

BIAA SURVEY: PSEUDOBULBAR AFFECT IN BRAIN INJURY

SUMMARY REPORT

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New York, NY 10011

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Project Background

- Avanir and the Brain Injury Association of America are interested in learning more about the behaviors, experiences and attitudes of people with brain injuries and its relation to exhibiting symptoms of PBA.
- They are also interested in gauging the proportion of brain injury patients that exhibit symptoms of PBA as well as the awareness of PBA amongst brain injury patients.

Method

- To achieve these objectives Avanir has partnered with the Brain Injury Association of America (BIAA) to administer a to BIAA members. To qualify for the survey, the respondent had to:
 - Be a brain injury patient or the main caregiver of a person with a brain injury
- To complete the survey, the respondent had to:
 - Score a 13 or greater on the Center for Neurologic Study Lability Scale (CNS-LS)
- 366 people responded to the survey:
 - 55 were terminated from the survey due to not qualifying as a brain injury patient or the main caregiver of a person with a brain injury
 - 311 qualified to take the survey as a brain injury patient or caregiver
- 248 respondents had a CNS-LS score of 13 or greater and completed the survey:
 - 158 brain injury patients
 - 90 caregivers of a brain injury patient

Areas Of Questioning

- After establishing whether the participant was a person with a brain injury or the main caregiver of a person with a brain injury , respondents were asked about:
- **Demographics**
 - Age
 - Gender
- **Brain Injury Patient Profile**
 - When diagnosed
 - Type of brain injury
 - Severity of brain injury
- **Respondents were then administered the CNS Liability 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
 - 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 how the respondent became aware of the survey and the ability for them 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 brain injury patient
 - 35-54 years old, average age 42
 - Diagnosed with a brain injury more than 2 years ago
 - Traumatic brain injury
 - Severe in classification
 - Score of 16 or more on CNS-LS Scale

Presence Of PBA Symptoms

- Of the total respondents (n=311) approximately 80% exhibit symptoms of PBA.
 - Of the total respondents with PBA (n=248) approximately 41% had CNS-LS scores indicative of moderate to severe symptoms
- About one in three brain injury 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 six in ten indicate that PBA episodes interfere with social activities and spending time with friends and family.
- Approximately 60% of the respondents also indicate that these episodes have contributed to difficulty making/ keeping friends. Four in ten say it contributed to becoming housebound.
- Of those who are treated for their PBA episodes (33%) only ten percent are satisfied with their treatment.

PBA Awareness

- Fewer than one in ten brain injury patients are familiar with the term pseudobulbar affect or PBA.
- About half indicate they experience symptoms of PBA frequently or often.
- Other emotional expressions reported, at least somewhat often, include frustration, irritability, agitation and anger.

Survey Statistics

- The majority of the respondents became aware of the survey through an e-mail informing them about it.

Detailed Findings

Respondent Profile

Respondent Profile Summary*

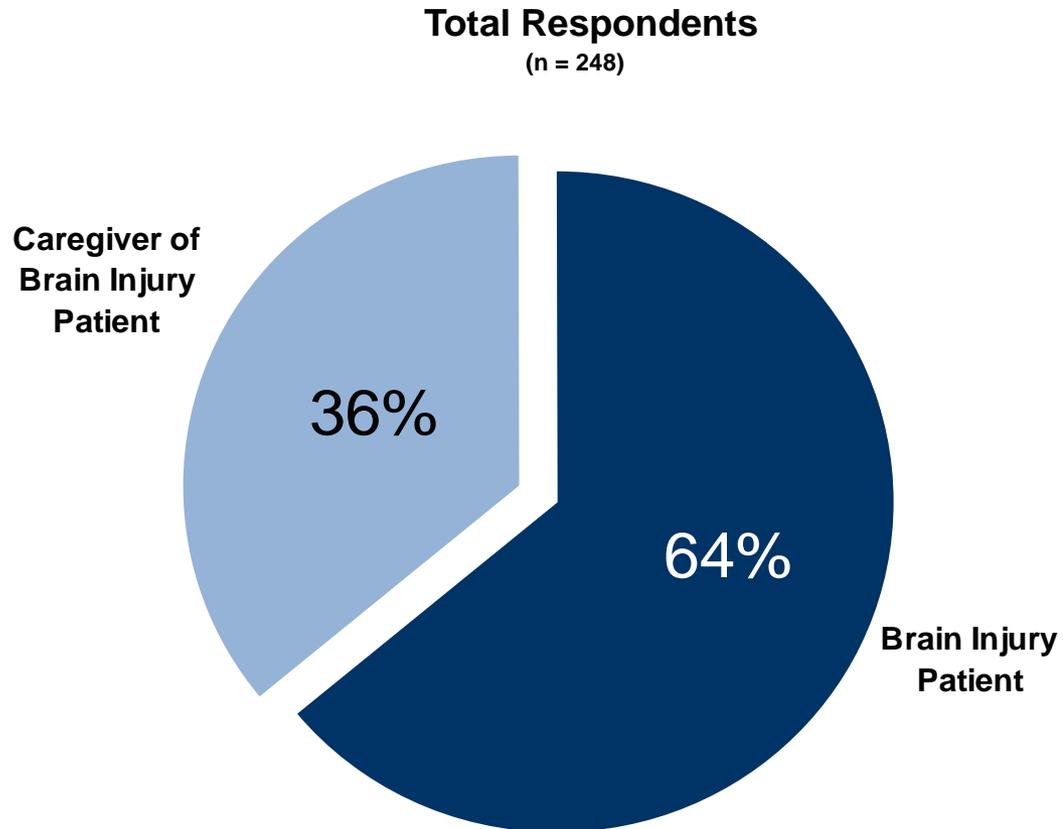
	<u>Total Completers</u> n=248 %
Respondent	
Patient	64
Caregiver	36
Gender	
Male	48
Female	52
Age	
Under 35	35
35 - 54	42
55 +	23
When Diagnosed	
Less than 2 years ago	31
3 - 5 years ago	21
6 - 9 years ago	16
10 years ago or more	32

