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Summary of the Centers for Disease Control and Prevention's self-reported traumatic brain injury survey efforts

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Abstract

Objective: Surveillance of traumatic brain injury (TBI), including concussion, in the United States has historically relied on healthcare administrative datasets, but these methods likely underestimate the true burden of TBI. The Centers for Disease Control and Prevention (CDC) has recently added TBI prevalence questions to several national surveys. The objective of this article is to summarize their recent efforts and report TBI prevalence estimates.

Setting: Surveys.

Participants: Adult and youth respondents to a series of national surveys.

Design: Recent nationally representative surveys with either 12-month or lifetime TBI prevalence questions were identified.

Main Measures: For each data source, survey methodology, TBI definition, question wording, and prevalence estimates were examined.

Results: TBI prevalence varied depending on the question wording and data source. Overall 12-month prevalence of concussion/TBI among adults ranged from 2–12% while overall lifetime prevalence of concussion or TBI ranged from 19–29%. Overall 12-month prevalence of concussion/TBI among children and adolescents was 10% while 12-month prevalence of sports- and recreation-related concussion for youth ranged from 7–15%. Overall lifetime prevalence of TBI among youth ranged from 6–14%.

Conclusion: Survey data based on self-reported concussions and TBIs resulted in larger prevalence estimates than would be expected based on traditional surveillance methods. Analyses of the various surveys shows that how the questions are asked and what terminology is used can notably affect the estimates observed. Efforts can be made to optimize and standardize data collection approaches to ensure consistent measurement across settings and populations.

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Keywords

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Introduction

Caused by a bump, blow, or jolt to the head, a traumatic brain injury (TBI) affects how the brain works.[1] Determining the prevalence of TBI in the United States is difficult. The most common methods of TBI surveillance rely on administrative healthcare datasets: counting the number of people who seek care, typically in a hospital setting, for a TBI. However, recognizing and diagnosing a TBI is not straightforward. People who sustain a TBI can experience a broad range of signs or symptoms, ranging from common somatic symptoms such as headache and nausea to experiencing uncommon signs such as a loss of consciousness.[2] Any two people who sustain a TBI may not have any overlap in the symptoms they experience. This is further complicated by a lack of definitive tools to diagnose a TBI (e.g., a blood test, imaging used in isolation). In the absence of objective criteria, unlike other health conditions, a TBI diagnosis relies largely on a combination of clinical assessments of symptoms exhibited by the individual. This requires an individual suffering from a suspected TBI to recognize this fact, seek healthcare, and receive a diagnosis. Even among those who seek care for their injuries, many are not evaluated for a TBI and do not receive an appropriate diagnosis.[3] TBI is often considered a “hidden injury” because the physical damage is internal and unseen.

Reliance on administrative healthcare data also is limited in that it only represents those who seek care for their injury. Previous research has demonstrated that a substantial proportion of people with a suspected TBI, perhaps up to half, do not seek care for their injury.[4] Common reasons for not seeking care for a suspected TBI include not believing it is serious and not having access to care.[4] Among those with a suspected TBI who do seek healthcare, a large proportion (if not a majority) seek care at locations outside of the hospital setting.[4] A 2016 study reported that in a large, urban healthcare network, over 80% of pediatric patients seeking care for a concussion (mild TBI) had their initial visit at a primary care clinic, not a hospital.[5] Additionally, one study[6] reported that nearly one-half (46%) of adult patients sought care for a TBI in physician offices or clinics, rather than in a hospital emergency department. Hospital-based administrative datasets do not include visits made to primary care offices. For all these reasons, relying on administrative healthcare data alone undercounts the true burden of TBI in the United States.

An alternative approach to TBI surveillance is to make use of national self-report surveys that ask respondents to report their experience with head injuries. This enables identification of those who may have sustained a head injury at some point in the past but may not have sought care and/or did not receive a diagnosis, and therefore would not appear in healthcare administrative datasets. In recent years, programs within the Centers for Disease Control and Prevention (CDC), the United States’ federal public health agency, have sponsored questions in several national surveys in an attempt to better quantify the burden of TBI in the United States. However, these surveys are not specifically designed for injury assessments.

This limits their capacity to capture detailed injury-related data as they seek to balance survey length and respondent burden with a multitude of other health measures. The lack of standardized or "gold standard" methodology for self-reporting TBIs on a survey is also a challenge. As such, researchers have chosen various ways to assess TBI experience among survey respondents, including by asking a single question,[7] a series of questions,[8] or using validated instruments.[9]

In recent years, there have been considerable public health investments for prevention of TBI. However, a gap remains in that the continuous and consistent surveillance efforts necessary to measure the impact of prevention strategies have not been implemented. CDC has made progress to fill this data need through self-reported national surveys. This article summarizes the recent efforts CDC has made to assess both lifetime and past 12-months prevalence of TBI among adults and children in self-reported national surveys. Without such estimates, it is difficult to determine whether strategies and programs to prevent TBI have been effective. Capturing and reflecting on recent TBI surveillance efforts will help support continued refinement of methods aimed at obtaining the most accurate and reliable estimates of TBI burden.

