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## Symptom profile of affirmative responses to a self-report concussion question, United States 2019

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### Abstract

Information is limited about signs and symptoms experienced by individuals who self-report a concussion within surveys. The objective of this study was to assess the number and types of signs/symptoms adults experienced and whether or not medical attention was reported after sustaining a self-reported concussion in the past year. A sample of 3,624 adults responded to the web-based 2019 FallStyles survey. Respondents were asked if they had sustained a concussion in the past 12 months and if so, which (if any) signs/symptoms they experienced following the injury. The frequency and percentages of symptoms were calculated. Approximately 2.9% of respondents reported a concussion in the past year. Approximately two-thirds of respondents who reported sustaining a recent concussion stated that they experienced two or more signs/symptoms; the remaining one-third reported zero or one symptom. The findings suggest self-report concussion questions need additional improvement, particularly those that capture concussion using a single question, to improve the validity of self-reports.

### Keywords

Concussion; injury prevention; survey methodology

### Introduction

Millions of Americans sustain traumatic brain injuries (TBI), including mild TBI (or concussion), each year (1). However, current estimates are generally considered to be undercounts of the true incidence of concussion. These estimates rely solely on administrative hospital records (2,3), despite the fact that it is known that a large proportion of individuals who sustain a concussion either seek care outside of a hospital setting or do not seek care at all (2,4–6). In addition, studies have consistently shown that a

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Disclosure of Interest

the authors report no conflicts of interest

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large percentage of patients who present to the emergency department (ED) for treatment of injuries are not screened for concussion, therefore many concussions are likely going unidentified and undiagnosed in the ED setting (7,8). An alternative to relying on healthcare datasets is to conduct large national surveys that allow respondents to self-report concussion, some of which have produced important estimates of lifetime concussion prevalence (9,10). However, the validity of self-reported data has not been assessed. Current self-reported data collections of concussion have known limitations. For example, some surveys require the respondent to only report concussions for which they received a diagnosis (11), experienced a loss of consciousness (12), or ask about concussions using a single question that includes a list of multiple symptoms (13,14) that may not include the full constellation of possible concussion symptoms. Any of these situations could lead to undercounting in concussion incidence estimates.

On the other hand, one potential cause of false positive cases – when a concussion is self-reported but in reality did not occur – is that more nonspecific symptoms (e.g., headache, fatigue, and difficulty concentrating) may be due to other conditions and falsely attributed to a concussion. When a concussion is self-reported it is not clear how often these nonspecific symptoms are the primary or sole basis for individuals to infer that they have had a concussion. Another key factor in having confidence in a self-reported concussion is the number of symptoms reported. There can be greater confidence that those endorsing a greater number and more serious (e.g. loss of consciousness, post-traumatic amnesia) symptomatology and definitional elements of a concussion actually sustained a concussion (15). An important step in establishing the validity of self-report questions, particularly single-item questions, is to explore which symptoms are reported by those who self-report a concussion. This paper assesses which individual signs and symptoms, the number, and whether medical attention was sought among adult respondents who self-reported that they had sustained a concussion in the past 12 months.

## Materials and Methods

Self-report data were collected from the fall wave (“FallStyles”) of Porter Novelli’s 2019 ConsumerStyles survey (<http://styles.porternovelli.com>). FallStyles is an annual web-based survey of U.S. adults aged 18 years or older that was fielded during October 2019. The survey was sent to a sample of 4,677 panelists who had previously participated in the earlier SpringStyles survey. A total of 3,624 of these panelists completed the FallStyles survey (77.5%). Respondents were drawn from the GfK KnowledgePanel® that gathers insights about U.S. consumers. Panel members were initially recruited using probability-based sampling of addresses. This study was exempt from institutional review board review because personal identifiers were not included. Access to the FallStyles data was granted through a data-use agreement with Porter Novelli Public Services.

## Measures

Respondents were randomly assigned by Porter Novelli to receive one of three definitions of a concussion, one of which was no definition (full survey in Appendix). Each respondent was then asked, “In the past 12 months, do you believe that you have had a concussion?”