	<u>Total Completers</u> n=248 %
Type of Brain Injury	
Traumatic	81
Acquired	19
Severity of Brain Injury	
Mild	15
Moderate	32
Severe	53
CNS-LS Score	
13 - 15	18
16 - 20	41
21 - 35	41
Involuntary Laughing/Crying - Top 2 Box	
Frequency of Episodes	48
Burdensomeness	35
Treatment Importance	39
Treatment Satisfaction	10
Aware of PBA	7

*311 respondents qualified for the survey; 248 respondents completed the survey (CNS-LS score was ≥ 13)

Respondents

- About two-thirds of the respondents were brain injury patients themselves.



[S1] Are you a person with a brain injury, main caregiver of a person with a brain injury or neither.

Age and Gender

- Respondents were mostly between 35 and 54 years old.

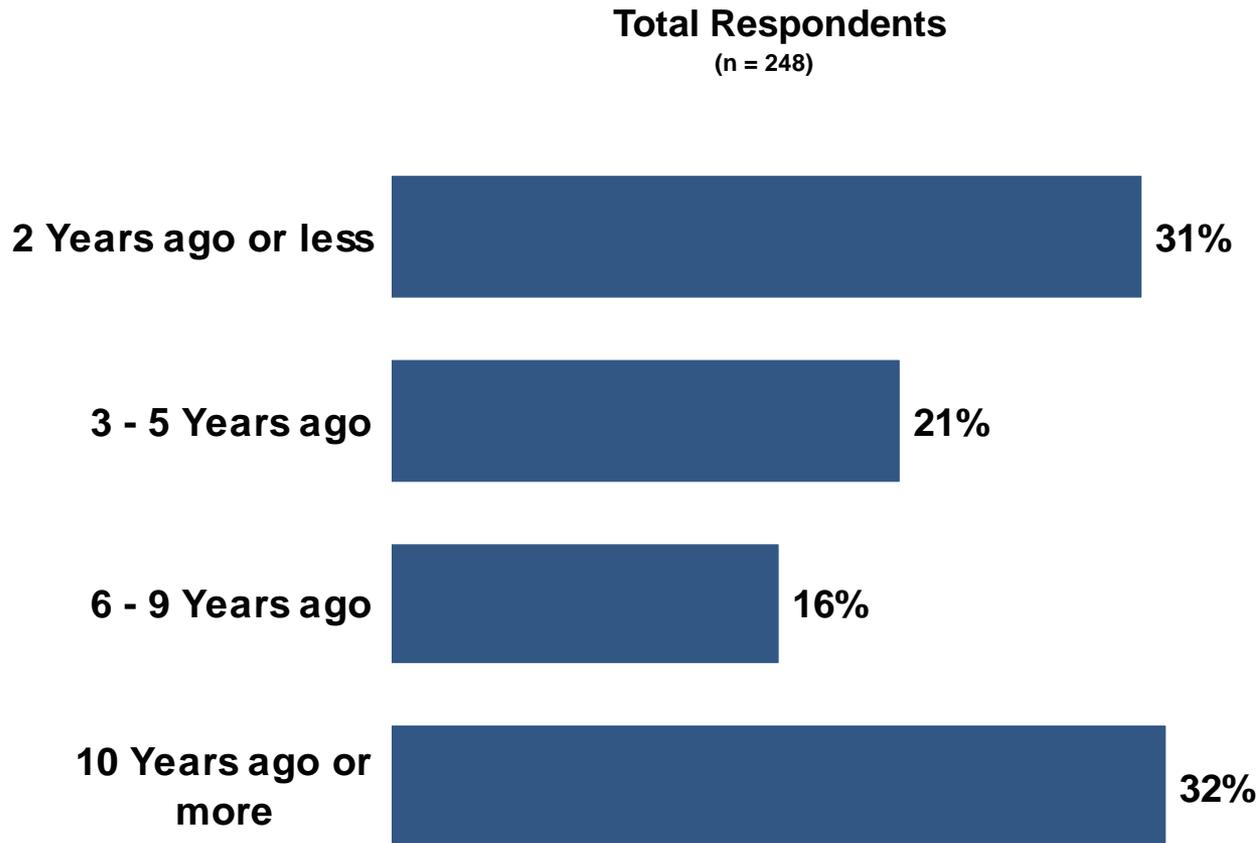
	Total n=248 %
Age	
Under 35	35
35 - 54	42
55 +	23
Mean	42
Gender	
Male	48
Female	52

[S1.5] What is the age of the brain injury patient?