Methods

Sources of nationally representative survey data that were sponsored or accessed by the CDC to measure topic areas related to head injuries, concussions, or TBIs were included in these analyses. For each data source, a broad overview of the survey methodology, administration, question text for content specific to head injuries, concussions, or TBIs, and prevalence estimates with 95% confidence intervals are provided. Estimates are derived from published reports unless otherwise noted. We first detail surveys that measured past 12-month prevalence of TBI, followed by surveys that examine lifetime prevalence of TBI.

Past 12 Month TBI Prevalence Estimates

Pilot National Concussion Surveillance System (NCSS)—The pilot administration of NCSS was fielded September 2018 through September 2019.[10] NCSS utilized a random-digit-dial telephone survey using computer-assisted telephone interviewing to collect self-reported data across the United States. Although sampled adults ages 18 and over (n = 10,130) were initially surveyed about their own head injuries, respondents with children aged 5–17 years in the household were also asked about head injuries sustained by their children (n = 3,557), referred hereafter as parent-proxy reporting.

Adult respondents were instructed to think about times, in the last year, when they or their child experienced a bump, blow, or jolt to their head. They were then given two questions to determine whether they sustained a head injury in the past 12-months:

1. In the last year, that is since [date 1 year ago from interview date inserted] were you/your child examined in a doctor's office, clinic, hospital or elsewhere because of a head injury?

2. In the last year, that is since [date 1 year ago from interview date], did you/your child experience any other injuries to the head that you did not see a doctor about?"

Following a "yes" response to either question, adult respondents were asked 12 yes/no questions regarding signs and symptoms that may have occurred because of their/their child's head injury. Definitions of "probable TBI" and "possible TBI"[1] were established based on the series of signs and symptoms.[10]

Estimates about sports- and recreation-related TBIs were also obtained for children. Following a parent-proxy respondent's "yes" that their child experienced at least one head injury and endorsed at least one sign or symptom that resulted from the child's head injury, the role of sport and recreation engagement during the injury was assessed from two questions:

1. Did your child experience this head injury while playing a sport, or while engaged in physical fitness or a recreational activity for fun or competition?
2. Which activity was your child doing at the time of the head injury?

The pilot NCSS survey was approved to support TBI case ascertainment and measure development. Therefore, weighted estimates from this pilot were not intended to produce nationally representative estimates of TBI.

ConsumerStyles (SpringStyles, SummerStyles, FallStyles, YouthStyles) Surveys—Three times each year, Porter Novelli fields a web-based consumer survey with a sample of U.S. adults ages 18 years and older. Data were weighted to be nationally representative based on sex, age, race/ethnicity, education, household income and size, U.S. census region, metropolitan status, and parental status of children ages 12 to 17 years. Respondents are panel members from Ipsos KnowledgePanel® who were initially recruited using probability-based sampling of addresses. Data are weighted to be nationally representative. A sample of adolescents ages 12–17 (the children of the adult respondents in the spring surveys) are also surveyed annually in the Spring. Access to the ConsumerStyles data is granted to CDC through a data-use agreement with Porter Novelli Public Services. ConsumerStyles surveys have gathered information from adults and youth about both past year and lifetime TBI prevalence. Due to sampling coverage challenges, estimates were not weighted for some of the Styles surveys, including SpringStyles 2018, YouthStyles 2018, and FallStyles 2019. Therefore, for these surveys, results are presented as unweighted estimates without 95% confidence intervals.

FallStyles 2019—FallStyles 2019 was fielded in October 2019 among U.S. adults ages 18 years and older (n = 3,624). Respondents were randomized to receive one of three past 12-month concussion prevalence questions[2]:

[1] *Probable* TBIs were those in which the respondent sustained a head injury and experienced difficulty remembering, loss of consciousness, or three or more symptoms from the *possible* TBI tier. *Possible* TBIs were those in which the respondent sustained a head injury and experienced being dazed/confused/trouble thinking straight, nausea, headache, dizziness/clumsiness/balance problems, blurred or double vision, trouble concentrating, difficulty learning or remembering new things, sensitivity to light or noise, change in mood or temperament, and/or change in sleep/more tired than usual.

1. A concussion can happen anytime a blow to the head caused 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? (long definition)
2. A concussion has occurred anytime a blow to the head caused 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? (short definition)
3. In the past 12 months, do you believe that you have had a concussion? (no definition)

SummerStyles 2022—SummerStyles 2022 was fielded in June and July of 2022 among U.S. adults ages 18 years and older (n = 4,156). Respondents were instructed to think about all head injuries, for example, from playing sports, car accidents, falls, or being hit by something or someone that may have occurred in the past 12 months. They were then asked to answer two 12-month TBI prevalence questions:

1. During the past 12 months, as a result of a blow or jolt to the head, have you been knocked out or lost consciousness, been dazed or confused, or had a gap in your memory? (Probable TBI)
2. During the past 12 months, as a result of a blow or jolt to the head, have you had headaches, sensitivity to light or noise, balance problems, or changes in mood or behavior? (Possible TBI)

The results of this analysis have not been previously published.