Affirmative answers, regardless of the concussion definition received, were classified as a self-reported concussion. There were no statistically significant demographic differences between the three groups. Chi-square analysis found no significant variation in reporting of concussion by definition (version 1: n = 1,234, prevalence = 2.9%; version 2: n = 1,186, prevalence = 2.9%; version 3: n = 1,197, prevalence = 2.0%), therefore all responses were combined.

Respondents who self-reported a concussion were asked to indicate which signs and symptoms they experienced after their most recent concussion. Response options included: blurred or double vision; headaches; bothered by light or noise; trouble sleeping, dizziness or balance problems; nausea; vomiting; feeling tired or fatigued; dazed or confused; trouble remembering; trouble concentrating; knocked out (lost consciousness); other symptom not listed; and no symptoms. Respondents were permitted to select multiple symptoms. However, if they selected “no symptoms,” the other response choices were blocked.

### Statistical analysis

Unweighted frequency distributions were calculated. While Porter Novelli supplies weights so that the FallStyles data can be nationally representative of the non-institutionalized U.S. population using Current Population Survey distributions, these weights were not used because our analytic sample was smaller than anticipated and the analysts had concerns about making claims of national representation. Analyses were conducted using SAS version 9.4.

### Results

The FallStyles sample included more males (52.5%) than females (47.5%) (Table 1). The largest age groups were those 60 or older (41.5%) and 45–59 (26.9%). About one-third of the sample had a bachelor’s degree or higher. Respondents were majority non-Hispanic white (73.2%); 8.5% of respondents were non-Hispanic Black, and 7.9% self-identified as Hispanic. One-half of respondents had a household income of more than \$75,000 a year.

Approximately 2.6% of respondents in the sample self-reported sustaining a concussion in the past 12 months (Table 2). Among those who reported a concussion, 13.5% subsequently reported experiencing no signs/symptoms, 19.1% experienced one sign/symptom, 15.7% experienced two signs/symptoms, and 51.7% experienced three or more signs/symptoms. Of those who reported one symptom (n = 17), the symptoms reported most frequently were dizziness (n = 4) and headache (n = 3).

Headache was the most commonly reported symptom overall (55.1%), followed by dizziness or balance problems (40.5%), feeling tired or fatigued (29.2%), trouble concentrating (28.1%), and feeling dazed or confused (27.0%). The remaining signs/symptoms were reported by about a quarter or fewer of individuals. The least common sign/symptom mentioned was trouble sleeping (12.4%).

Among the respondents who self-reported a concussion and reported experiencing at least one symptom, 46.8% said that they were evaluated by a doctor or nurse for their most

recent concussion (Table 3). Of those who sought care, half (50.0%) were evaluated at an emergency department or hospital and 30.6% were evaluated at their regular doctor's office. Finally, about 7 in 10 (71.4%) who were evaluated reported that they were diagnosed with a concussion or traumatic brain injury.

## Discussion

It is critical to produce more comprehensive national estimates of concussion prevalence in order to better understand the true burden of this injury, identify at-risk groups, and inform implementation of prevention strategies. Findings from this paper suggest that potentially fewer than 1 in 5 concussions may be captured in current ED-based surveillance systems. More specifically, current surveillance would not capture the 53.2% of people who reported a concussion in this study who did not seek care, and it would not capture the half who sought care but did so outside of the ED or hospital. Self-report surveys hold promise in addressing these gaps and providing truly comprehensive prevalence estimates of concussion.

An unexpected finding in this study was that approximately 14% of those who endorsed the concussion question subsequently reported that they experienced no symptoms. It is unclear why a respondent would indicate they had sustained a concussion without experiencing symptoms. One potential way to address this problem is to provide a definition for concussion that includes a list of concussion symptoms. The current study did provide a varying definition for concussion with one-third of respondents being prompted with a comprehensive concussion symptom list. The varying definitions did not result in statistically significant differences for the overall concussion question. Due to the small number of those who subsequently reported no symptoms ( $n = 12$ ), significance testing did not show any differences when examining whether a more comprehensive definition resulted in fewer respondents reporting no symptoms. A study with a larger sample size might be able to identify whether the provision of a detailed concussion definition that included a comprehensive list of possible symptoms could reduce this problem. A revised question set might be needed to minimize concussion endorsement without symptoms.

