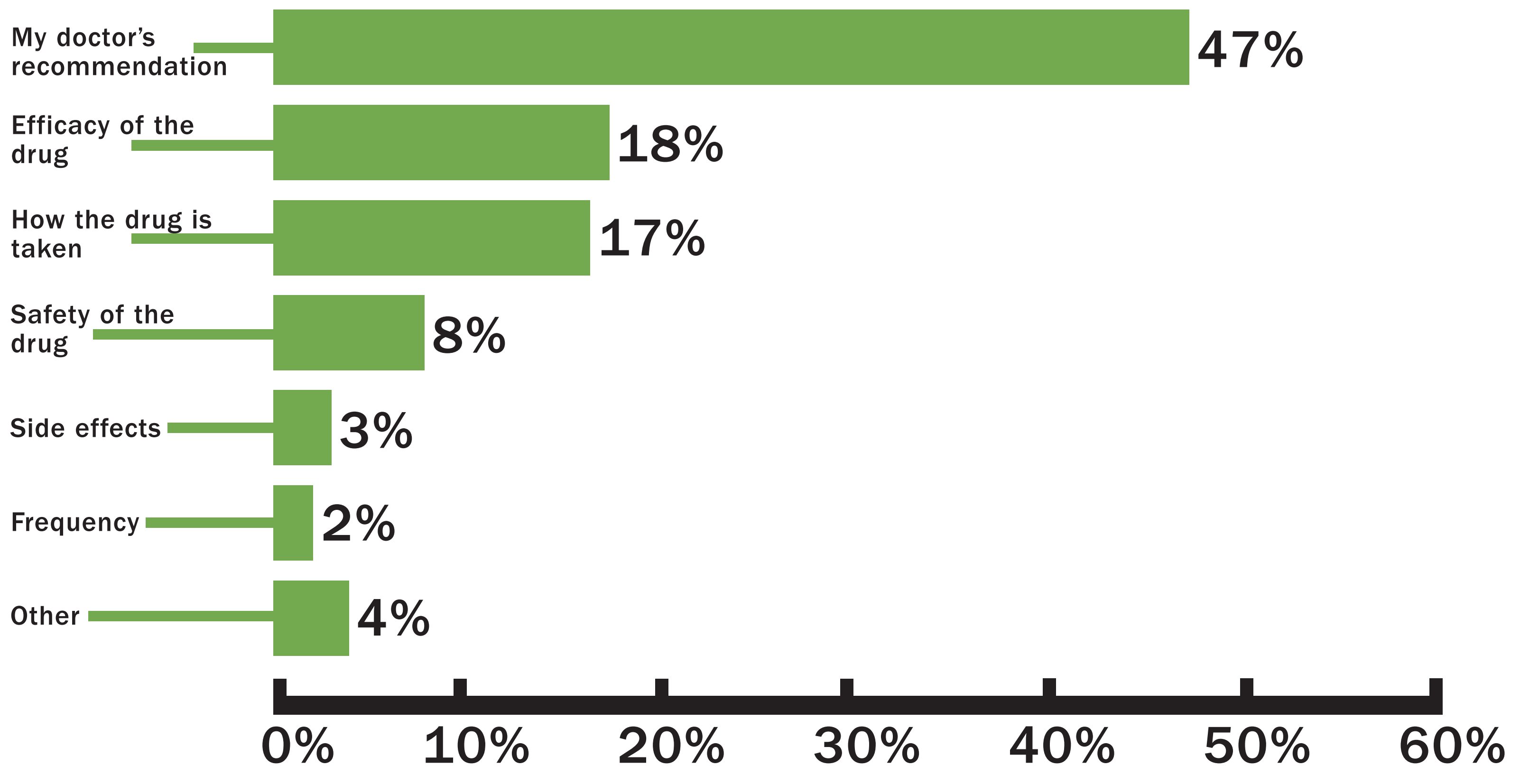
"Watching my body deteriorate inside and out and not being able to stop it. This disease has taken almost everything out of me. Almost everything. I still fight."

*Note multiple responses coded per respondent. Responses with 7% or more are shown.

Q12. Sometimes MS makes it more difficult to do certain activities in our day-to-day lives. This progression of MS has been called "disability progression" and it varies depending on the activities most important to you. From your perspective, what would you deem to be "disability progression" for you personally? What would it look like or mean for you? (Open end response)

Almost 1 in 2 respondents felt that a doctor's recommendation was paramount in order to make a decision on a DMT.

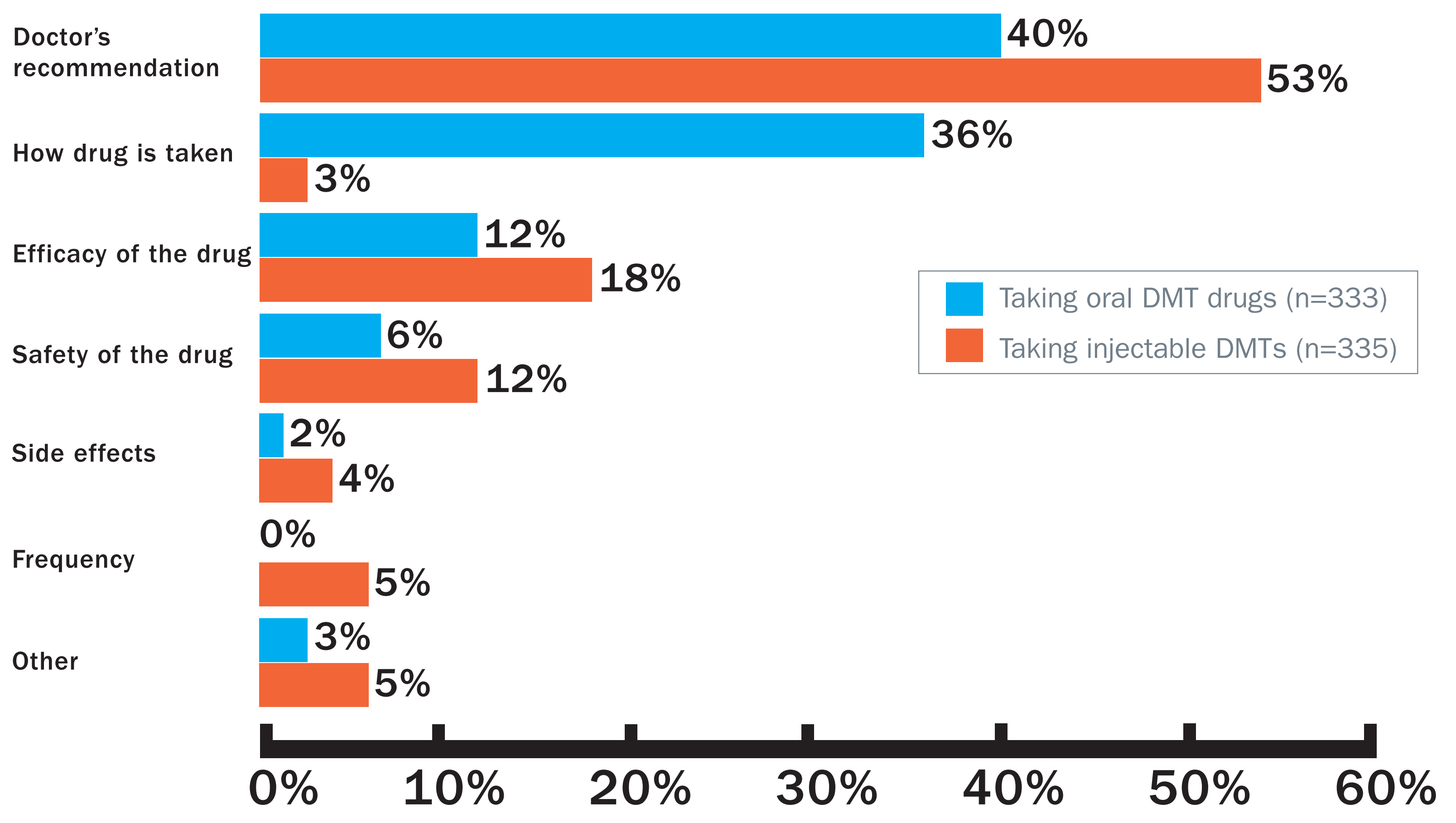
Most Important Factor When Selecting a Disease Modifying Therapy Among Those on a DMT at the Time of the Survey (n=819)



Q10 When you made the decision to go on your current medication, which of the following factors was most important to you in your decision?

For those who were taking oral DMTs, how the drug was taken mattered almost as much as a doctor's recommendation. Among those treating their MS with injections at the time of the survey, 53% said the doctor's recommendation mattered most.

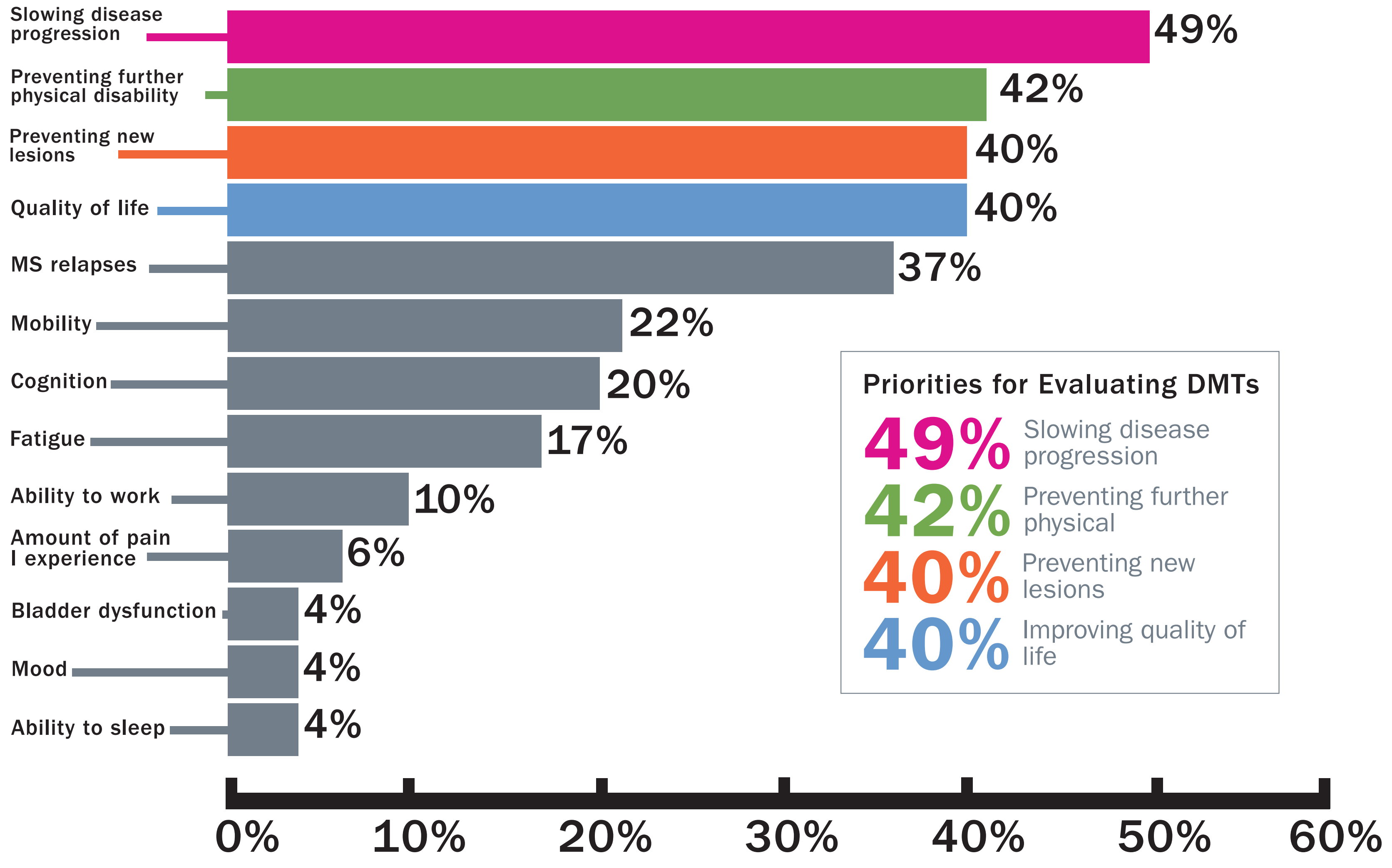
Most Important Factor in Decision to Select DMT Among Those Currently Taking Either Oral Drugs (n=333) or Injections (n=335)



Q10 When you made the decision to go on your current medication, which of the following factors was most important to you in your decision?

Respondents measured DMTs' efficacy by evaluating the treatments' ability to slow progression, prevent further physical disability, prevent new lesions, and improve quality of life.

Most Important Factor When Evaluating a Drug's Efficacy or Impact Among All Respondents* (n=1,042)



*Note multiple responses coded per respondent. Responses with 4% or more shown.

Q11 When you evaluate a drug's efficacy or impact, which of the following are most important to you? (check 3 boxes) The drug's impact on….

References [5]Livingston, T, Fay, M, Iyer, R, *et al. J Manag Care Spec Pharm.* 2016;22(12):1385-91. **Disclosures** TL and MF are employees of Biogen and hold stock/options in Biogen. Other authors have nothing to disclose. **Acknowledgments** This study was sponsored by Biogen (Cambridge, MA, USA).

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