SummerStyles 2023—SummerStyles 2023 was fielded in June 2023 among U.S. adults ages 18 years and older (n = 4,303). The goal of this data collection was to assess whether self-reported 12-month adult prevalence of TBI differs by a single question that defines concussion through a comprehensive list of signs/symptoms versus a “select all that applies” approach, which allows respondents to indicate which individual signs/symptoms they experienced after their head injury. All respondents received an introductory statement that instructed them to think about all head injuries, for example, from playing sports, car accidents, falls, or being hit by something or someone that may have occurred in the past 12 months. The sample was split, and respondents received one of two questions:

1. During the past 12 months, as a result of a blow or jolt to the head, did you experience any of the following symptoms: 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, changes in mood or behavior, or being knocked out?

2. During the past 12 months, as a result of a blow or jolt to the head, did you experience any of the following symptoms? With a list of 13 signs and symptoms (see above) with the instruction to select all that apply.

For question 2, respondents that endorsed at least one sign or symptom were considered to have sustained a TBI. Definitions of "probable TBI" and "possible TBI" were also established. The results of this analysis also have not yet been published.

Research and Development Survey (RANDS)—RANDS is a series of surveys conducted by CDC's National Center for Health Statistics (NCHS).[11] RANDS was designed to explore the feasibility of using online panels to collect information on national health outcomes and to supplement NCHS's question evaluation and research program. Round 7 of RANDS (the only round that included head injury questions) was conducted by NORC at the University of Chicago and used a stratified sample design to obtain a random and representative sample of U.S. adults aged 18 and over from the AmeriSpeak Panel (n = 6,821).[12] RANDS 7 was administered via either online web surveys or phone interviews. Data are weighted to be nationally representative based on demographic factors such as age group, sex, race and ethnicity, and education level.

RANDS 7 was fielded from November 2022 through December 2022. The respondents were first provided a prompt about head injuries[13]: "The next questions are about head injuries that may have occurred in the past 12 months. Please think about all head injuries, for example, from playing sports, car accidents, falls, or being hit by something or someone that may have occurred in the past 12 months." The respondent was then asked:

1. During the past 12 months, as a result of a blow or jolt to the head, have you been knocked out or lost consciousness, been dazed or confused, or had a gap in your memory?
2. During the past 12 months, as a result of a blow or jolt to the head, have you had headaches, sensitivity to light or noise, balance problems, or changes in mood or behavior?

A respondent was considered to have sustained a TBI if they answered affirmatively to either question.

Youth Risk Behavior Surveillance System (YRBSS)—YRBSS is a biennial, cross-sectional survey that monitors health risk behaviors among school-based youth. YRBSS uses a multi-stage cluster sampling design to produce nationally representative samples (based on student sex, grade, and race/ethnicity) of high school students in grades 9–12[14] and some middle schoolers. In accordance with local parent permission procedures, students voluntarily completed an anonymous, self-administered questionnaire via a computer-scannable answer sheet.

In 2017 (n = 14,765), 2019 (n = 13,677), and 2021 (n = 17,232), the national high school YRBSS questionnaire included a question about sports and recreation-related (SRR) concussions in the past 12-months.[15,16] Respondents were first provided a definition of concussion: "When a blow or a jolt to the head causes problems such as headaches,

dizziness, being dazed or confused, difficulty remembering or concentrating, vomiting, blurred vision, or being knocked out." The respondent was then asked:

1. During the past 12 months, how many times did you have a concussion from playing a sport or being physically active?

Lifetime TBI Prevalence Estimates

SpringStyles 2018—SpringStyles 2018 was fielded in March and April 2018 among U.S. adults ages 18 years and older (n = 6,427). Respondents were randomly assigned to receive one of three definitions of a concussion used in the FallStyles 2019 survey (see above). However, these questions pertained to their lifetime experiences with concussions.[17]

SummerStyles 2020—SummerStyles 2020 was fielded in June of 2020 among U.S. adults ages 18 years and older (n = 4,053). Respondents were randomly assigned to receive one of two lifetime concussion/mild TBI prevalence questions[18]:

1. 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 your lifetime, do you believe that you have ever had a concussion?
2. A mild traumatic brain injury [mTBI] 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 your lifetime, do you believe that you have ever had a mild traumatic brain injury?

SummerStyles 2021—SummerStyles 2021 was fielded in June of 2021 among U.S. adults ages 18 years and older (n = 4,082). Respondents were randomized to receive a question about whether they had ever sustained a concussion *or* mild traumatic brain injury in their lifetime.[19]

1. In your lifetime, do you believe that you have ever had a concussion?
2. In your lifetime, do you believe that you have ever had a mild traumatic brain injury?

YouthStyles 2018—YouthStyles 2018 was fielded in June and July of 2018 among adolescents ages 12–17 (n = 845). The adolescent respondents were also randomized to receive different versions of a lifetime concussion prevalence question, this one focusing on SRR concussions.[20] The respondents were first provided a definition of concussion: "A concussion is when a blow or a jolt to the head causes problems such as headaches,

dizziness, being dazed or confused, difficulty remembering or concentrating, vomiting, blurred vision, or being knocked out." The respondent was then asked either:

1. During your lifetime, how many times did you have a concussion from playing a sport or being physically active?
2. During your lifetime, how many times did you have a concussion from playing a sport or being physically active? Please include concussions even if you did not go to see a doctor or nurse.