Findings from this paper suggest that requiring endorsement of at least one symptom would result in 86.5% of individuals who reported sustaining a concussion meeting the case definition of a concussion. Applying this additional criterion would result in an adjustment to the proportion of respondents in the sample classified as having a concussion in the past 12 months. Specifically, 2.2% of respondents in the sample endorsed the concussion question and reported 1 or more symptoms; 1.8% of respondents in the sample endorsed the concussion question and reported 2 or more symptoms. Consideration as to whether additional criteria, such as the endorsement of a certain number of symptoms, could be helpful in identifying true cases of concussion.

For respondents who reported 2 or more signs/symptoms, there can be greater certainty that they truly experienced a concussion (15). The remaining 32.6% reported zero or one symptoms, so there is less certainty as to whether these individuals had sustained a concussion. However, some of these respondents reported a single symptom that is more

specifically associated with concussion (e.g., being knocked out [lost consciousness], dazed/confused, trouble remembering). Thus, there might be greater confidence that a concussion occurred for some of these respondents who reported a single symptom, at least relative to those reporting one or more nonspecific symptoms (such as headache) or those reporting no symptoms. Future studies may also consider including questions which assess the onset, duration, and course of reported symptoms to determine if these factors contribute to self-reporting validity as well. Improving the validity of single-item concussion questions might involve question wording that asks respondents to give an affirmative response if they have sustained two or more symptoms provided in a list of concussions (vs. one or more as in this study).

## Limitations

This analysis is subject to at least four limitations. First, a relatively small percentage of respondents reported having sustained a concussion in the past year; consequently, analyses of some questions within this subgroup were underpowered. Second, data in the survey are based on self-report and subject to recall bias, such as telescoping (i.e., believing that an event occurred closer in time than it did). This could potentially inflate the percentage of respondents who reported sustaining a concussion in the last 12 months. Third, these data cannot be considered nationally representative. It is possible that other samples would produce different results. Fourth, the survey was only offered in English and the results are thus missing those respondents who could not participate due to language barriers. Despite these limitations, the data from this study can be used to inform how these types of questions can be better operationalized in future surveys.

## Conclusion

Approximately two-thirds of respondents who reported sustaining a recent concussion stated that they experienced two or more symptoms; however, the remaining one-third reported one or no symptoms. This suggests the need for improved concussion self-report questions, particularly those that are a single item, to enhance the validity of concussion self-report. Further, improving awareness of possible concussion symptoms among the public may be beneficial, both for improving concussion recognition and for concussion surveillance.

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## APPENDIX

### Full Survey

1A. A concussion can happen anytime a blow to the head causes you to have one or more symptoms, whether just for a short time or lasting a while. Symptoms include: blurred or double vision, being bothered by light or noise, headaches, dizziness or balance

problems, nausea, vomiting, trouble sleeping, feeling tired, being dazed or confused, trouble remembering, trouble concentrating, or being knocked out. In the past 12 months, do you believe that you have had a concussion?

**Select one**

- 
- 1 Yes
- 
- 2 No
- 

1B. A concussion can occur anytime a blow to the head causes you to have one or more symptoms, whether just for a short time or lasting a while. Symptoms include: being dazed or confused, trouble remembering, or being knocked out. In the past 12 months, do you believe that you have had a concussion?

**Select one**

1Yes2No

1C. In the past 12 months, do you believe that you have had a concussion?

**Select one**

1Yes2No

2. How many concussions have you had in the past 12 months?

3. When you sustained your most recent concussion, were you ... ?

**Select one**

1In a motor vehicle crash2Riding a bicycle3Experiencing a trip, slip, or fall4In a blast or explosion5Struck by or against something during a fight or an argument6Collided with another person by accident7Hit by an object by accident8Doing something else

4. When you had your most recent concussion, were you ... ?

**Select one**

1Working for pay2Engaging in a sport or recreational activity3Engaging in regular activities around the home4Doing something else

5. Did a doctor or nurse evaluate you for your most recent concussion?

**Select one**

1Yes2No

6. Where did the doctor or nurse first evaluate your most recent concussion?

**Select one**

1At your regular doctor's office2At a hospital or emergency department3At an urgent care clinic4At a sports medicine or concussion clinic5Someplace else

7. Did the doctor or nurse diagnose you with a concussion or traumatic brain injury?

**Select one**

1Yes2No

8. Sometimes it is very difficult for people to receive the health care that they need or want. Please select the primary reason you did not receive health care for your most recent concussion.

