

# MSAA SURVEY: PSEUDOBULBAR AFFECT IN MULTIPLE SCLEROSIS

SUMMARY REPORT

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# Project Background

- Avanir and the Multiple Sclerosis Association of America are interested in learning more about the behaviors, experiences and attitudes of people with MS and its relation to exhibiting symptoms of PBA.
- They are also interested in gauging the proportion of multiple sclerosis (MS) patients that exhibit symptoms of PBA as well as the awareness of PBA amongst MS patients.

# Method

- To achieve these objectives Avanir has partnered with the Multiple Sclerosis Association of America (MSAA) to administer a survey to MSAA members. To qualify for the survey, the respondent had to:
  - Be a MS patient or the care partner or family member/friend of a person with MS
- To complete the survey, the respondent had to:
  - Score a 13 or greater on the Center for Neurologic Study Lability Scale (CNS-LS)
- A total of 5,294 individuals responded to the survey:
  - 65 were terminated from the survey due to not qualifying as a MS patient nor the care partner/family member/friend of a MS patient
  - 5,229 qualified to take the survey as a MS patient or the care partner/family member/friend of a MS patient
- 2,504 respondents had a CNS-LS score of 13 or greater and completed the survey:
  - 2,389 MS patients
  - 115 care partners or family member/friend of a MS patient

# Areas Of Questioning

- After establishing whether the participant was a person with MS or the care partner/family member/friend of a person with MS, respondents were asked about:
  - **Demographics**
    - Age
    - Gender
  - **MS Patient Profile**
    - Type of MS
    - When diagnosed
- **Respondents were then administered the CNS Lability Scale questions to establish the presence and severity of PBA symptoms.**

## Areas Of Questioning (continued)

- **Respondents were asked questions about to their episodes of involuntary crying or laughing related to:**
  - Frequency
  - Burdensomeness (overall and compared to other MS symptoms)
  - Activity limitations
  - Interference with daily activities
  - Life situation contributions
  - Importance and satisfaction of treatment
- **Respondents were then asked about their awareness of PBA.**
- **The survey closed with asking where the respondent has looked for information on PBA and the ability to leave their contact information if they wanted to share their story or learn more about PBA.**

# Executive Summary

## Respondent Profile

- The majority of the respondents were:
  - The MS patient
  - Female
  - 35-54 years old, average age 47
  - Diagnosed more than 2 years ago
  - Suffer from Relapsing – Remitting MS
  - Score of 16 or more on CNS-LS Scale

## Presence Of PBA Symptoms

- Of the total respondents (n=5,229) approximately 48% exhibit symptoms of PBA.
  - Of the total respondents with PBA (n=2,504) approximately one in five (19%) exhibit symptoms of PBA frequently or often.
- About one in seven MS patients consider these episodes of involuntary crying/laughing to be extremely or very burdensome. Another third say these symptoms are somewhat burdensome.

## Executive Summary (continued)

- About a third indicate that the PBA episodes interfere with spending time with friends and family. About one in four say it interferes with talking on the telephone, social situations or interacting with healthcare professionals.
- One in four of the respondents also indicate that these episodes have contributed to difficulty making/keeping friends. One in five say it contributed to becoming housebound.
- Of those who are treated for their PBA episodes (25%) only ten percent are satisfied with their treatment.

### **PBA Awareness**

- About 10% of MS patients are familiar with the term pseudobulbar affect or PBA.
- Other emotional expressions reported, at least often, include frustration, agitation and irritability.

### **Sources Of information on PBA**

- Among those respondents who have looked for information regarding involuntary crying or laughing, most have turned to health websites and advocacy groups or have asked their doctor.



# Detailed Findings

# Respondent Profile

# Summary Of Key Findings\*

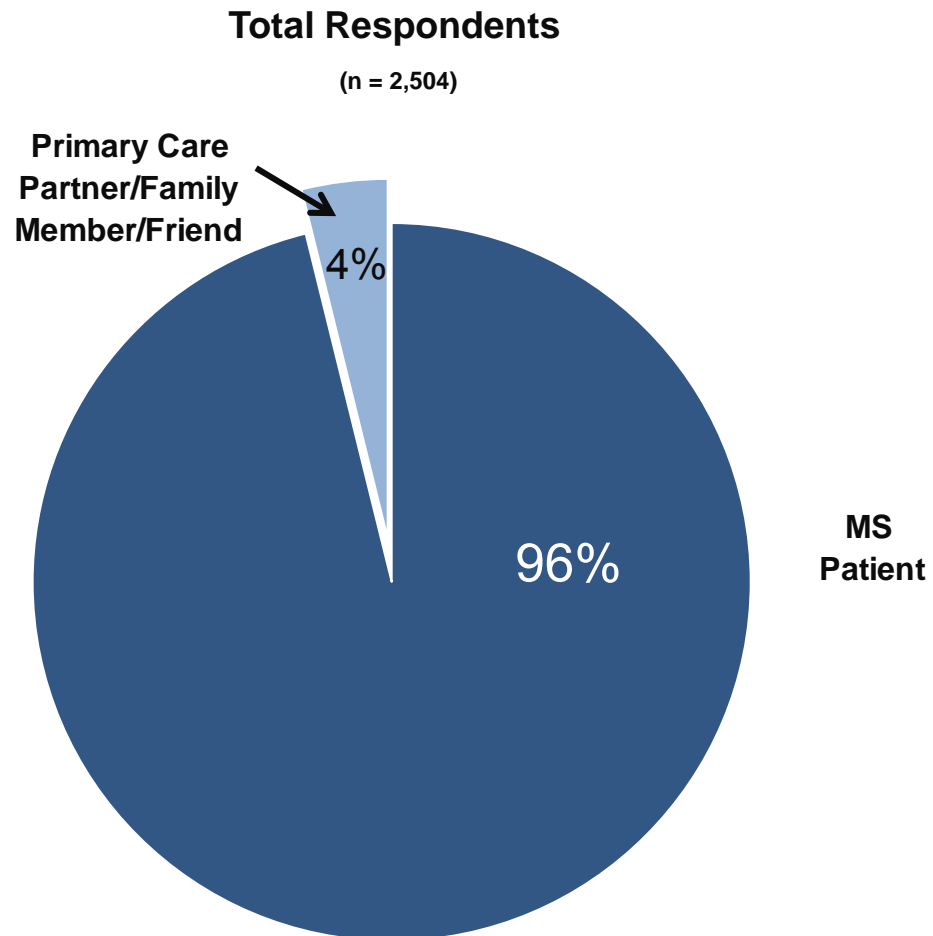
	<u>Total Completers</u> n=2,504 %
<b>Respondent</b>	
Patient	96
Primary Care Partner/Family Member/Friend	4
<b>Gender</b>	
Male	16
Female	84
<b>Age</b>	
Under 35	13
35 - 54	60
55 +	27
<b>When Diagnosed</b>	
Less than 2 years ago	22
3 - 5 years ago	23
6 - 10 years ago	23
More than 10 years ago	32

	<u>Total Completers</u> n=2,504 %
<b>Type of MS</b>	
Relapsing-Remitting	69
Secondary-Progressive	11
Primary-Progressive	7
Progressive-Relapsing	5
Benign	1
Don't Know	7
<b>CNS-LS Score</b>	
13 - 15	38
16 - 20	41
21 - 35	21
<b>Involuntary Laughing/Crying - Top 2 Box</b>	
Frequency of Episodes	19
Overall Burdensomeness	14
Burdensomeness Compared to Other MS Symptoms	3
Treatment Importance	15
Treatment Satisfaction	11
<b>Aware of PBA</b>	11

\*5,229 respondents qualified for the survey; 2,504 respondents completed the survey (CNS-LS score was  $\geq 13$ )

# Respondents

- Almost all of the respondents were MS patients themselves.