YouthStyles 2021—YouthStyles 2021 was fielded in June of 2021 among adolescents ages 12–17 (n = 833). Respondents were randomly assigned to receive one of two questions[7]:

1. In your lifetime, do you believe that you have ever had a concussion?
2. In your lifetime, do you believe that you have ever had a mild traumatic brain injury?

National Health Interview Survey (NHIS)—The NHIS is an annual household survey of the civilian, noninstitutionalized population.[21] The NHIS sample is designed to obtain nationally representative estimates. Interviews are conducted in person by trained interviewers, and in some instances conducted over the telephone. From each household, one adult and one child are randomly selected to be the subject of a detailed health interview. For children, an adult who is knowledgeable and responsible for the health of the child responds on behalf of the child (usually a parent). Survey content of the NHIS is a mixture of either annual (asked every year), rotating (asked every one or two years with a fixed periodicity), or emerging (asked with unfixed periodicity to respond to public health surveillance needs). Beginning in 2020, content on head injuries were included on the Sample Child survey as emerging content to better assess symptoms of concussions or TBIs.[22] The total sample size for the Sample Child portion of the NHIS was 5,790 in 2020, 8,261 in 2021, and 7,464 in 2022. An introduction statement of "The next questions are about head injuries that may have occurred anytime in (Sample Child's) life. Please think about all head injuries, for example, from playing sports, car accidents, falls, or being hit by something or someone" was provided to orient respondents to the topic followed by three questions used to assess lifetime symptoms of concussion or TBI:

1. As a result of a blow or jolt to the head, has (Sample Child) ever been knocked out or lost consciousness?
2. As a result of a blow or jolt to the head, has (Sample Child) ever been dazed or had a gap in his/her memory?
3. As a result of a blow or jolt to the head, has (Sample Child) had headaches, vomiting, blurred vision, or changes in mood or behavior?

Respondents who indicated "yes" to the first question did not receive subsequent questions. An affirmative response to any of three questions indicated lifetime symptoms of a concussion or TBI.

Analysis

Unless otherwise indicated, weighted prevalence estimates (based on age, sex, race/ethnicity, education, MSA status, Census division, and housing tenure of respondents), along with their 95% confidence intervals, are presented for each survey.

Results

Past 12-Months TBI Prevalence Estimates

NCSS pilot 2018–2019—Approximately 12.1% (95% confidence interval (CI): 11.3%,12.9%) of adults reported a TBI in the past 12 months. This percentage included 8.4% (95% CI: 7.6%,9.1%) of adults with a probable TBI and 3.7% (95% CI: 3.3%,4.2%) of adults with a possible TBI (based on the signs and symptoms reported) (Table 1).[10] Via proxy-reporting, 10.4% (95% CI: 9.3%,11.5%) of children ages 5–17 reported sustaining a TBI in the past 12 months; 4.9% (95% CI: 4.1%,5.7%) had a probable TBI and 5.5% (95% CI: 4.6%,6.3%) had a possible TBI (Table 2).[23] When broken down by age, 11.8% (95% CI: 9.8%,13.9%) of children ages 5–9, 10.6% (95% CI: 8.5%,12.8%) of children ages 10–12, and 8.8% (95% CI: 7.2%,10.4%) of children ages 13–17 reported a TBI in the past 12 months (data not shown).[2] Approximately 6.9% of youth ages 5–17 sustained an SRR concussion in the past 12 months.

FallStyles 2019—Overall, 2.6%[3] of adults reported sustaining a concussion within the past 12 months (Table 1).[2] This percentage did not vary significantly by whether the respondent received the long definition (2.9%), short definition (2.9%), or no definition (2.0%) of concussion.

SummerStyles 2022—Overall, a total of 3.5% (95% CI: 2.9%,4.2%) of adults reported experiencing a TBI in the past 12 months (Table 1).[4] This included 2.4% (95% CI: 1.8%,2.9%) who reported experiencing a probable TBI and 1.2% (0.7%,1.6%) who reported experiencing a possible TBI (based on the signs and symptoms they experienced).

SummerStyles 2023—Overall, a total of 6.2% (95% CI: 5.3%,7.1%) of adults reported experiencing a TBI in the past 12 months (Table 1).[§] A significantly higher proportion of respondents endorsed the version of the question where a list of symptoms with a “select all that applies” approach was provided (8.3%; 95% CI: 6.8%,9.8%) versus a version where a list of symptoms was provided using the comprehensive approach of asking 1 question (5.5%; 95% CI: 3.2%,5.3%).

Research and Development Survey (RANDS) 7 2022—Approximately 3.1% (95% CI: 2.5%,3.7%) of adults reported a head injury in the past 12 months that resulted in a loss of consciousness, being dazed or confused, and/or a gap in memory (Table 1).[13] Approximately 2.5% (95% CI: 2.1%,3.0%) of adults reported a head injury in the past 12 months that resulted in headaches, sensitivity to light or noise, balance problems, and/or

[2]This/these estimate(s) does not appear in the previously published document.
[3]Unweighted data used in published paper so 95% CIs were not reported.
[4]Analyses of these data have never previously been published.

changes in mood or behavior. When added together, 5.6% (95% CI: 4.8%,6.4%)[5] of adults reported a TBI in the past year.

YRBSS 2017, 2019, 2021—Overall, 15.1% (95% CI: 13.6%,16.6%) in 2017,[15] 15.1% (95% CI: 14.1%,16.3%) in 2019,[16] and 11.9% (95% CI: 11.2%,12.7%) in 2021[16] of high school students self-reported sustaining a concussion from playing a sport or being physically active in the past 12 months (Table 2).

Lifetime TBI Prevalence Estimates

SpringStyles 2018—Overall, 28.9%[6] of adults reported sustaining a concussion in their lifetime (combined from all questions) (Table 3).[17] The lifetime prevalence of concussion did not vary significantly by whether they received the short definition (27.7%), long definition (29.8%), or no definition (29.1%) of concussion.

SummerStyles 2020—Overall, a total of 21.3% (95% CI: 19.8%, 22.8%) of adults reported sustaining a lifetime concussion or mTBI (Table 3).[18] A higher proportion responded affirmatively if they received the concussion version of the question (25.5%; 95% CI: 23.2%,27.8%) than the mild TBI version of the question (17.2%; 95% CI: 15.2%,19.2%).

SummerStyles 2021—Overall, 18.8% (95% CI: 17.4%,20.3%) of adults reported that they had sustained a concussion/mild TBI in their lifetime (Table 3).[19] A significantly higher proportion of respondents reported having sustained a concussion (26.2%; 95% CI: 23.9%,28.4%) than an mTBI (11.4%; 95% CI: 9.7%,13.1%).

YouthStyles 2018—Overall, 14.0%[7] of adolescents reported sustaining an SRR concussion in their lifetime (combined questions) (Table 4).[20] There was no significant difference in the prevalence of concussion by question wording – specifically, whether the respondent was prompted to think about concussions that they did not see a doctor or nurse about.

YouthStyles 2021—Overall, 8.5% (95% CI: 6.1%,11.0%) of adolescents reported sustaining a concussion or mild TBI in their lifetime (Table 4).[7] A significantly higher proportion of respondents endorsed experiencing a lifetime concussion (11.3%; 95% CI: 7.4%,15.3%) over an mTBI (5.5%; 95% CI: 2.8%,8.3%).

National Health Interview Survey (NHIS) 2020, 2021, 2022—Overall, according to parent-proxy reporting, 6.8% (95% CI: 5.9%,7.7%) of children in 2020, 5.6% (95% CI: 5.0%,6.1%)[§§] of children in 2021, and 5.7% (95% CI: 5.1%,6.3%)[8] of children in 2022 ever had symptoms of a concussion or brain injury (Table 4).[22] The percentage varied by age,

[5]This estimate does not appear in the previously published document.
[6]Unweighted data used in published paper so 95% CIs were not reported.
[7]Unweighted data used in published paper so 95% CIs were not reported.
[8]Data have not been previously published.

ranging from 2.0% (95% CI: 1.2%,3.0%) among children aged 5 and under to 12.2% (95% CI: 10.4%,14.2%) among children aged 12–17 years (data not shown).

Discussion

Based on the self-report surveys included in this review, the past year prevalence of TBI among adults varied, ranging from 2%[2] to 12%,[10] while the past year prevalence of TBI among youth was about 10%.[23] Lifetime prevalence of TBI among adults likely ranges around 19–29%[18,19] and the lifetime prevalence of TBI in children and adolescents likely ranges between 7–14%.[7,22] These results demonstrate that TBI is a common health condition in the United States, and one that is likely underestimated by typical healthcare surveillance estimates that only capture the number of Americans who are seen in an emergency department or hospitalized for a TBI. For example, there were approximately 214,000 TBI-related hospitalizations[24] in 2020 out of a population of 331,400,000 Americans.[25] This equates to a fewer than 0.1% of Americans needing to be hospitalized for a TBI in 2020. Even compared to the lowest past 12-month estimate of TBI provided in this review (2%), healthcare-based surveillance estimates are likely missing a large proportion of those with suspected TBI.

There are a variety of explanations for the disparate estimates found in the self-report surveys that were reviewed. Because there is not a gold standard question to assess TBI experiences, variance in questionnaire wording and context may have led to different estimates across surveys. For example, when respondents are given the opportunity to list individual signs or symptoms that they experienced after their head injury, TBI prevalence is likely going to be higher than if they are responding to a single question.[8] TBIs can cause a variety of signs or symptoms, ranging from post-traumatic amnesia to nausea and vomiting to a severe headache and/or behavioral and mood changes. Surveys that require a respondent to have experienced a loss of consciousness after their head injury exclude the majority of individuals who have sustained a TBI, given that it is estimated that only about 10% of people lose consciousness after a TBI.[26–28] Surveys also had variation in the type and amount of introduction text used to orient the respondent to the questions to follow (e.g., examples of head injuries and settings in which injuries may occur) which may affect estimates.

Each survey has different reasons for choosing the format and number of questions to assess self-reported TBI. For example, many national general health surveys that cover a variety of topics (e.g., NHIS or YRBSS) typically have to limit the number of questions to reduce respondent burden and include questions that are brief to reduce cognitive burden. Surveys that are fielded with a more narrow scope (e.g., the pilot National Concussion Surveillance System) have more space to dedicate to the format of assessing exposure (in this case, a hit to the head) and then asking about resulting signs and symptoms. This format allows researchers flexibility in reporting of the level of certainty that a TBI occurred, as we did here, reporting both “probable” and “possible” TBIs. Other surveys (e.g., the ConsumerStyles surveys) are limited by the survey format itself; there are word count and response options limits put in place by the survey administrator and are related to the mode (e.g., self-administered web). However, the variety of survey questions summarized in this

review showcases the strengths and limitations to various approaches and that informative data can be gleaned from any of the survey questions.

Specific head injury terminology was an important factor that impacted the prevalence. Specifically, if the term “concussion” was used in the question, it was much more likely to be endorsed than “mild traumatic brain injury,” despite generally being considered synonymous by the brain injury community. The SummerStyles 2020, SummerStyles 2021, and YouthStyles 2021 all assessed the impact of using the term “concussion” vs. “mild TBI” for self-report lifetime history and the difference in prevalence ranged from concussion being 48% higher than mTBI in SummerStyles 2020 (25.5% vs. 17.2%) all the way to concussion being 130% higher than mTBI in SummerStyles 2021 (26.2% vs. 11.4%).[18, 19] There are long-standing definitional challenges and confusion regarding the term “concussion”,[29] and it is unclear which term healthcare providers use with their patients (e.g., concussion, traumatic brain injury, brain injury, head injury, etc.). It may be that clinicians prefer the term “concussion” over TBI because it is more well-known and less likely to elicit fear.[30,31] Based on the findings from our research, it seems possible that the public understands a “mild traumatic brain injury” to be a less common, and more serious, injury than concussion, and thus survey respondents are more hesitant to endorse that item. This is despite the fact that the mechanism of injury (i.e., what caused the injury) as well as the signs and symptoms that result from the injury have been self-reported to be similar when either term is used in survey research.[18] More research is needed to gain insight into the public’s understanding of terms commonly used in both research and in clinical settings to describe a brain injury. It is clear that using the term “mild TBI” on self-reported surveys will result in lower estimates which has implications for public health research and practice.

When looking specifically at the prevalence of lifetime TBI among pediatric populations, we found differences based on the age of the children being surveyed or reported on: younger children had a lower prevalence of lifetime history of TBI (for example, 2.0% among children under the age of 5, as seen in NHIS) and adolescents had a higher prevalence (for example, 8.5% among adolescents ages 12–17, as seen in the ConsumerStyles surveys). We found mixed results in prevalence based on whether the children were self-reporting or their parents were reporting on their behalf (proxy reporting). Previous evidence suggests that there may be a mismatch or disagreement between parents’ reports on their children’s behavior or health conditions versus the children reporting on themselves.[32,33] This may have contributed to the smaller proportion of past 12-months TBIs among children that were labeled “probable TBIs” (more certainty) than among adults and a greater proportion were “possible TBIs” than among adults in the pilot NCSS, suggesting that parents may be less certain about their child’s TBI than their own. More research can be done to directly determine whether proxy reporting accurately approximates children’s TBI experiences.

Historically, CDC’s TBI surveillance has been achieved through a multi-pronged approach including analysis of administrative healthcare data, abstracted medical record data, and self-reported survey data. Comparing estimates between each of these data for the purpose of TBI surveillance is challenging due to the variation in methodology used for data collection and breadth of information available for analysis (e.g., injury circumstances such as cause of injury and symptoms experienced). Estimates of TBI surveillance are also

affected by the population assessed: whether it is at the person level, injury level (which can capture multiple TBIs), or medical encounter-level (seen in administrative data sources; e.g., emergency department visits or hospitalizations). The overall intent of a self-reported survey can also affect estimates of TBI surveillance as a survey solely intended to capture head injuries versus a general household survey of health will obtain a variation in estimates primarily driven by the depth of data able to be collected. For example, a general household survey of health may ask a single TBI prevalence question due to space limitations of the survey and respondent burden, while a targeted survey focused on head injuries can assess symptoms after each head injury reported. Thus, a targeted survey on head injuries, which would require additional resources, may improve calculation of more comprehensive surveillance estimates.

Limitations

There are limitations to each survey used (e.g., recall bias for all surveys that assess lifetime prevalence of TBI, respondent bias, lack of validation of some of the survey questions). More generally, this summary of CDC's self-reported TBI surveillance efforts did not include surveys that did not have national reach for assessing TBI prevalence (e.g., the Behavioral Risk Factor Surveillance System, BRFSS) nor surveys that are not administered by or licensed to CDC (e.g., National Survey of Children's Health), the inclusion of which may have altered the conclusions that we drew. However, we have included a summary of questions that have appeared on recent BRFSS's state surveys that included TBI content as an optional module in select states as supplemental digital content. It is possible that self-reports may either underestimate or overestimate the prevalence and incidence of TBI, depending on survey question wording. For example, previous research has demonstrated that the terms "concussion" and "brain injury" (e.g., like the questions used on YRBSS, SpringStyles 2018, and YouthStyles 2018) may be misunderstood by the public and that there may be a lack of awareness and/or differing levels of health literacy,[34] which may contribute to underestimating the prevalence of TBI in surveys. On the other hand, it is possible that some of these surveys are overestimating the prevalence of TBI, especially given that several signs and symptoms included in the survey questions (e.g., NHIS) are general and can be caused by other conditions (e.g., heatstroke, anxiety, etc.). Additionally, variation in definitions used in surveys also likely contributes to variation in estimates. For example, definitions of TBI that require both a hit to the head and at least one sign and symptom (e.g., NCSS) could inflate TBI prevalence, particularly if the symptom is common and attributable to other conditions (e.g., headaches). Further, our TBI prevalence estimates were generated as overall percentages from surveys, which at times compared different ways of asking about TBI, which can impact survey-specific estimates (e.g., the question experiments found in SummerStyles 2020). Finally, because the question wording varied by survey type, the estimates may not be strictly comparable to each other. Future research may focus on evaluating and validating self-report survey questions to ensure they are both sensitive and specific to TBI.

Conclusion

Self-report surveys demonstrate a greater burden of TBI than estimates that only capture the number of Americans hospitalized for TBI. Future research may focus on refining the

content and wording of TBI questions for surveys based on the findings of this summary. Researchers may want to be intentional about the scope of the question (past year, lifetime) as well as the terms used, given that these decisions greatly impact prevalence estimates. Self-report surveys have shown to be an effective way to gain information about difficult to identify conditions including TBI. In turn, obtaining accurate and reliable TBI estimates will make it easier to determine if strategies and programs to prevent TBI are effective.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Adult past 12-month prevalence of traumatic brain injury (TBI)/concussion

	Weighted %	95% CI
National Concussion Surveillance System pilot, 2018–2019 [#]		
Overall (sum) [*]	12.1	(11.3,12.9)
Probable TBI[1]	8.4	(7.6,9.1)
Possible TBI[2]	3.7	(3.3,4.2)
FallStyles 2019		
Overall (average) [†]	2.6	---
Long definition of concussion[3]	2.9	---
Short definition of concussion[4]	2.9	---
No definition of concussion[5]	2.0	---
SummerStyles 2022		
Overall (sum) [*]	3.5	(2.9,4.2)
Probable TBI[6]	2.4	(1.8,2.9)
Possible TBI[7]	1.2	(0.7,1.6)
SummerStyles 2023		
Overall (average) [†]	6.2	(5.3,7.1)
Comprehensive symptom question[8]	5.5	(3.2,5.3)
Select all that apply symptom question[9] (overall) [*]	8.3	(6.8,9.8)
Probable TBI[10]	4.0	(2.9,5.0)
Possible TBI[11]	4.3	(3.3,5.4)
Research and Development Survey 2022		
Overall (sum) [*]	5.6	(4.8,6.4)
Probable TBI[10]	3.1	(2.5,3.7)
Possible TBI[11]	2.5	(2.1,3.0)

[#] 95% CIs were not reported in the published paper

[*] Overall estimate is a sum of probable and possible TBIs

[†] Overall estimate is an average of different question types

--- Unweighted data used in published paper so 95% CIs were not reported

1. Respondent reported experiencing a hit to the head plus difficulty remember what happened just before or after the injury, loss of consciousness, or three or more symptoms from the possible TBI list (see below).

2. Respondent reported experiencing a hit to the head plus feeling dazed, confused, or having trouble thinking straight; having nausea or vomiting; have a headache; feeling dizzy, clumsy, or having balance problems; having blurred or double vision, having trouble concentrating; having difficulty learning or remembering new things; experiencing sensitivity to light or noise; having a change in mood or temperament; or having a change in sleep or feeling more tired than usual.

3. 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?

4. 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?

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

6. During the past 12 months, as a result of a blow or jolt to the head, have you been knocked out or lost consciousness, been dazed or confused, or had a gap in your memory?

7. During the past 12 months, as a result of a blow or jolt to the head, have you had headaches, sensitivity to light or noise, balance problems, or changes in mood or behavior?

8. During the past 12 months, as a result of a blow or jolt to the head, did you experience any of the following symptoms: 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, changes in mood or behavior, or being knocked out?

9. During the past 12 months, as a result of a blow or jolt to the head, did you experience any of the following symptoms?" A list of 13 symptoms were then presented (the same list of symptoms asked in the other half of the sample) and the respondent was asked to select all the symptoms that apply.

10. During the past 12 months, as a result of a blow or jolt to the head, have you been knocked out or lost consciousness, been dazed or confused, or had a gap in your memory?

11. During the past 12 months, as a result of a blow or jolt to the head, have you had headaches, sensitivity to light or noise, balance problems, or changes in mood or behavior?

Table 2.

Youth past 12-month prevalence of traumatic brain injury (TBI)/concussion

	Weighted %	95% CI
National Concussion Surveillance System pilot, 2018–2019 [#] [¶]		
Overall (sum) [†]	10.4	(9.3,11.5)
Probable TBI	4.9	(4.1,5.7)
Possible TBI	5.5	(4.6,6.3)
Sports- and recreation-related (SRR) TBI [†]	6.9	(6.0,7.8)
Probable SRR TBI	3.3	(2.7,4.0)
Possible SRR TBI	3.6	(2.9,4.2)
Youth Risk Behavior Surveillance System 2017 [*] [§] [3]	15.1	(13.6,16.6)
Youth Risk Behavior Surveillance System 2019 [*] [§] [3]	15.1	(14.1,16.3)
Youth Risk Behavior Surveillance System 2021 [*] [§] [3]	11.9	(11.2,12.7)

[#] 95% CIs were not reported in the published paper

[¶] Estimates are proxy-reported (i.e., parent or guardian)

[†] Overall estimate is a sum of probable and possible TBIs

[*] Only ascertained experience with sports-related concussions

[§] Estimates are self-reported

1. Respondent reported experiencing a hit to the head plus difficulty remember what happened just before or after the injury, loss of consciousness, or three or more symptoms from the possible TBI list (see below).

2. Respondent reported experiencing a hit to the head plus feeling dazed, confused, or having trouble thinking straight; having nausea or vomiting; have a headache; feeling dizzy, clumsy, or having balance problems; having blurred or double vision, having trouble concentrating; having difficulty learning or remembering new things; experiencing sensitivity to light or noise; having a change in mood or temperament; or having a change in sleep or feeling more tired than usual.

3. During the past 12 months, how many times did you have a concussion from playing a sport or being physically active?

Table 3.

Adult lifetime prevalence of traumatic brain injury (TBI)/concussion

	Weighted %	95% CI
SpringStyles 2018		
Overall†	28.9	---
Long definition of concussion[1]	29.8	---
Short definition of concussion[2]	27.7	---
No definition of concussion[3]	29.1	---
SummerStyles 2020		
Overall†	21.3	(19.8,22.8)
Concussion question[4]	25.5	(23.2,27.8)
mTBI question[5]	17.2	(15.2,19.2)
SummerStyles 2021		
Overall†	18.8	(17.4,20.3)
Concussion question[6]	26.2	(23.9,28.4)#
mTBI question[7]	11.4	(9.7,13.1)#

CI = Confidence interval

---Unweighted data used in published paper so 95% CIs were not reported

†Overall estimate is an average of different question types

#Confidence intervals not published in original manuscript

1. A concussion can happen anytime a blow to the head caused 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 your lifetime, do you believe that you have had a concussion?

2. A concussion has occurred anytime a blow to the head caused 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 your lifetime, do you believe that you have had a concussion?

3. In your lifetime, do you believe that you have had a concussion?

4. 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 your lifetime, do you believe that you have ever had a concussion?

5. A mild traumatic brain injury 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 your lifetime, do you believe that you have ever had a mild traumatic brain injury?

6. In your lifetime, do you believe that you have ever had a concussion?

7. In your lifetime, do you believe that you have ever had a mild traumatic brain injury?

Table 4.

Youth lifetime prevalence of traumatic brain injury (TBI)/concussion

	Weighted %	95% CI
YouthStyles 2018 [*] [¶]		
Overall [†]	14.0	---
No medical evaluation prompt [1#]	13.3	---
Medical evaluation prompt [2#]	14.7	---
YouthStyles 2021 [¶]		
Overall [†]	8.5	(6.1,11.0)
Concussion question [3]	11.3	(7.4,15.3) [#]
mTBI question [4]	5.5	(2.8,8.3) [#]
National Health Interview Survey 2020 [5] [§]	6.8	(5.9,7.7)
National Health Interview Survey 2021 [5] [§]	5.6	(5.0,6.1)
National Health Interview Survey 2022 [5] [§]	5.7	(5.1,6.3)

CI = Confidence Interval

---Unweighted data used in published paper so 95% CIs were not reported

[*]Only ascertained experience with sports-related concussions

[¶]Estimates are self-reported

[†]Overall estimate is an average of different question types

[#]Estimates not published in original manuscript

[§]Estimates are proxy-reported (i.e., parent or guardian)

[1.]During your lifetime, how many times did you have a concussion from playing a sport or being physically active?

[2.]During your lifetime, how many times did you have a concussion from playing a sport or being physically active? Please include concussions even if you did not go to see a doctor or nurse.

[3.]In your lifetime, do you believe that you have ever had a concussion?

[4.]In your lifetime, do you believe that you have ever had a mild traumatic brain injury?

[5.]Parent responded affirmatively to any of these three questions: As a result of a blow or jolt to the head, has (Sample Child) ever been knocked out or lost consciousness? As a result of a blow or jolt to the head, has (Sample Child) ever been dazed or had a gap in his/her memory? As a result of a blow or jolt to the head, has (Sample Child) had headaches, vomiting, blurred vision, or changes in mood or behavior?