[S2] What is the brain injury patient's gender?

When Brain Injury Occurred

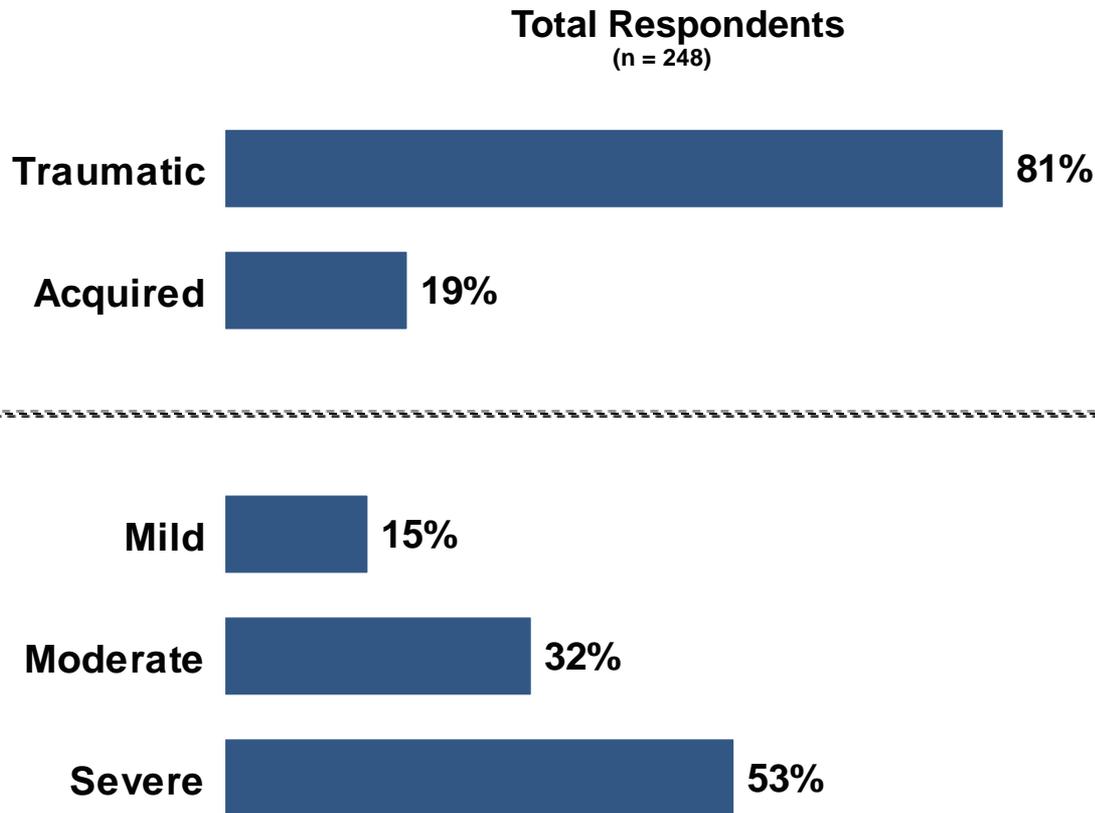
- For most respondents, their brain injury occurred more than two years ago.



[S3] How long ago were you diagnosed with a brain injury?

Type of Brain Injury/Severity of Brain Injury

- The majority of respondents suffered from a traumatic brain injury and for most it was considered severe.



[S4] What type of brain injury is it?

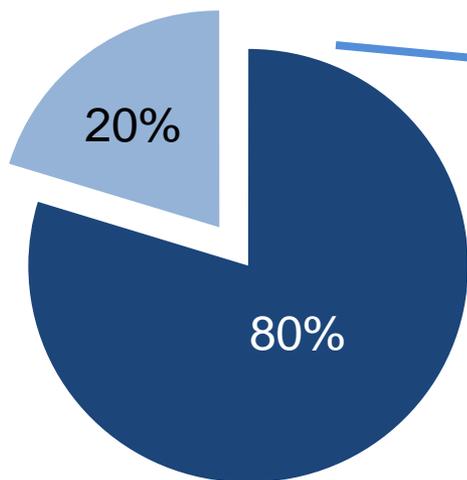
[S5] Is the injury considered mild, moderate, or severe?

Involuntary Crying/Laughing Experiences

Prevalence of PBA Symptoms in BIAA Membership

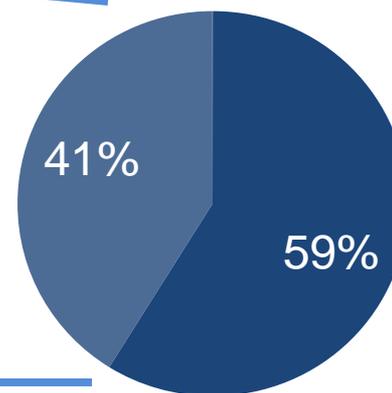
- 80% of respondents exhibited symptoms of PBA^a