[S1] Which of the following best describes you?

# Age and Gender

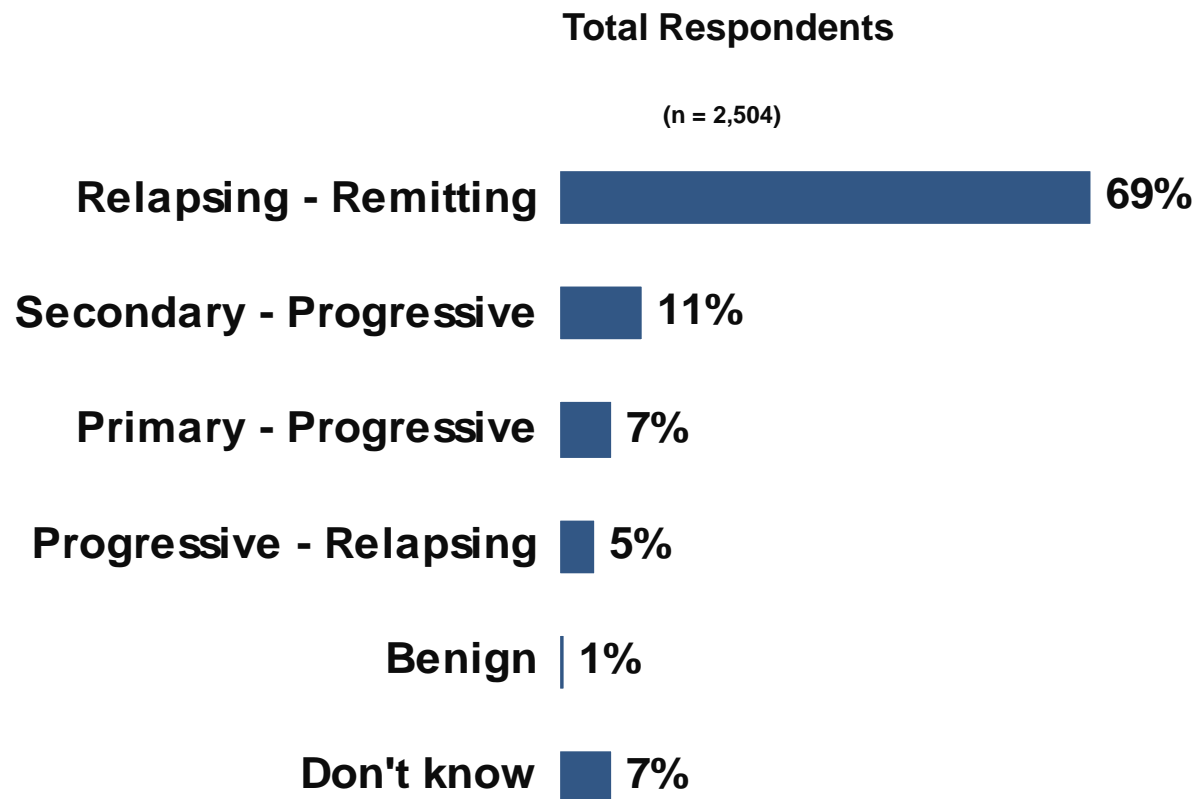
- Respondents were mostly female and between the ages of 35 and 54 years old.

	<u>Total</u> n=2,504 %
<b>Age</b>	
Under 35	13
35 - 54	60
55 +	27
Mean	47
<b>Gender</b>	
Male	16
Female	84

[S1.5] What is your [the patient's] age?  
[S2] What is your [the patient's] gender?

# Type of MS

- The majority of respondents suffer from Relapsing – Remitting MS.

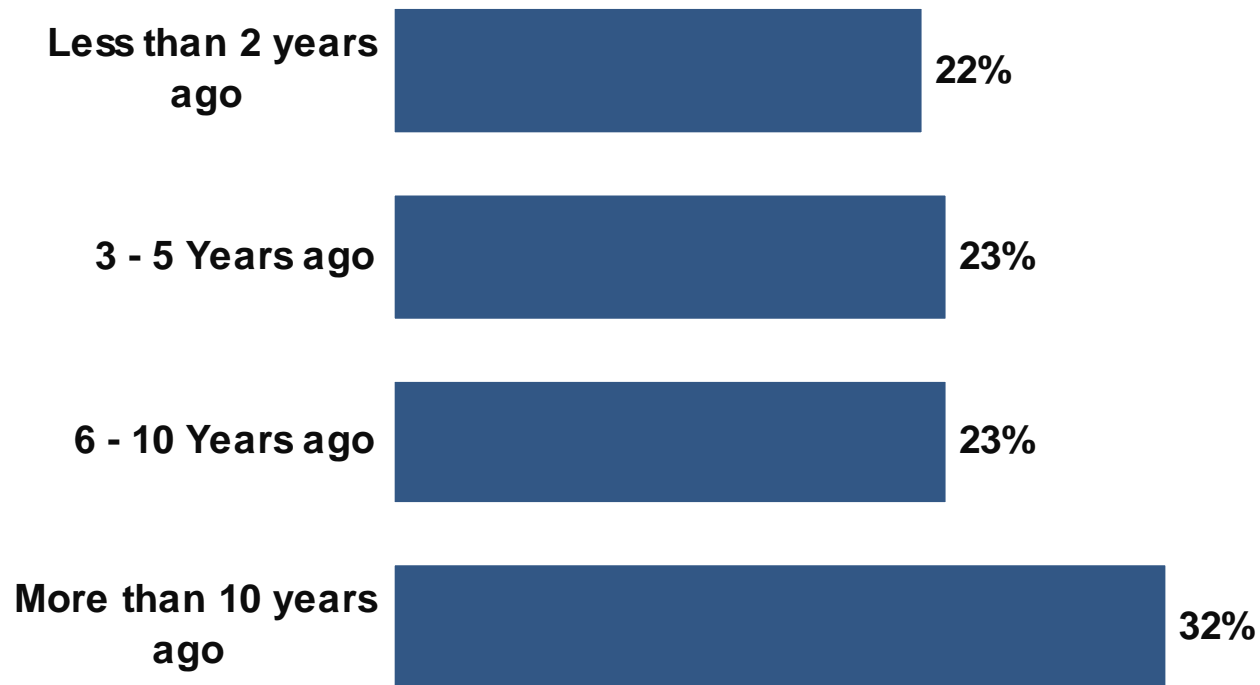


[S3] Which of these categories best describes the type of MS you have [the patient has]?

# When MS Was First Diagnosed

- For most respondents, their MS was first diagnosed more than two years ago.