**Select one**

1I would have difficulty paying for it2I had difficulty scheduling an appointment3I did not have transportation4I did not know where to go to get care5I could not take time off work6I did not think the injury was serious7Symptoms went away quickly8Treatment might cause problems at work9No one could watch my children10Some other reason

9. Did you experience any of the following symptoms after your most recent concussion?

**Select all that apply**

1Blurred or double vision2Headaches3Bothered by light or noise4Trouble sleeping5Dizziness or balance problems6Nausea7Vomiting8Feeling tired or fatigued9Dazed or confused10Trouble remembering11Trouble concentrating12Knocked out (lost consciousness)13Other symptom not listed14I experienced no symptoms

**Data Availability**

Data are not publicly available

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**Table 1.**

Characteristics of respondents in 2019 Porter Novelli FallStyles Sample, n = 3,624, United States.

Characteristic	Frequency	Percent
<i>Sex</i>		
Male	1,904	52.5
Female	1,720	47.5
Total	3,624	100.0
<i>Age</i>		
18–29	374	10.3
30–44	770	21.3
45–59	975	26.9
60 or over	1,505	41.5
Total	3,624	100.0
<i>Education</i>		
High School grad or less	1,199	33.1
Some college	1,063	29.3
Bachelors degree or higher	1,362	37.6
Total	3,624	100.0
<i>Race/Ethnicity</i>		
Non-Hispanic White	2,654	73.2
Non-Hispanic Black	307	8.5
Hispanic	285	7.9
Non-Hispanic Other	378	10.4
Total	3,624	100.0
<i>U.S. Region</i>		
Northeast	672	18.5
Midwest	837	23.1
South	1,293	35.7
West	822	22.7
Total	3,624	100.0
<i>Income</i>		
<\$25,000	476	13.1
\$25,000-\$74,999	1,257	34.7
\$75,000	1,891	52.2
Total	3,624	100.0

**Table 2.**

Individual and number of symptoms experienced after sustaining self-reported concussion within the past 12 months, 2019 Porter Novelli FallStyles Sample, United States.

<u>Past 12 months concussion?</u>	<u>Frequency</u>	<u>Percentage</u>
Yes	94	2.6
No	3,523	97.4
<u>Number of Symptoms Reported</u> <sup>1</sup>		
0	12	13.5
1	17	19.1
2	14	15.7
3+	46	51.7
<u>Symptoms reported</u> <sup>1</sup>		
Headaches	49	55.1
Dizziness or balance problems	36	40.5
Feeling tired or fatigued	26	29.2
Trouble concentrating	25	28.1
Dazed or confused	24	27.0
Nausea/Vomiting	23	25.8
Bothered by light or noise	19	21.4
Trouble remembering	19	21.4
Blurred or double vision	12	13.5
Knocked out (lost consciousness)	12	13.5
Trouble sleeping	11	12.4
Other symptom not listed	9	10.1
No symptoms reported	12	13.5

<sup>1</sup>5 respondents did not respond to this question

**Table 3.**

Healthcare Experience among those who reported sustaining a concussion in the past 12 months, 2019 Porter Novelli FallStyles Sample, United States.

<b>Did a doctor or nurse evaluate you for your most recent concussion?*</b>	<b>Frequency</b>	<b>Percent</b>
Yes	36	46.8
No	41	53.2
Total	77	100.0
<u>Where did the doctor or nurse first evaluate your most recent concussion? *</u>		
At your regular doctor's office	11	30.6
At a hospital or emergency department	18	50.0
At an urgent care clinic	2	5.6
At a sports medicine or concussion clinic	1	2.8
Someplace else	4	11.1
Total	36	100.0
<u>Did the doctor or nurse diagnose you with a concussion or traumatic brain injury? *</u>		
Yes	25	71.4
No	10	28.6
Total	35	100.0

\* Only includes those respondents who reported at least one symptom after sustaining a concussion