Total Respondents



- With PBA Symptoms
- Without PBA symptoms

Severity of PBA Symptoms



- Mild
- Moderate to severe^b

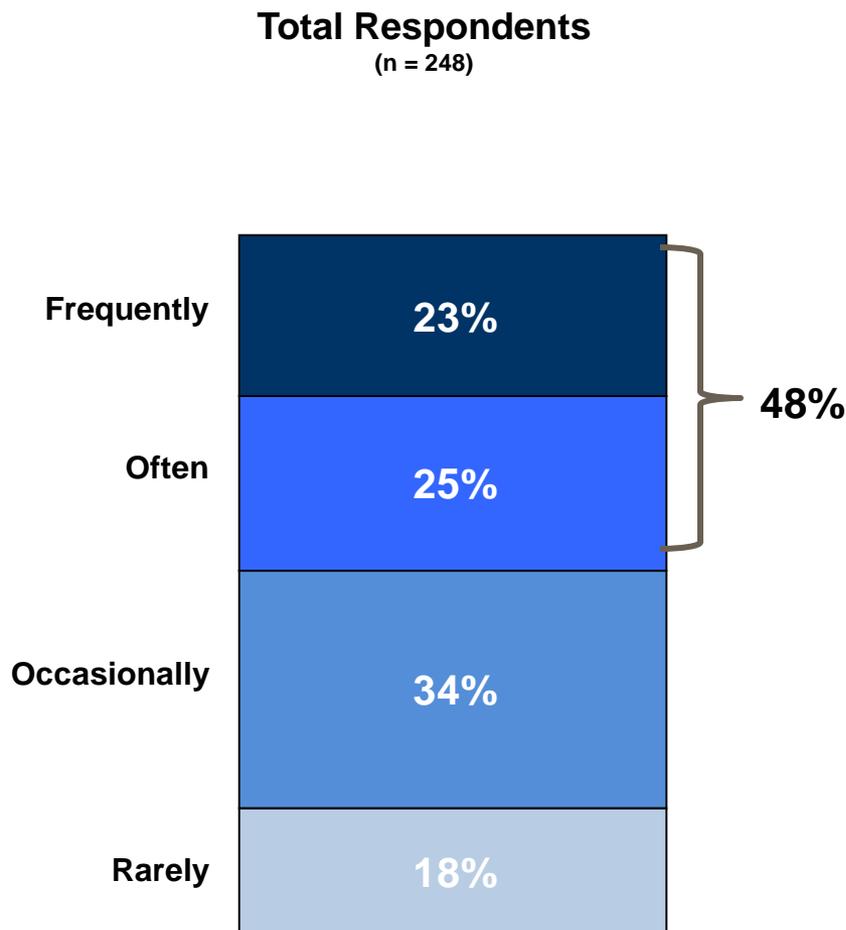
[PBA1] Please rate each of the following statements using the scale below. Please enter the associated numeric value next to each question.

^a Score of 13 or greater on CNS-Lability Scale

^b Score of 21 or greater on CNS-Lability Scale

Frequency Experience Episodes Of Involuntary Crying/Laughing

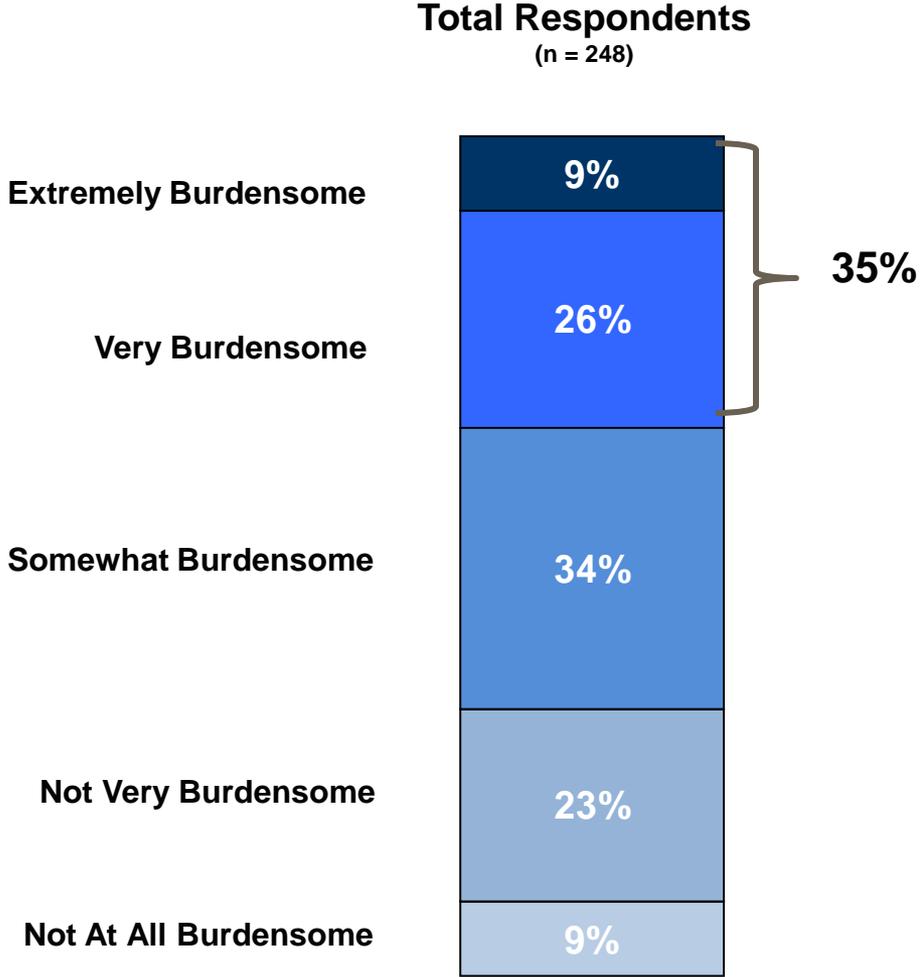
- About half the brain injury patients indicate that they experience PBA episodes frequently or often.