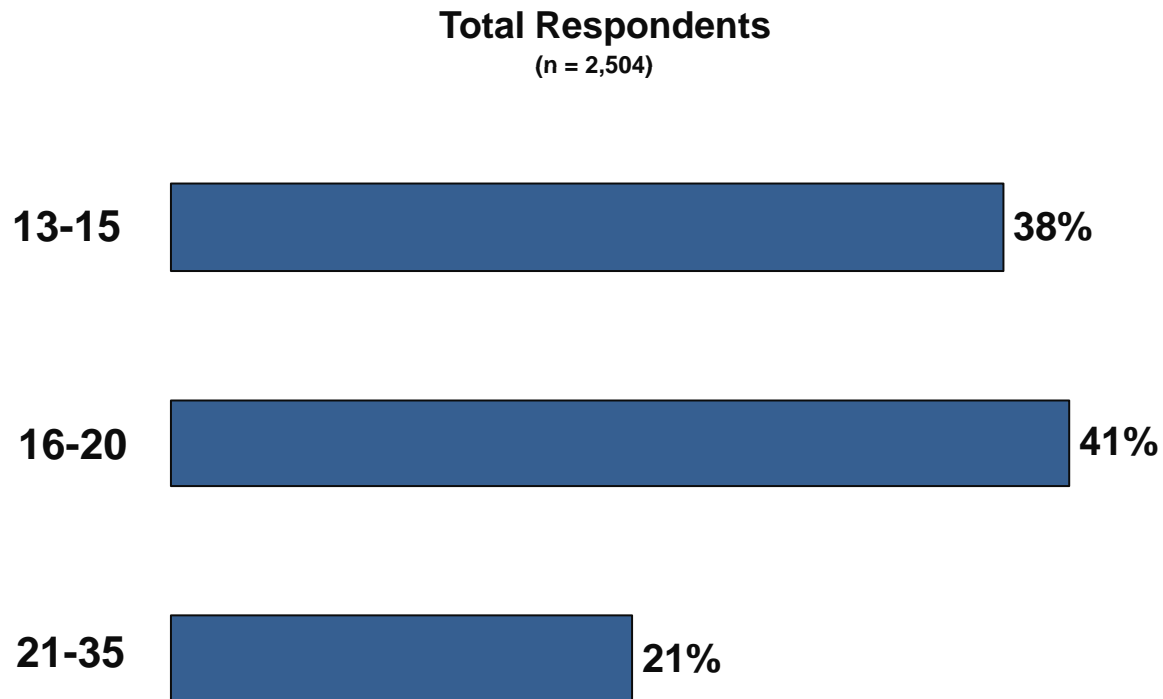
**Total Respondents**  
(n = 2,504)



[S4] Approximately how long ago were you [was the patient] first diagnosed with MS?

# CNS-LS Score

- About six in ten respondents scored 16 or higher on the CNS-LS Scale.



[S5] Below you will find statements that sometimes apply to patients with MS. Please rate each of the following statements by how often that statement applies to you [the patient] using the scale below.

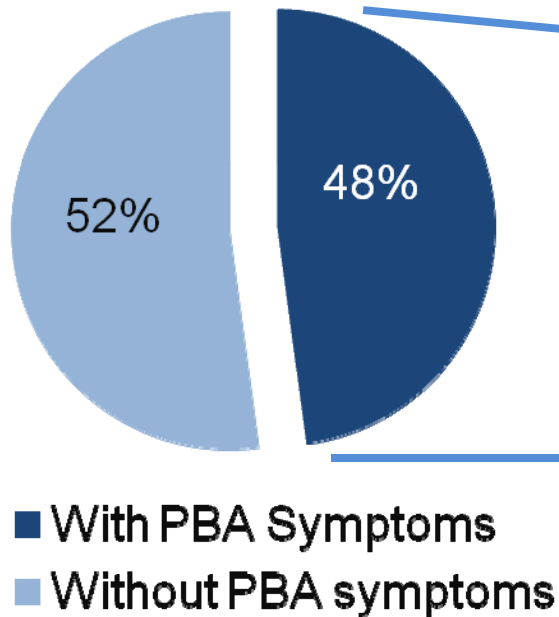


# Involuntary Crying/Laughing Experiences

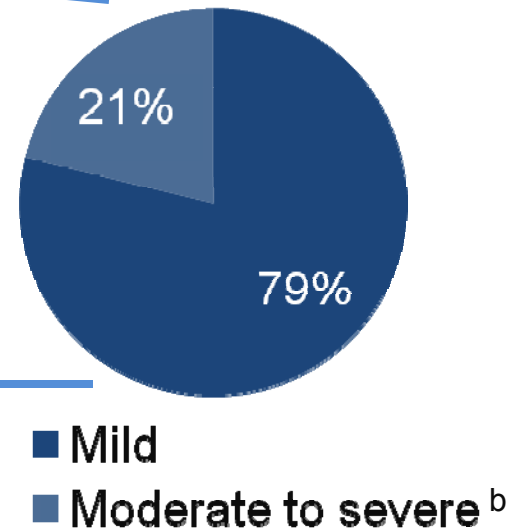
# Prevalence of PBA Symptoms in MSAA Membership

- 48% of respondents exhibited symptoms of PBA<sup>a</sup>

## Total Respondents



## Severity of PBA Symptoms



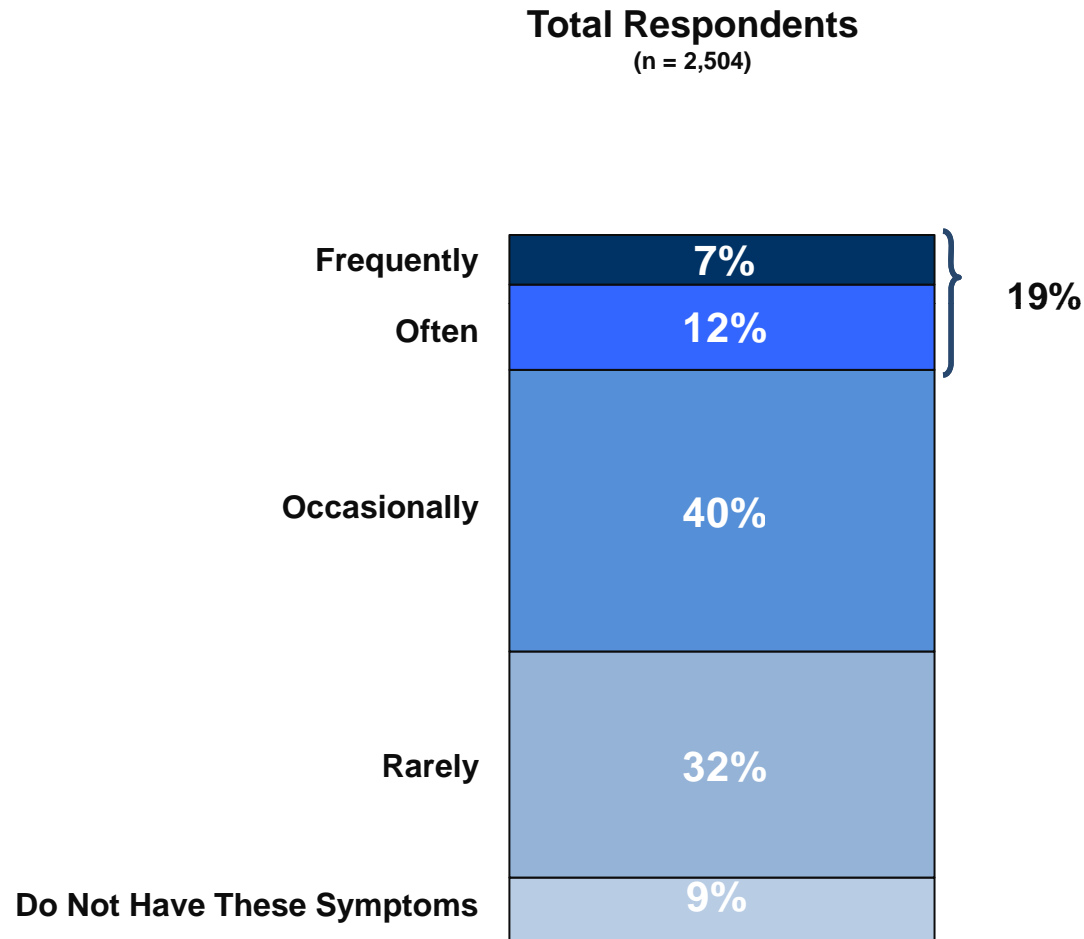
[PBA1] Please rate each of the following statements using the scale below. Please enter the associated numeric value next to each question.

<sup>a</sup> Score of 13 or greater on CNS-Lability Scale

<sup>b</sup> Score of 21 or greater on CNS-Lability Scale

# Frequency Experience Episodes Of Involuntary Crying/Laughing

- About one in five MS patients indicate that they experience PBA episodes frequently or often.



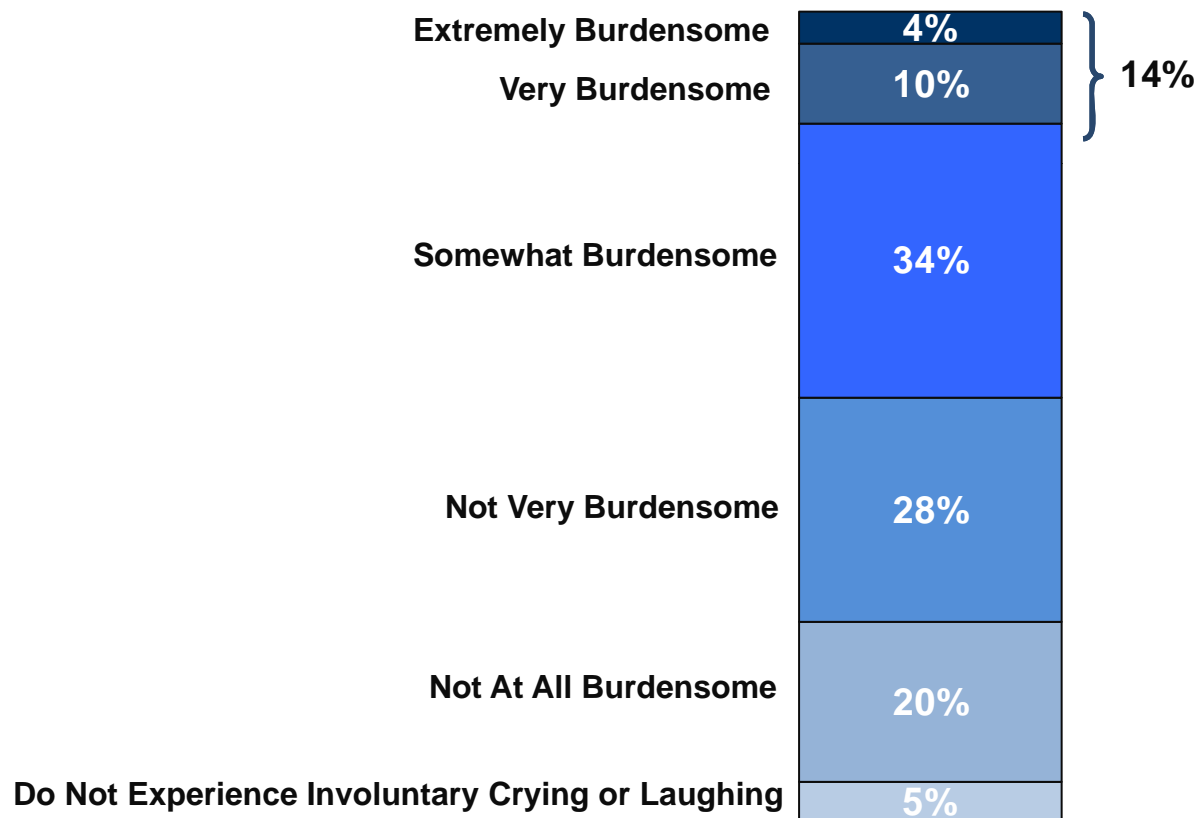
[Q5] How frequently do you [does the patient] experience these episodes of involuntary crying and/or laughing?

# Burdensomeness

- Approximately one in seven respondents find their PBA episodes to be extremely or very burdensome. A third find it to be somewhat burdensome.

## Total Respondents

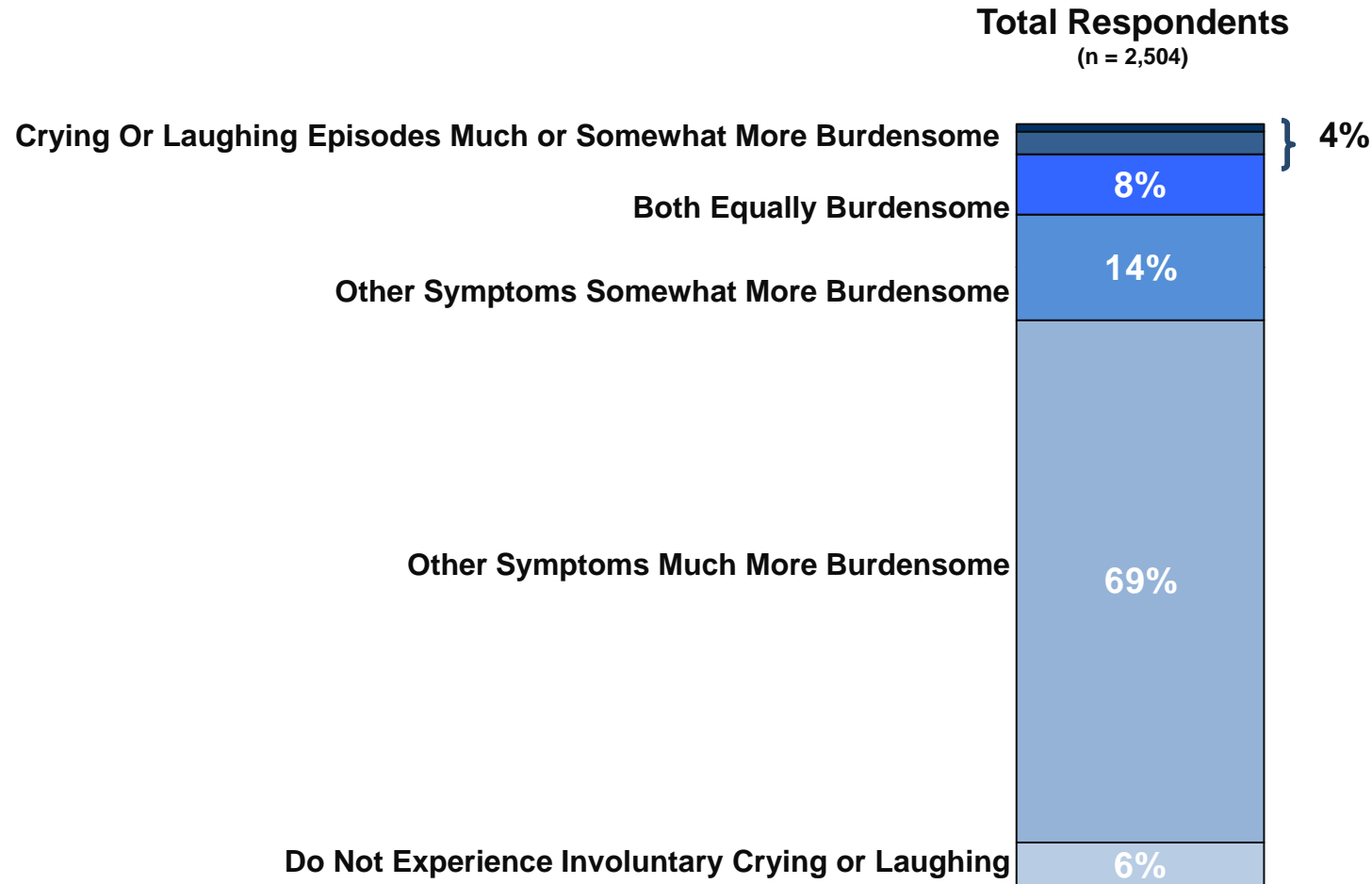
(n = 2,504)



[Q1] You had mentioned that sometimes you experience [the patient experiences] symptoms of involuntary crying or laughing. How burdensome are these involuntary crying or laughing episodes to you [the patient]?

# Burdensomeness Compared To Other MS Symptoms

- Very few respondents find their PBA episodes to be more burdensome than their other symptoms of MS.

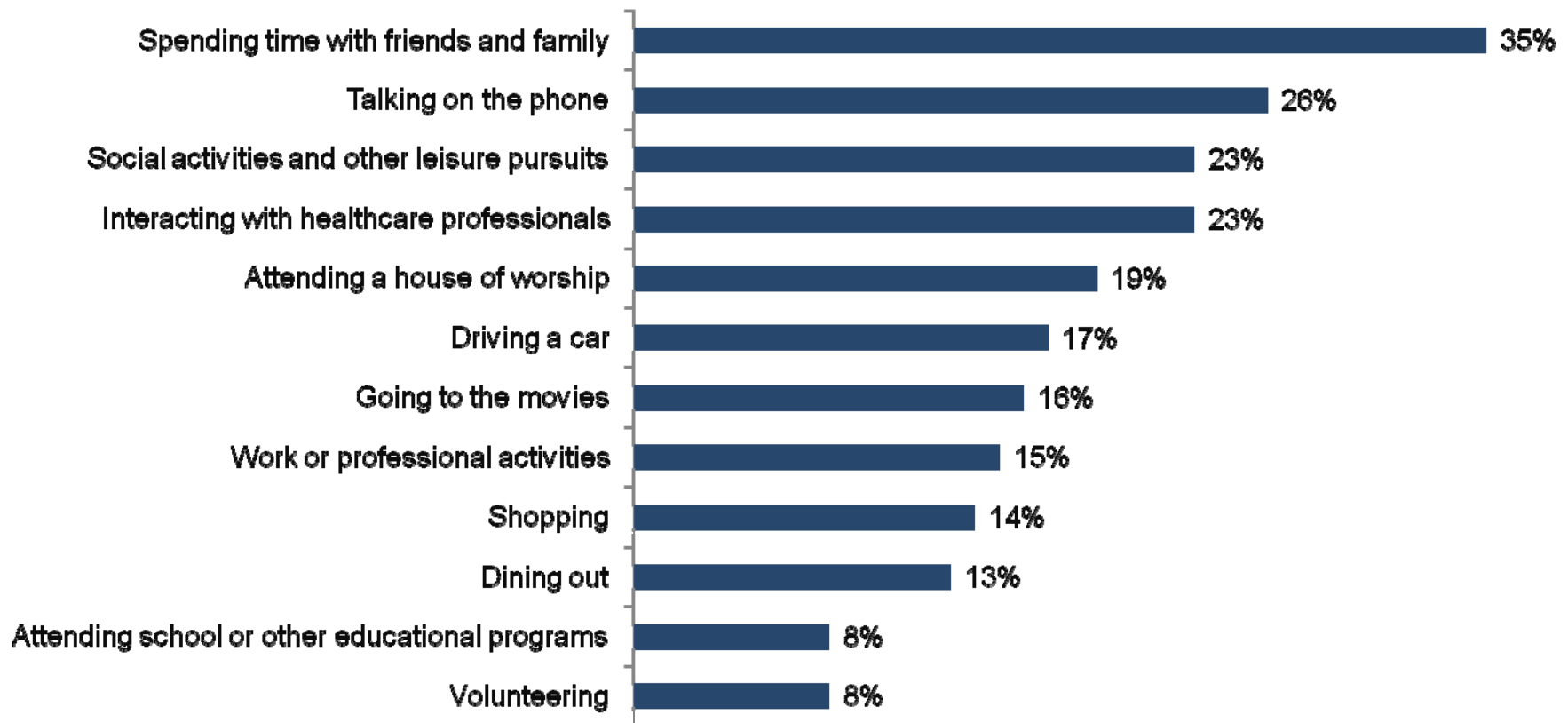


[Q1.5] How burdensome are your [the patients] involuntary crying or laughing episodes compared with the other symptoms of your [the patients] underlying MS?

# Level of Interference with Daily Activities

- PBA interferes most with spending time with friends and family, talking on the phone, social activities and interacting with healthcare professionals.

## Interferes Extremely/Very/Somewhat Often\*



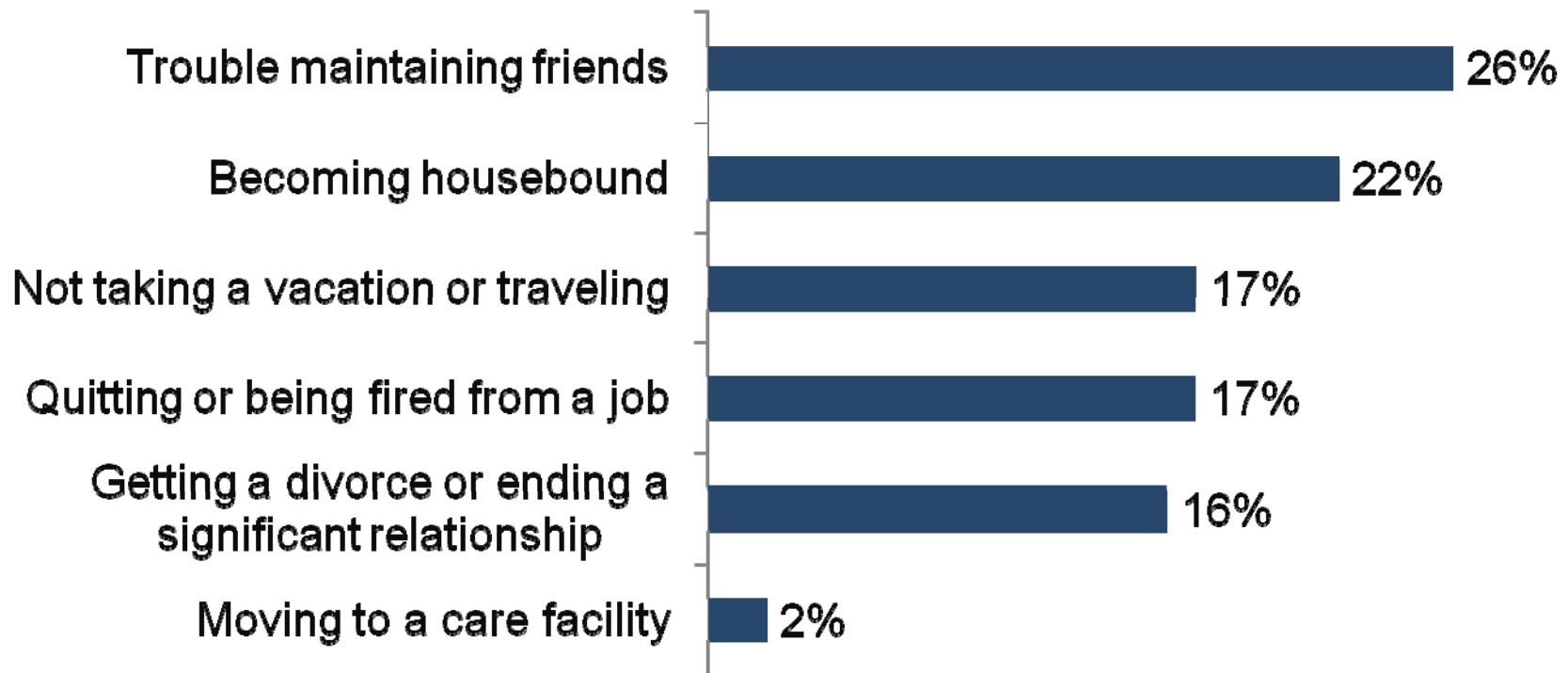
\*Percent of respondents that PBA interferes extremely/very/somewhat often with daily activities (n=2,504)

[Q2] Using the scale below, please indicate how often you would say the episodes of involuntary crying and/or laughing interfere with your [the patient's] participation in each of the following activities. If you do [the patient does] not participate in an activity, please select "Does Not Apply To Me [The Patient]."

# Contributions to Life Situations

- About one in four respondents indicate that their PBA episodes have contributed to difficulty keeping friends and about one in five indicated that it contributed to becoming housebound.

## Contributed Somewhat or More\*



\*Percent of respondents that PBA contributed somewhat or more to life situations (n=2,504)

[Q4] To what extent have your [the patients] involuntary episodes of laughing and/or crying ever contributed to the following life situations?

# Limitations Due to PBA

What can't you do because of your involuntary crying or laughing episodes?

- Public speaking or anything that I might be the center of attention.
- I just only go out when I have to go to the doctor or to the grocery store.
- Sometimes it is hard to have a conversation with someone when you can not control your crying. Sometimes it makes me mad and that makes the crying worse.
- I cannot attend funerals without crying uncontrollably, excessively, loud sobbing that interrupts and can be heard by everyone, parades, anything sentimental tears me up and makes me cry, but not uncontrollably. TV shows or movies, especially reality shows like Biggest Loser or where there are real people sharing their emotions.
- I have restricted my number of friends and the amount of interaction I have with family and others. I am more comfortable being by myself.
- The stress especially work and feeling I can't complete a task makes me cry and makes me tired. I get very anxious about attending my children's school/sport functions because I never know when I may start crying for no reason.
- It interferes with my ability to be assertive or stick up for myself.
- Avoid talking about topics that cause an emotional response, especially when in a professional context. I also look away when someone is suffering for fear I will laugh spontaneously.
- Driving by myself I cry a lot.

[Q3] Are there additional things that you [the patient] cannot do or choose not to do because of your [their] involuntary crying or laughing episodes?



# Limitations Due to PBA

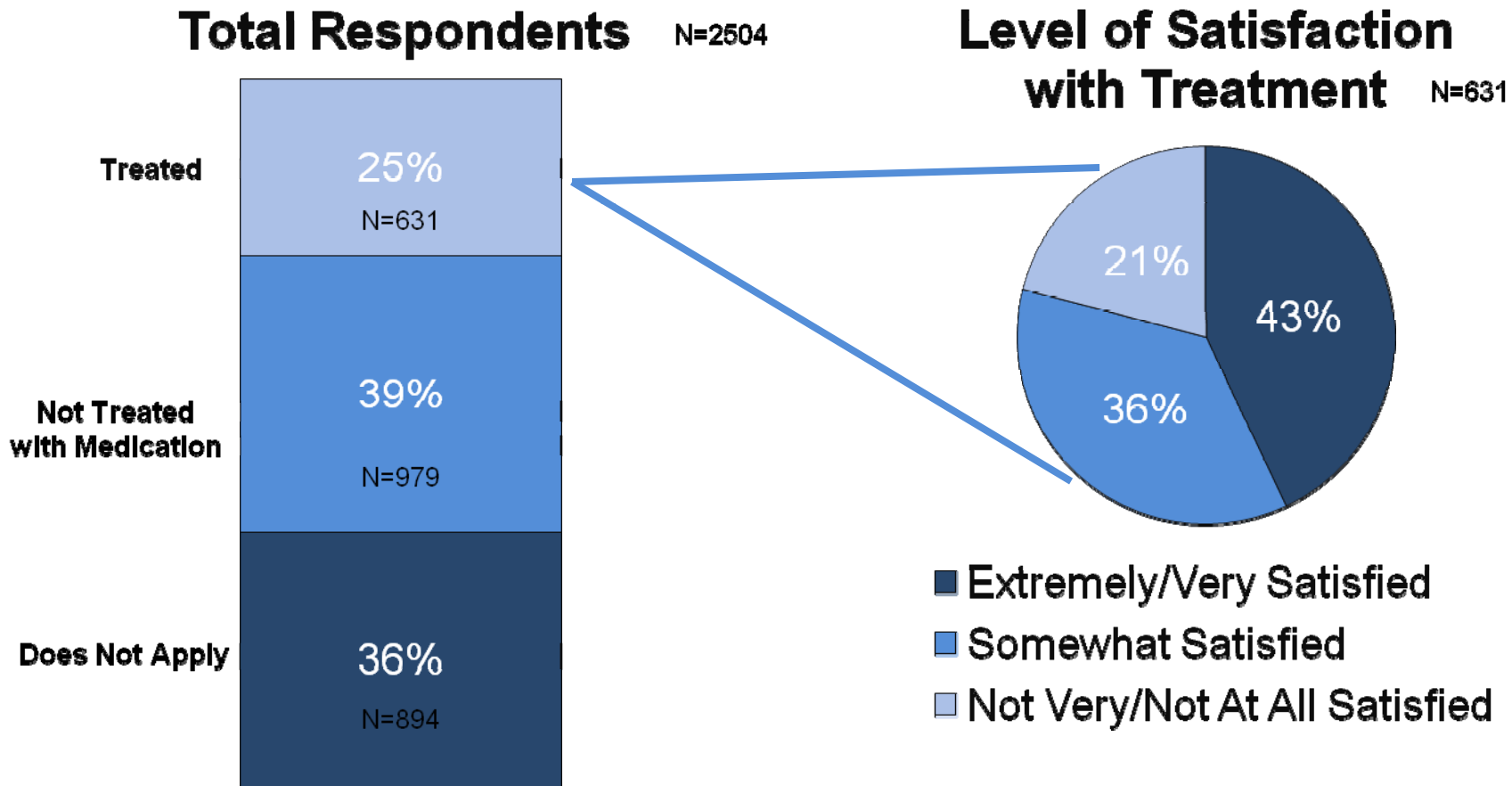
## What can't you do because of your involuntary crying or laughing episodes?

- I do not currently work, however, it would most definitely cause problems if I did. My family and friends do not seem to understand that I do not have control over these involuntary responses.
- I own a business and it is very hard to maintain a professional environment when I am crying over things that are inappropriate to cry about or laughing at things that are not funny to anyone else.
- Dating because others do not understand.
- Reading stories for my church. Volunteer for other activities.
- Have a normal relationship with my companion.
- I keep to myself and family, shopping as needed and work when I can get it. All other activities have been suspended.
- I am having a very hard time at work because of my inability to control my emotions.
- I exercise at home not in public because of this. Have a hard time finding a job.
- I don't like to interact with my 4 children when I can't stop crying. I don't want them to see me like that.
- I don't go long distances or take trips because it hits me with no warning. It hits me several times a day, so I avoid any commitments that involve more than an hour or two away from the house.
- I choose not to leave my home and go out in public because of involuntary crying episodes.

[Q3] Are there additional things that you [the patient] cannot do or choose not to do because of your [their] involuntary crying or laughing episodes?

# Satisfaction With Treatment

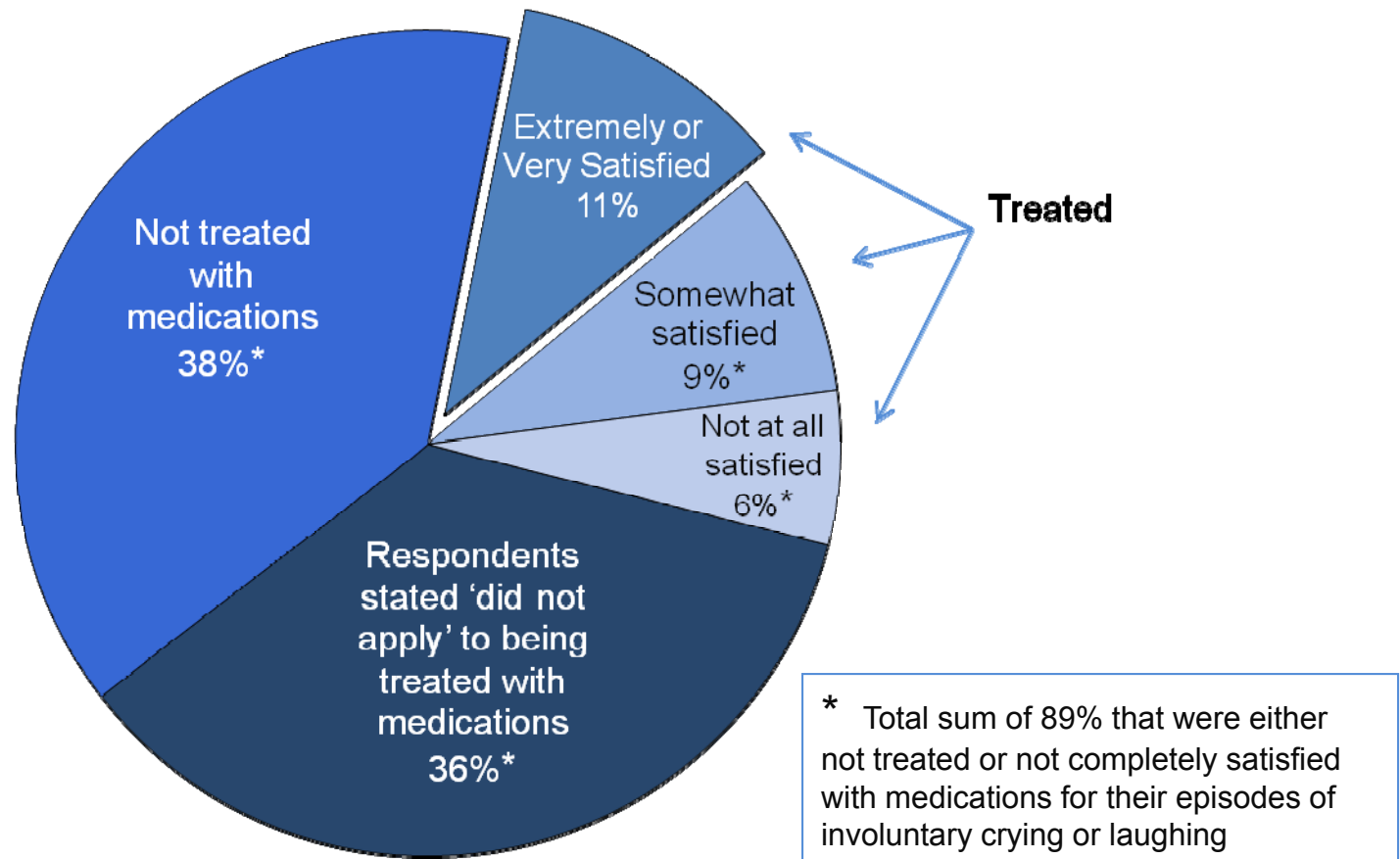
- Only 25% of the 2,504 respondents reported being treated with medication for their episodes of involuntary crying or laughing.



[Q7] How satisfied are you [is the patient] with the medication prescribed by your [the patient's] doctor to treat your [the patient's] episodes of involuntary crying and/or laughing?

# Satisfaction With Treatment

- 2504 respondents attained a score of 13 or greater on the Center of Neurological Study Lability Scale. Of these, 89% were either not treated with medications for their episodes of involuntary crying or laughing or were not completely satisfied with their treatment.

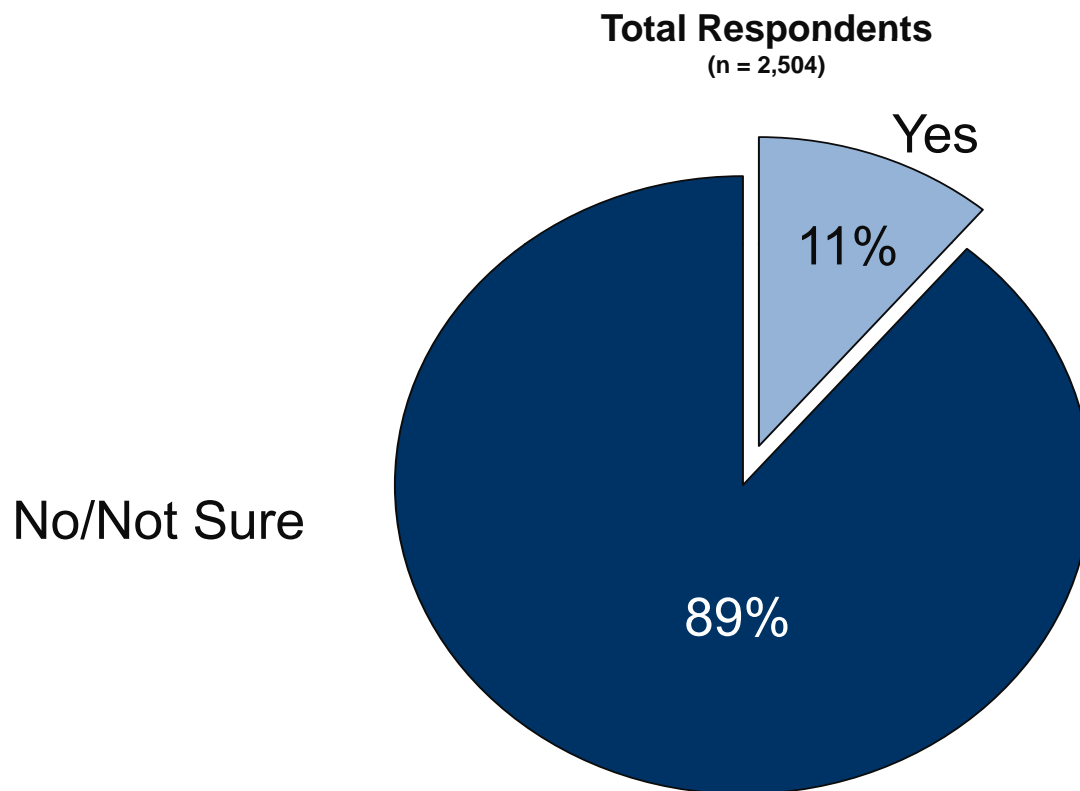


[Q7] How satisfied are you [is the patient] with the medication prescribed by your [the patient's] doctor to treat your [the patient's] episodes of involuntary crying and/or laughing?

# **Awareness Of PBA and Frequency of Other Emotional Disinhibition Symptoms**

# Awareness Of PBA

- About one in ten respondents are aware of the term pseudobulbar affect or PBA.

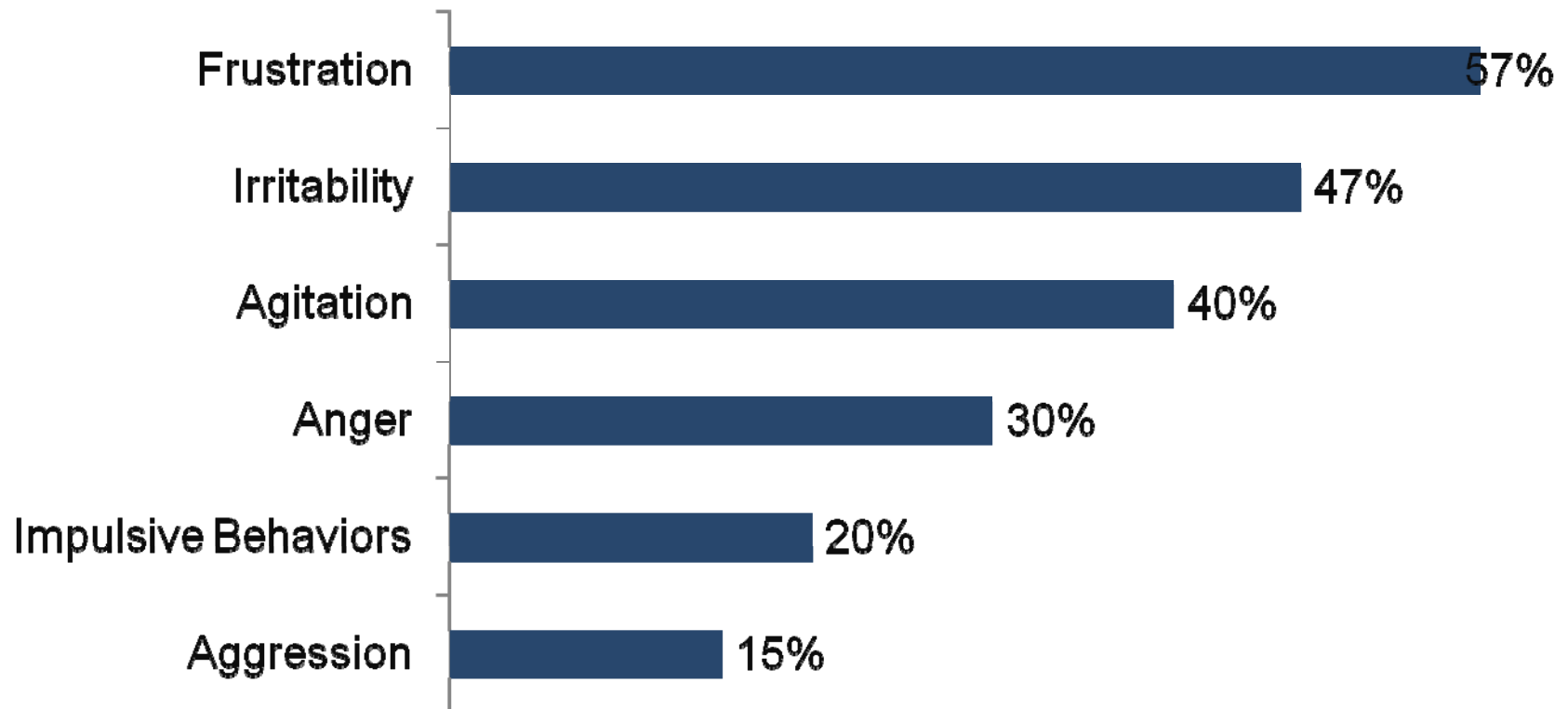


[Q8] Have you ever heard of the term "Pseudobulbar Affect" or "PBA"?

# Frequency Experience Other Behavioral Disinhibition

- About half the respondents experience frustration and irritability at least often.

## Experiencing Extremely Often/Very Often/Often\*



\*Percent of respondents that experience other behavioral disinhibition (n=2,504)

[Q9] During the past week, please indicate how often you have [the patient has] experienced each of the following, using the scale provided.

# Sources Of Information on PBA

- Few respondents have looked up information on PBA symptoms. Among those who have, they mostly looked at health websites or talked to their doctor or HCP.

## Sources of Information Used\*



\*Percent of respondents that have looked for information on involuntary laughing/crying (n=2,504)

[Q8.7] Where have you looked for information about your [the patients] involuntary crying or laughing episodes?

# Appendix



# Survey Questions

- Question S1: Which of the following best describes you?
- Question S1.5: What is your [the patient's] age?
- Question S2: What is your [the patient's] gender?
- Question S3: Which of these categories best describes the type of MS you have [the patient has]?
- Question S4: Approximately how long ago were you [was the patient] first diagnosed with MS?
- Question S5: Below you will find statements that sometimes apply to patients with a brain injury. Please rate each of the following statements by how often that statement applies to you [the patient] using the scale below.
  - 1. There are times when I feel fine one minute, and then I'll become tearful the next over something small or for no reason at all.
  - 2. Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny.
  - 3. I find myself crying very easily.
  - 4. I find that even when I try to control my laughter I am often unable to do so.
  - 5. There are times when I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts.
  - 6. I find that even when I try to control my crying I am often unable to do so.
  - 7. I find that I am easily overcome by laughter.
- Question 1: How burdensome are these involuntary crying or laughing episodes to you [the patient]?
- Question 1.5: How burdensome are your [the patients] involuntary crying or laughing episodes compared with the other symptoms of your [the patients] underlying MS?

# Survey Questions (continued)

- Question 2: Using the scale below, please indicate how often you would say the episodes of involuntary crying and/or laughing interfere with your [the patient's] participation in each of the following activities. If you do [the patient does] not participate in an activity, please select "Does Not Apply To Me [The Patient]".
  - 1. Work or professional activities
  - 2. Social activities and other leisure pursuits
  - 3. Shopping
  - 4. Driving a car
  - 5. Talking on the telephone
  - 6. Going to the movies
  - 7. Dining out
  - 8. Spending time with friends and family
  - 9. Attending church, synagogue or other house of worship
  - 10. Interacting with nurses or other health care professionals
  - 11. Attending school or other educational programs
  - 12. Volunteering
- Question 3: Are there additional things that you [the patient] cannot do or choose not to do because of your [their] involuntary crying or laughing episodes?
- Question 4: To what extent have your [the patients] involuntary episodes of laughing and/or crying ever contributed to the following life situations?
  - 1. Getting a divorce or ending a significant relationship
  - 2. Not taking a vacation or traveling
  - 3. Quitting or being fired from a job
  - 4. Making and/or keeping friends
  - 5. Moving to a care facility
  - 6. Becoming housebound

# Survey Questions (continued)

- Question 5: How frequently do you [does the patient] experience these episodes of involuntary crying and/or laughing?
- Question 6: How important is it to you [the patient] that these episodes of involuntary crying and/or laughing be treated?
- Question 7: How satisfied are you [is the patient] with the treatment prescribed by your [the patient's] doctor to treat your [the patient's] episodes of involuntary crying and/or laughing?
- Question 8: Have you ever heard of the term “Pseudobulbar Affect” or PBA?
- Question 8.7: Where have you looked for information about your [the patients] involuntary crying or laughing episodes?
- Question 9: During the past week, please indicate how often you have [the patient has] experienced each of the following, using the scale provided.
  - 1. Anger
  - 2. Irritability
  - 3. Aggression
  - 4. Agitation
  - 5. Impulsive behavior
  - 6. Frustration
- Question 10: In addition, if you would be interested in sharing your story, please provide us with your name and a preferred way to contact you: