Living With Secondary Progressive Multiple Sclerosis

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Conclusions

Understanding the quality-of-life impact of SPMS along with patient desired outcomes can help neurologists develop the most effective approach to treating patients for whom MS is advancing. This includes listening to patient issues with their most troubling symptoms, helping them weigh the concerns against benefits of Disease Modifying Treatments (DMTs) and other medications and educating their RRMS counterparts on the importance of treatments to slow progression rather than first waiting for MS to worsen.

Background

Multiple sclerosis (MS) is a progressive disease that can have a devastating impact on quality of life. As MS progresses to secondary, the toll on quality of life and physical abilities becomes more acute.

Objectives

Research was undertaken to ascertain unique differences between those with secondary progressive (SPMS) versus relapsing remitting (RRMS) MS, including day to day life, medication regimen and treatment goals.

Method

In January 2024, an email invitation to an online survey was sent to US members of MyMSTeam. MyMSTeam is a patient community with over 219,000 patients living with a form of MS. Patients come together in this password protected community to get access to medically reviewed information on symptoms, treatments, etc. as well as to get support from others going through similar challenges.

Results

In total, 243 members with SPMS and 653 with RRMS completed the 32-question survey. Respondents were largely female (75% SPMS, 82% RRMS). Ethnicity/race profiles were White (90%, 80%), Black (4%, 12%), Latino (3%, 5%). SPMS patients were more likely to be living with MS for 16 or more years (73%, 45%).

Few described their overall MS health as excellent/very good (14%, 22%). (Figure 1) The devastating toll of MS was particularly pervasive for patients living with SPMS. They were

more likely to struggle with everyday activities (92%, 80%) and find it hard to get around physically (91%, 70%). The majority were also more likely to feel MS has impacted overall quality of life (89%, 79%). (Figure 2)

Two-thirds struggled with anxiety (69%, 67%) or depression (61%, 62%) regardless of diagnosis. (Figure 3)

Given the more pervasive mobility challenges of SPMS patients, they were more likely to select improved mobility as one of their top three desirable outcomes for a DMT (61%, 35%) and were less likely to select decreasing relapses (12%, 35%). (Figure 4)

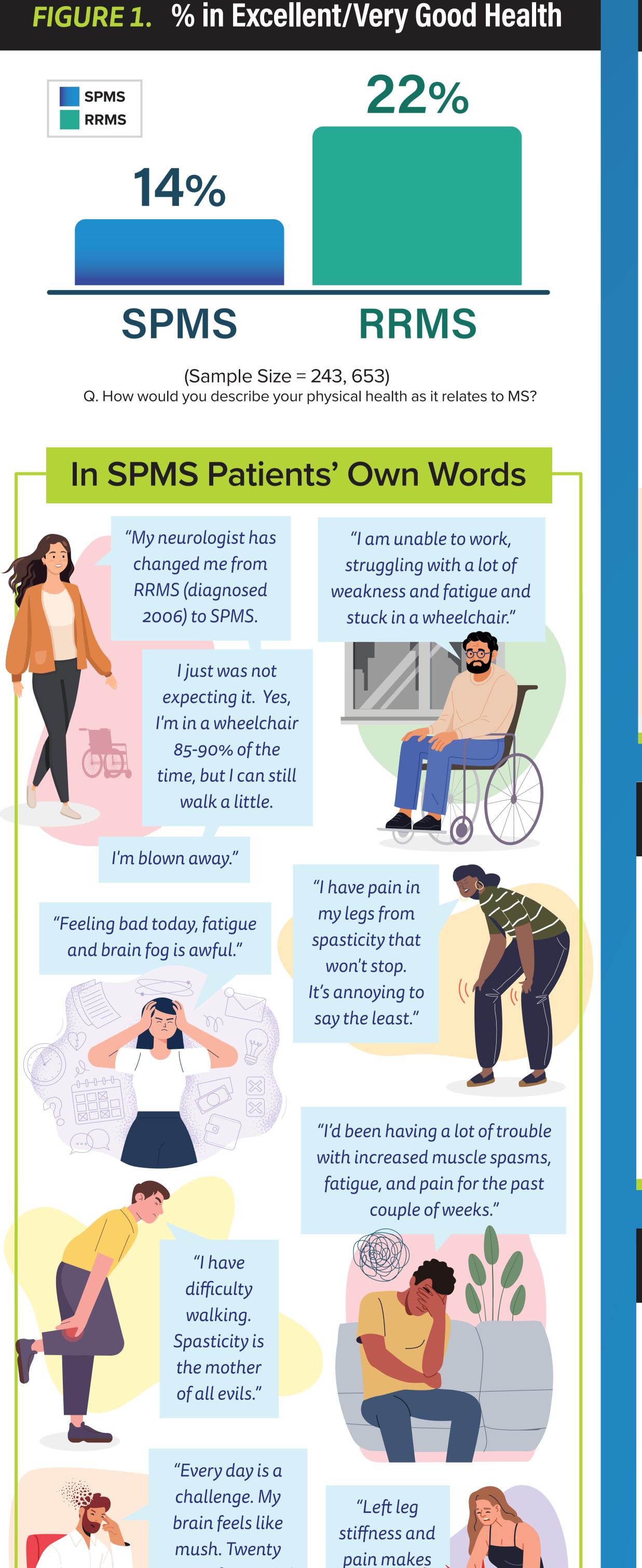
Current DMT usage is lower for SPMS patients (51%, 68%). (Figure 5)

For SPMS patients who are currently on a DMT, there is less satisfaction (58%, 77%), or perceived effectiveness (55%, 77%) than among RRMS patients. (Figure 6)

Further, fewer with SPMS report experiencing benefits such as preventing new lesions (52%, 63%) or symptoms from arising (35%, 47%). (Figure 7)

The large majority rely on other medications to address symptoms of MS. This is especially true for SPMS patients (95%, 81%). This includes medications to address spasticity (59%, 40%), bladder dysfunction (42%, 21%), and mobility issues (30%, 13%). (Figure 8)

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years of pain and

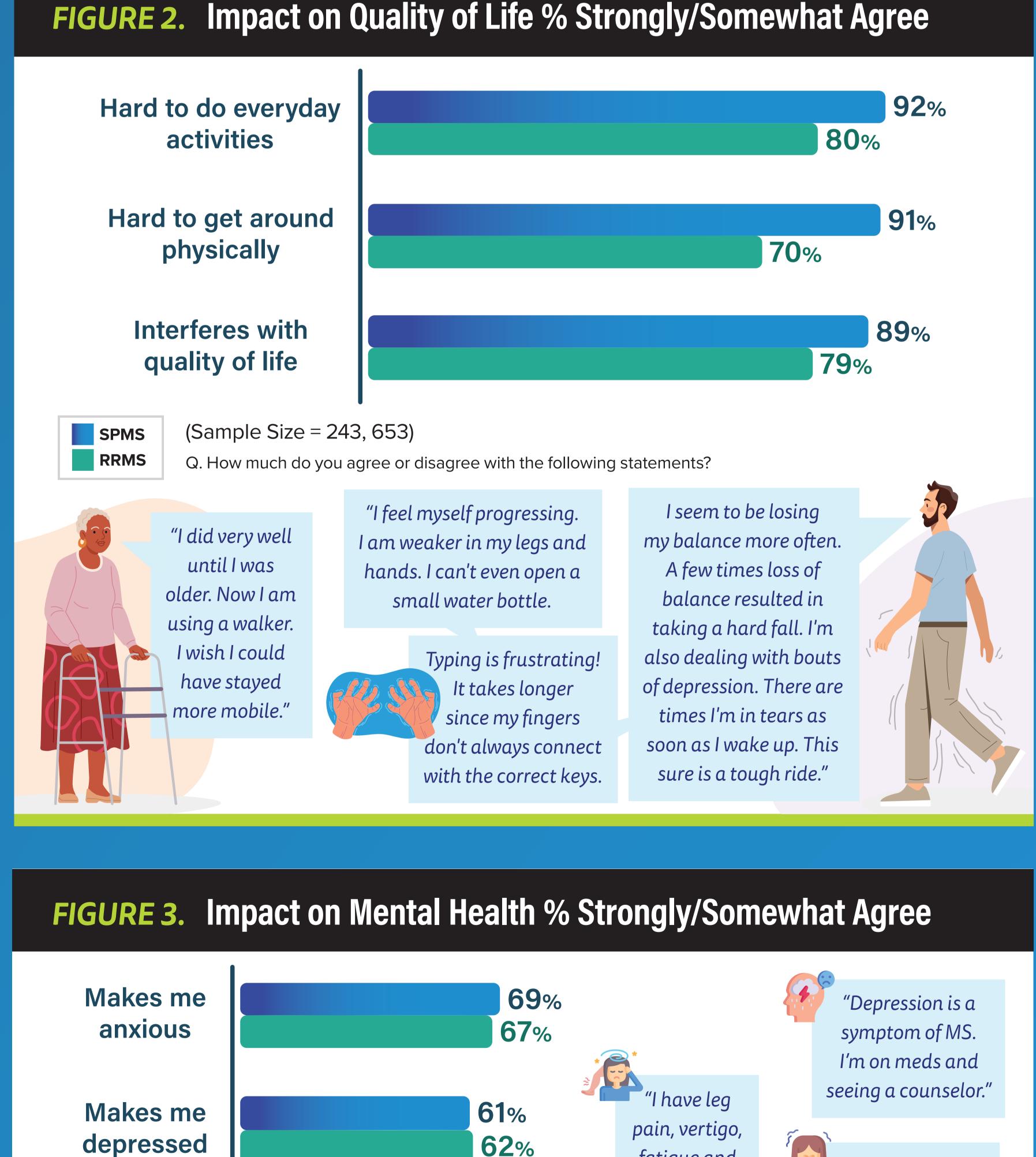
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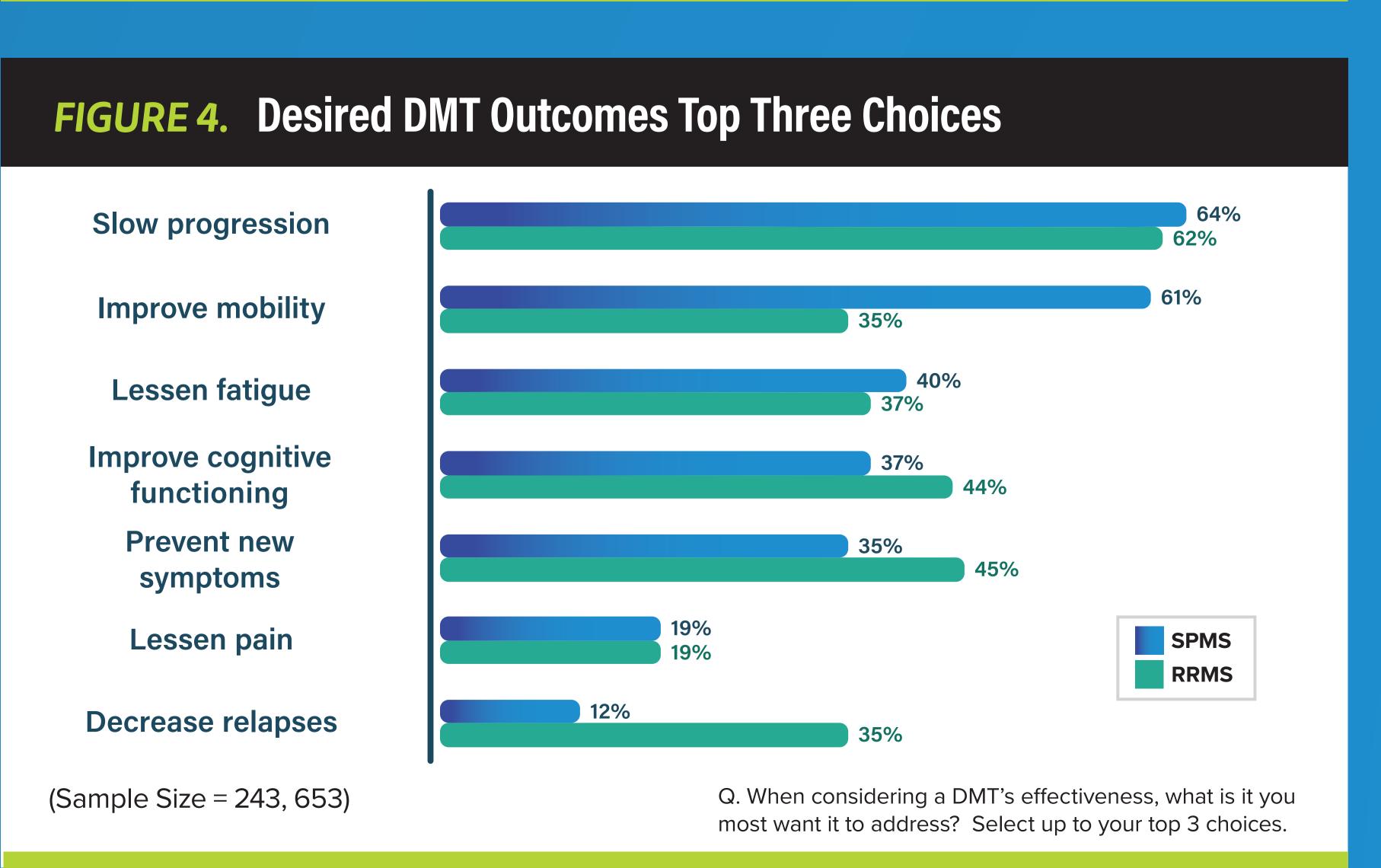
me feel more like

95 then 52."

walking

difficult."





(Sample Size = 243, 653)

with the following statements?

Q. How much do you agree or disagree

fatigue and

anxiety."

'"I've been dealing

with depression

and fear of my

future with MS."