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

Burdensomeness

- Approximately a third of the respondents find their PBA episodes to be extremely or very burdensome, another third find it to be somewhat burdensome.

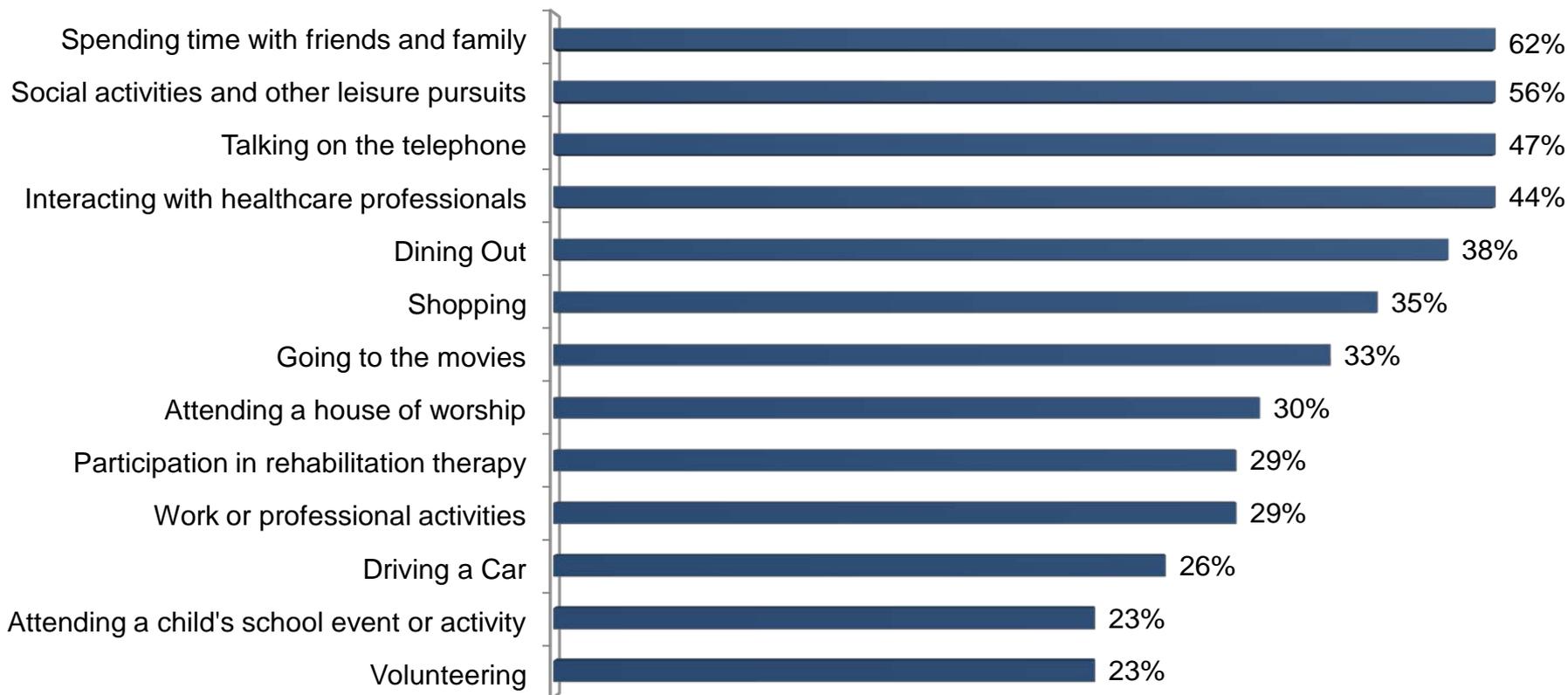


[Q1] You had mentioned that sometimes you experience symptoms of involuntary crying or laughing. How burdensome are these involuntary crying or laughing episodes to you?

Level of Interference with Daily Activities

- PBA interferes most with social activities and spending time with friends and family.

Interferes Extremely/Very/Somewhat Often*



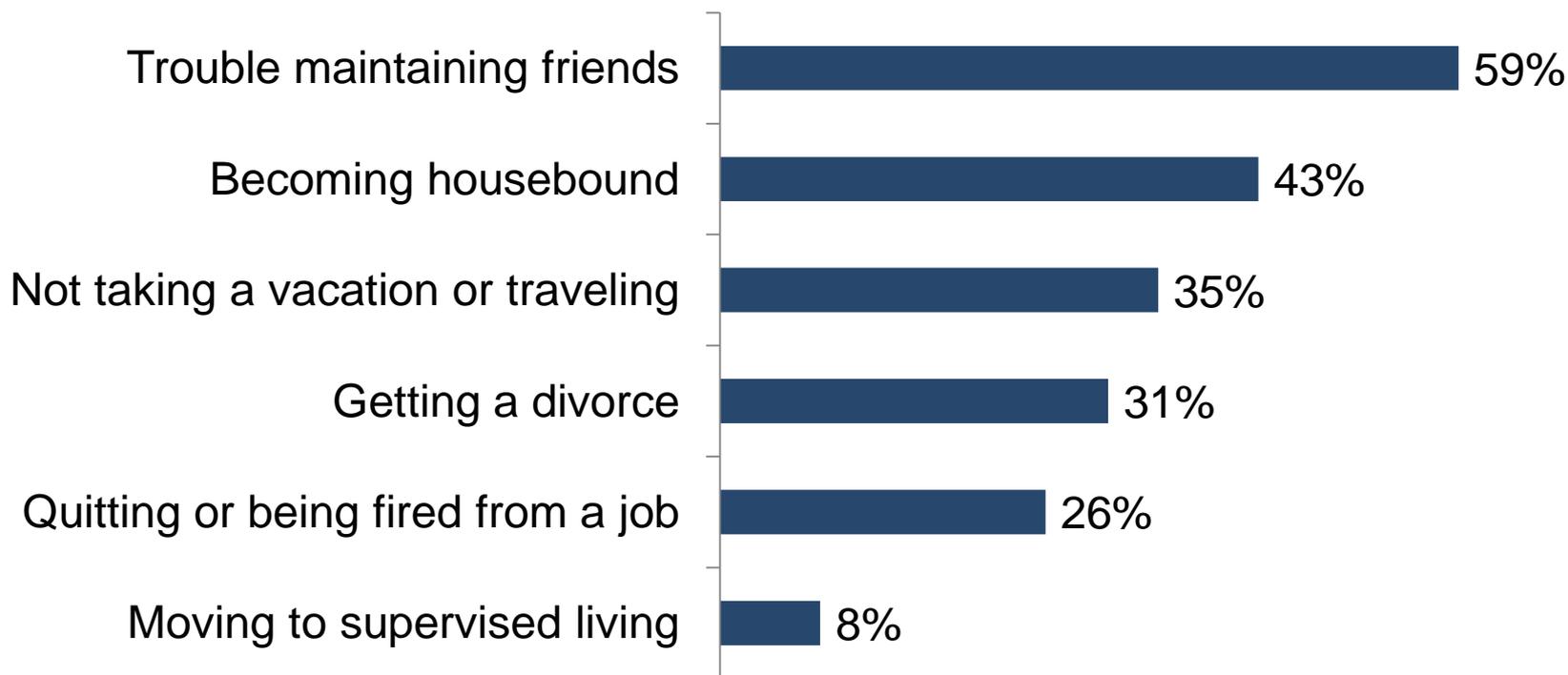
*Percent of respondents that PBA interferes extremely/very/somewhat often with daily activities (n=248)

[PBA4] Using the scale, please indicate how often you would say the episodes of involuntary crying and/or laughing interfere with your participation in each of the following activities. If you do not participate in an activity, please select 'Does not apply to me'.

Contributions to Life Situations

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

Contributed Somewhat or More*



*Percent of respondents that PBA contributed somewhat or more to life situations (n=248)

[PBA5] To what extent have your 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?

- “Go out of the house, be around friends, go to school.”
- “Concentrate on tasks/activities.”
- “A lot of times, I can not have a rational conversation without crying. It affects my everyday life. Even when I am happy, I cry.”
- “Having a job. Enjoying life the way its supposed to be enjoyed.”
- “I am not able to enjoy music or movies which sometimes evoke emotional responses from me which are seen as excessive or inappropriate to my wife or others with me.”
- “Talk to judges, police, doctors, anything serious.”
- “Basic conversations, coping skills, being misunderstood in pretty much any situation – physician appointments, restaurants.”
- “I have found myself staying inside, avoiding interaction with others, high anxiety when participating in family activities due to knowing I may break out in tears and never quite know when or sense it coming on so I can manage it. Makes others very uncomfortable, and I do not want others to feel sorry for me or have my injury be the center of all communications with others.”

[PBA3] What can't you do because of your involuntary crying or laughing episodes?

Limitations Due to PBA

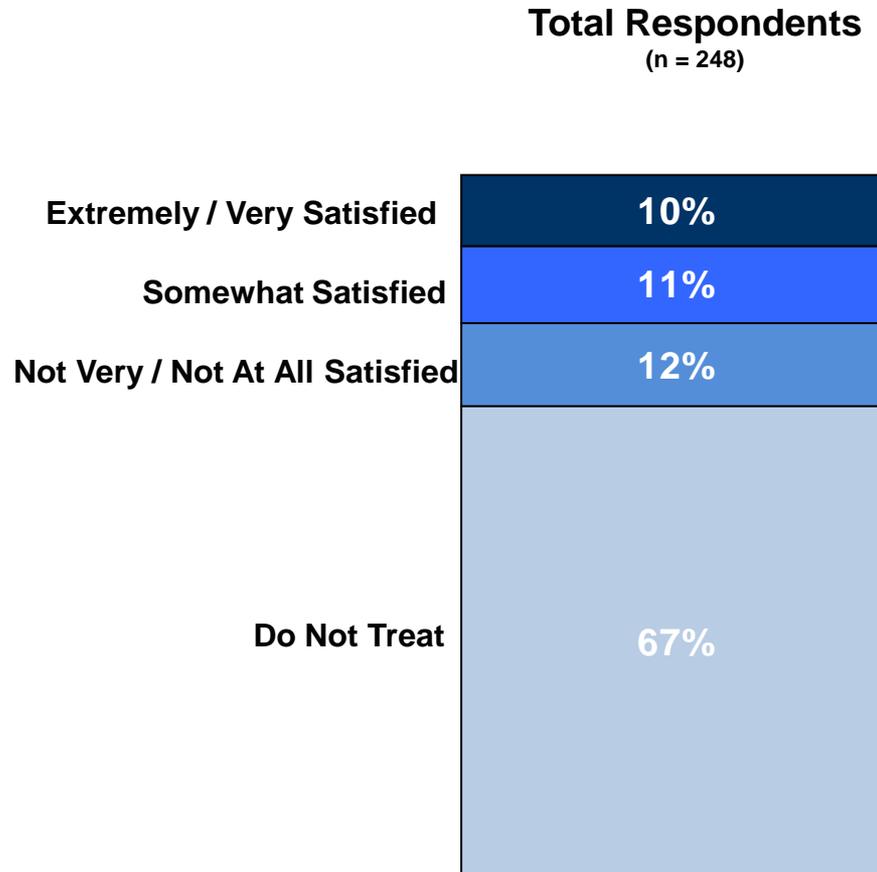
What can't you do because of your involuntary crying or laughing episodes?

- “I'm scared to be around people and that changes everything.”
- “Be with my family socially, afraid I'll breakdown. Feel I've been a burden to my family.”
- “Social activities are awkward because of his responses.”
- “Have fun and enjoyment of hobbies, outdoor activities, visit people and smile much anymore.”
- “I own a restaurant and I can't work when I have these episodes, I have to go in the back and I'm needed in the front of the restaurant.”
- “Can not finish his rehab sessions. When he cries it is very hard to get back to a conversation.”
- “Sometimes its so embarrassing to start crying and people don't know what to do and I can't explain why something makes me cry. I don't know when it is going to happen and so I don't talk very much to people who don't know me and don't understand me.”
- “Be around friends of my children...it is embarrassing to them and annoying to others who have to listen.”
- “Doesn't want to go out or associate with other people. Physically he is able to do a lot more than he will because of his emotions.”

[PBA3] What can't you do because of your involuntary crying or laughing episodes?

Satisfaction With Treatment

- Only 33% of brain injury patients with PBA are treated for their episodes of involuntary crying/laughing. Of those that treated, only 10% are satisfied.

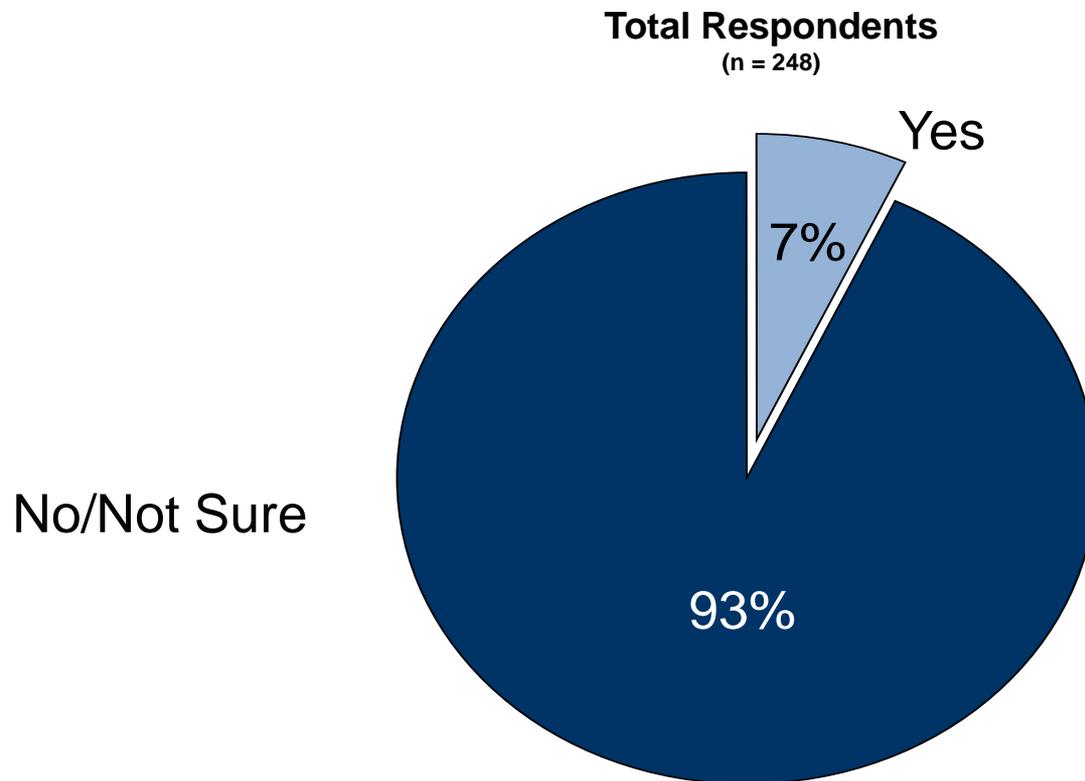


[Q7] How satisfied are you with the medication prescribed by your [the patient's] doctor to treat your episodes of involuntary crying and/or laughing?

Awareness Of PBA and Frequency of Other Emotional Disinhibition Symptoms

Awareness Of PBA

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

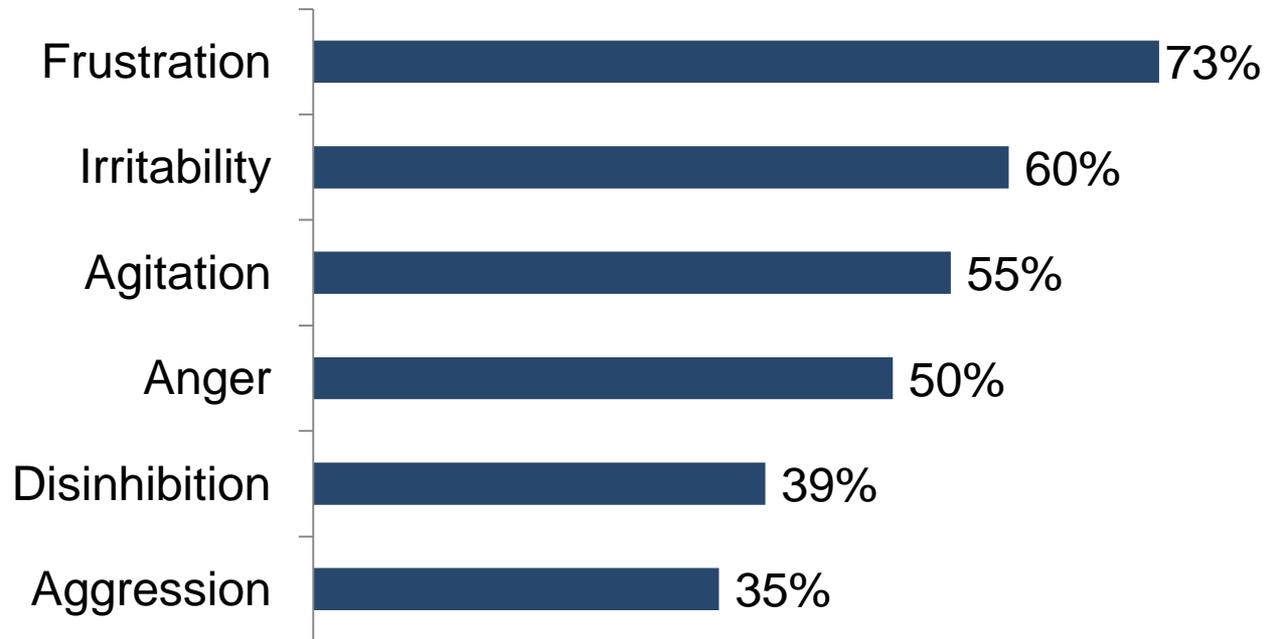


[Q8] Have you ever heard of the term "Pseudobulbar Affect" or "PBA"?

Frequency Experience Other Behavioral Disinhibition

- About a third of respondents experience other types of episodic emotional disinhibition at least somewhat often.

Experiencing Extremely Often/Very Often/Often/Somewhat Often*



*Percent of respondents that experience other behavioral disinhibition (n=248)

[PBA9] During the past week, please indicate how often you have experienced involuntary episodes of each of the following, using the scale provided.

Survey Awareness

- The majority of respondents received an e-mail informing them about the survey.

	Total (n=248) %
Received an email about it	60
Just while browsing the BIAA website	26
Through the BIAA newsletter	10
Other	7

[Q10] How did you become aware of this survey?

Appendix

Survey Questions

- Question S1: Are you a person with a brain injury/main caregiver of a person with a brain injury/neither?
- Question S1.5: What is your [the patient's] age?
- Question S2: What is your [the patient's] gender?
- Question S3: How long ago were you [was the patient] diagnosed with a brain injury?
- Question S4: What type of brain injury do you [does the patient] have?
- Question S5: Is the injury considered... mild/moderate/severe?
- Question S6: 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 2: What types of activities are you [is the patient] NOT able to do because of your [their] involuntary crying or laughing episodes?

Survey Questions (continued)

- Question 3: 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 a child's school event or activity
 - 10. Attending church, synagogue or other house of worship
 - 11. Interacting with nurses or other health care professionals
 - 12. Participation in rehabilitation therapy
 - 13. Volunteering
- 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. Difficulty making/keeping friends
 - 5. Moving to a nursing home or supervised living setting
 - 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 medication 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 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. Disinhibition
 - 6. Frustration
- Question 10: How did you become aware of this survey?
- Question 11: If you would be interested in sharing your story or want to learn more about PBA, please provide us with your name and your preferred contact method: