An Examination of Public Knowledge of Mild Traumatic Brain Injury:

Source of mTBI Knowledge and Implications

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Abstract

Almost three million traumatic brain injuries (TBIs) are reported in the United States annually. Although TBIs occur frequently, they are largely misunderstood by the public. Research indicates confusion regarding mechanism of injury, symptoms, and recovery. This study sought to build on previous research by collecting information about mild TBI (mTBI) knowledge, including information source and assessed TBI history. Participants answered questions related to mTBI. A total of 619 responses were collected from three separate samples: General Public, College Students, and Psychology Trainees/Clinicians. Overall accuracy for TBI knowledge fell at 69%, with highest accuracy on Symptoms questions (76.7%) and lowest accuracy on Treatment and Recovery questions (53.9%). Individuals reported gathering most of their TBI information from health care providers. Clinical implications for the general public, clinicians, and researchers are discussed as well as possible interventions.

Introduction

A traumatic brain injury (TBI) is "an alteration in brain function or other evidence of brain pathology caused by an external force" (Manley & Maas, 2013, p.1). The severity of a TBI is determined based on several criteria such as presence and temporal duration of loss of consciousness, presence and duration of post-traumatic amnesia, and initial score on the Glasgow Coma Scale (APA, 2013; Teasdale & Jennett, 1974). Severity is rated as either mild, moderate, or severe, depending on the extent of the brain damage and corresponding language, consciousness, and motor changes. Mild TBIs (mTBI), also known as concussions (Dematteo et al. 2015), are the most commonly experienced TBIs, accounting for up to 90% of all TBIs annually (Vos et al., 2012). Despite the frequency with which mTBIs occur, misconceptions are common; as such, the current study sought to examine commonly held misconceptions and inaccurate beliefs related to mTBI held by the public, while specifically examining knowledge source.

Sources of Misinformation Related to mTBI

One factor leading confusion about mTBIs, may be the lack of consensus regarding mTBI management amongst health care professionals. For example, Lebrun et al. (2012) reported that at one point, there were at least 17 different mTBI management guidelines, all of which were based on clinical practice rather than research. Due to the conflicting protocols, many clinicians were uncertain about mTBI management best-practice, leading to wide variation in treatment recommendations. In addition, many mTBI management recommendations have changed in recent years, leading to further confusion about treatment. Below, we highlight key

areas that address how the literature has shifted over previous decades, likely contributing to some misconceptions related to these areas of mTBI knowledge.

Current best practice guidelines for mTBI management include immediate removal of an athlete from play following a possible mTBI (Phillips & Woessner, 2015), allowing an individual to sleep after acquiring a TBI (Taubman et al., 2016), and gradual return to activities (Hardin, 2015). All of these recommendations are based on a substantial body of medical, neurological, and psychological research, but are counter to previously held "common sense" TBI recommendations such as letting athletes continue to play in the game if they appear fine, not letting them sleep after injury, and keeping them in dark room. Research now shows that many of these previously held beliefs regarding "best practices" are actually harmful and can impair mTBI recovery (e.g. Silverberg & Iverson, 2013). However, although this updated information is evident in the research literature, it does not seem to have translated to general knowledge.

TBI Knowledge Accuracy Research

In 1988, Gouvier and colleagues published a seminal paper that examined common misconceptions about TBIs held by the general public. They surveyed over 200 people about facts related to head injuries. Analysis of the data revealed several common misconceptions surrounding TBI. For example, 80% of the sample believed that survivors of a TBI "can forget who they are and not recognize others but be normal in every other way" (Gouvier et al., 1988, p. 336). The study also examined how people obtained their knowledge about brain injuries, with individuals citing discussions with professionals and television talk show hosts (e.g., Dr. Phil, Oprah) as the most common sources of information (42% for both; Gouvier et al., 1988). More recently, Merz, Van Patten and Lace (2017) examined mTBI knowledge in the general

public with a 32-item online survey. Building upon Gouvier et al. (1988), the authors found an overall accuracy rate of TBI knowledge for the population was 61%, which is comparable to previous studies (e.g., Willer, Johnson, Rempel & Linn, 1993).

The misconceptions about TBIs extend beyond the general public and into health professionals. Bradford (2015) surveyed 181 behavioral health professionals using questions from Gouvier et al. (1988), as well as new mTBI questions, to assess accuracy of TBI knowledge. Overall accuracy on the new and old items were 51% and 65%, respectively, with the highest accuracy for brain injury items and lowest accuracy on items addressing unconsciousness and memory loss. Many individuals incorrectly endorsed that mTBI outcomes were worse than concussion outcomes, although the terms are interchangeable. These findings highlight that misconceptions about mTBI are common, even in healthcare providers likely tasked to treat patients who have sustained a mTBI. Overall, there are ample studies to suggest that the general public and clinicians endorse inaccurate beliefs about mTBI.

These knowledge gaps are also believed to have practical implications for people who have sustained a concussion. In a college student sample, approximately 25% of participants reported having received a diagnosis of a TBI (Zurlinden, Savransky & Everhart, 2021). However, upon further questioning, over 70% of individuals reported experiencing a *probable* TBI, which is as defined as a blow to the head accompanied by a loss of consciousness and/or feeling dazed/confused (Kim et al., 2007). This suggests that people are not seeking care for potentially serious TBIs simply because they are not aware they suffered an injury to begin with. This is consistent with findings from other studies which indicate that significant numbers of mTBIs go unreported due to lack of knowledge regarding TBI etiology and symptomology (Delaney et al.,

2001; McCrea et al., 2004). This paper explores TBI knowledge source, and potential implications for the general public and health care providers.

Methods

Participants and Procedure

All participants (*N* = 619) provided informed consent, and all research was collected within pre-approved IRB standards. A college student sample (*n* = 333), general public sample (n = 196), and a psychology trainee/clinician sample (*n* = 90) were recruited online via email announcements on Listservs, social media posts, and through research recruitment systems (SONA and Amazon MTerk). The only inclusion criterion for participation were being >18 years of age and living in the United States at the time of participation.

Measures

Demographics

In addition to collecting relevant demographic data (see Table 1), participants were also asked to rate their identity as an athlete on a Likert scale from 0-100, with zero representing "not a part of my identity at all" and 100 reflecting "a crucial part of my identity." Due to the many socio-cognitive factors that may affect reporting of TBI symptoms (Bloom & Caron, 2019), it was vital to examine how self-identification as an athlete may affect TBI history and knowledge.

Traumatic Brain Injury History Assessments

Participants were asked several broad questions about TBI history, such as whether they personally suspected ever having obtained a concussion or TBI regardless of diagnostic history. They were also asked whether they have intentionally not reported a suspected TBI during their

lifetime. Participants who endorsed intentional non-reporting were then asked to qualitatively provide their reason for not reporting the suspected injury (e.g., did not think it was serious, wanted to continue activity, fear of consequences). Next, participants were taken to a question regarding formal diagnoses of TBI/concussion. If participants endorsed a formal TBI diagnosis, they were asked to provide further qualitative details about the nature of the injury.

mTBI Knowledge Assessments

There were three main sections that examined different areas of mTBI knowledge: symptoms, mechanism, treatment/recovery. Individuals answered true/false questions related to each of these three areas. A total percentage correct was calculated, as well as percentage correct for each of the three categories individually. This data will be explored in a separate paper but is outside of the scope of the current manuscript.

Questions about TBI Knowledge Acquisition

Participants were asked to consider what percentage of their knowledge came from various sources, such as print media (newspapers, magazines), television, social media, personal experience (themselves or someone they knew personally), formal TBI training (athletic trainers, team discussions, medical advice), professional education, and other. Participants were also asked to rate how accurate they believe portrayals of individuals with TBI are on television/in movies on a scale of 0-100. The final question about TBI knowledge asked the individual if they had actively sought out information about TBIs (yes/no). Finally, participants were asked to rate their confidence in their accuracy of TBI knowledge on a scale of 0-100, with 0 being not at all confident, and 100 being completely confident.

Results

All data were analyzed utilizing SPSS (IBM, version 26.0). A total of 1148 responses were initially recorded for this study. Of those 1148 responses, 33 were discarded due to discontinuation immediately following the informed consent, 294 were discarded for failing two or more embedded validity measures, and 201 were discarded for being incomplete. After data review, a total of 619 valid and complete responses remained.

mTBI Information Sources

In Table 2 the average percentage of knowledge gained from various information sources is listed. Due to specific patterns of "other" responses, two additional categories were created for TBI knowledge source: other education source (to include health class, psychology courses, and other curriculums) and health care providers. Of note, health care providers was a broad category and included anyone that 1) the participants identified as a health care provider and 2) identified gaining TBI knowledge from. This is important to note, as many individuals cited health care providers that they had personal relationships with (i.e. grandmother who was a nurse, friend who was a doctor) as opposed to their own health care provider providing patient education. Participants assigned a percentage out of 100% for each of the information sources. In Table 2 is the average score for each category, with answers ranging from 0-100. Individuals identified health care providers as the most heavily utilized information source, followed by other education sources.

Next, participants responded whether they had ever actively sought out information on TBI, and if so, to what extent. A total of 40.7% reported they have *never* sought out TBI information, 32.6% *a little*, 20.0% *some*, and 6.8% sought *a lot* of information. When asked to describe why they sought out TBI information, many participants cited either a personal

experience with a TBI or concern about a close friend or family member who sustained a TBI. Other individuals reported seeking out the information for professional reasons, such as research or patient care.

mTBI Knowledge Questions

Overall, across all three mTBI Knowledge categories, total mTBI accuracy fell at 69.0%. The highest accuracy was found for mTBI Symptoms (76.7%) followed by mTBI Mechanism (73.3%). The lowest overall accuracy was for the mTBI Treatment and Recommendations (53.9%). There was a statistically significant correlation between answers on the question "Even after several weeks in a coma, when people wake up, most recognize and speak to others right away" and belief in the accuracy of TV/movie portrayals of TBIs (r = -.11, p = .006); individuals with higher accuracy ratings of TV/movies were more likely to get the question wrong. This is unsurprising given the popular media portrayal of "spontaneous and immediate recovery."

A correlational analysis was also run between endorsement of False TBI Symptoms as common symptoms of TBI and belief in the accuracy of TV/movie portrayals of TBI (0-100), the correlation was not significant at the 95% confidence level (r = .02, p = .349). This suggests there is not a significant relationship between belief in media portrayal of TBI and endorsement of false TBI symptoms as common TBI symptoms.

Finally, analyses were run to determine significant predictors of mTBI knowledge accuracy. These correlations are presented in Tables 3 and 4. Analyses of gender differences were examined for individuals who identified as men and women, as there were not enough non-binary/non-confirming participants – discussed as a limitation later). Overall, females had higher mean mTBI accuracy rates *(M* = .70, *SD* = .11*)* than males *(M* = .66*, SD* = .13), *(t* = -3.72,

p= <.001, *d* = -.32). Of note, this discrepancy cannot be attributable to formal TBI diagnosis, as females had a higher rate of TBI diagnosis (40%) than males (35%). Additionally, individuals with a prior TBI diagnosis had lower accuracy than individuals without a diagnosis, which is discussed below.

Discussion

Summary of Results

Although millions of mild TBIs occur annually (Centers for Disease Control and Prevention, 2019), there is ample evidence to suggest that many people do not have an accurate understanding of injury presentation and treatment (i.e., Gouvier et al., 1988; Mertz et al. 2017). Previous studies show an overall accuracy rate of approximately 60% (Merz et al. 2017, Willer et al. 1993). This includes rates across different groups such as parents and children (O'Brien et al., 2019), nurses (Ernst et al., 2009), and pediatricians (Keenan et al., 2017). In the current study, overall accuracy was higher than previously reported averages at 69.1%, which is a substantial difference. Of note however, the mean accuracy of the general public sample was 63.9%, which is roughly consistent with the previously reported averages. The overall higher average in this study is skewed by the College Student (69.9%) and Psychology Trainee/Clinician (77.2%) averages, which are much higher than the general public average. The Psychology Trainee/Clinician sample differed from the general public group in that participants were predominantly female-identified, more ethnically diverse, and had the highest levels of education. Of note, however, one previous study examined knowledge about TBIs amongst behavioral health care providers (Bradford, 2015), and still found a lower rate across most categories (e.g., unconsciousness, memory loss, recovery). This suggests that

individuals currently training for psychology may be learning more, or at least more *accurate,* information about mTBIs during their training than previous cohorts of professionals did.

In this study, there was not a significant relationship between endorsement of false symptoms and belief in TBI/movie portrayal accuracy, which is inconsistent with the findings of Block and colleagues (2014). However, in the current study, participants had an overall high rate of endorsement of false TBI symptoms. This may have weakened the relationship between belief in television accuracy and endorsement of TBI symptoms, due to a ceiling effect. Additionally, the correlation between age and mTBI accuracy in this study is considered a small effect size, which is different than the small/medium effect size found in the study by Merz et al. (2017). Interestingly, the relationship is in the opposite direction compared to the former study. Notably, our sample differed from the previous in that it was a much younger sample (*M* = 25.48 years, median age = 20 years compared to *M* = 33.12 years, median age = 30.24 years). Finally, in this sample, men had overall poorer TBI knowledge accuracy. This is consistent with Bernstein, Calamia, and Mullenix (2019) who also found that men performed more poorly on mTBI symptoms assessment (ϕ=.09).

Looking only at individuals with and without a formal TBI diagnosis, there were significant differences in accuracy rates. Individuals who had previously been diagnosed with a TBI had lower rates of accuracy than individuals who had not had a formal TBI diagnosis. This is consistent with the research of Merz and colleagues (2017), as well as O'Jile and colleagues (1995), who found that previous TBI history was related to poorer performance on TBI knowledge questions. Merz and colleagues (2017) proposed that this discrepancy may be related to two main factors, with the first being a misunderstanding (or forgetting; see Hart et

al., 2018), of the information given by the medical provider following the injury. The second theory was that individuals with a poorer understanding of TBI knowledge may take fewer TBI precautions and may be more likely to sustain a TBI as a result. This theory may be partially supported by our data: in our study 107 (62%) of the individuals who reported receiving a TBI diagnosis reported sustaining more than one injury. In our sample, 3+ injuries (*n* = 54, 9%) were just as common as 2+ injuries (*n* = 53, 9%).

Possible Sources of Misinformation

In our study, the sources of information with the highest mean percentage of utilization for mTBI knowledge were Health Care Providers and education. Although it would seem that this would lead to overall higher accuracy, there are several studies documenting that health care providers do not have the most accurate mTBI knowledge (e.g., see Bradford, 2015; Ernst et al., 2009; Keenan et al., 2017). The utilization of health care providers for information is consistent with Gouvier et al. (1988), however one major discrepancy was that overall, reliance on visual media was much lower. Gouvier and colleagues found that individuals were just as likely to receive TBI information from health care providers as from talk show hosts; in our study, the combination of print media, digital media, and social media were statistically different than the rates found in Gouvier et al's study. However, it is important to note that many individuals identified family and friends as the health care providers they learned about TBIs from (e.g., "My mom is a nurse," or "My friend is a medical student.") Thus, individuals may accept the information as accurate medical advice, regardless of whether or not brain injuries are an area of expertise for the health care provider, and subsequently, whether their

beliefs are guided by research or “common knowledge.” Thus, individuals may incorrectly endorse common misconceptions as “medical advice.” This is a possible major pathway for the perpetuation of false beliefs and should be explored.

Another major source of information was related to personal experience, either themselves or a loved one. Although personal experience can be one way to learn about TBIs, TBIs are idiosyncratic, and as the saying goes, “Once you’ve seen one brain injury, you’ve seen ONE brain injury” (Stejskalm, 2013). As such, while the information may have applied to one person, it may not be accurate for all individuals, painting a vague or inaccurate picture of TBIs in general (see Zillmann [1999] for a theoretical explanation of this phenomenon, called Exemplification). Overall, this may explain why individuals endorse many common misconceptions related to TBIs even though they cite credible sources.

Clinical Implications

Provider Education

Regarding source of TBI information, the findings from the current study highlight how much individuals look to health care professionals for disease-specific information. However, even with this reliance on providers for information we found low rates of mTBI knowledge. This could be related to many factors, most concerning of which is the information they are receiving from providers may be inaccurate or incorrect. Several previous studies examining accuracy of TBI knowledge in health care professionals found major gaps existed in provider knowledge, and many endorsed common misconceptions related to TBI (e.g., See Bradford 2015; Ernst et al., 2009; and Keenan et al., 2017). As discussed earlier, information related to mTBI treatment has changed dramatically over the past several decades, emphasizing the

necessity of providers to seek updated research evidence about these conditions. When providers dispense incorrect information in their professional and personal lives it can have a lasting effect on that individual's understanding of a disease state.

Patient Education

The results of this study highlight the importance of TBI education following a TBI diagnosis. It cannot be assumed that an individual accurately understands TBI information just because they have sustained one, and as proposed above, this misunderstanding may lead to further injury. The data suggest that there is a need for TBI education, especially after individuals sustain a first TBI. Accurate information regarding TBI may help improve recovery and may help an individual recognize and seek care for future injuries. It also may lead to individuals taking more preventative measures to avoid injury and reduce TBI risk. The Center for Disease Control (CDC) has a thorough educational resource related to TBIs called "Heads Up" (https://www.cdc.gov/headsup/index.html). There are specific resources tailored to different groups (e.g., educators, parents, coaches, athletes) that explain signs and symptoms of TBI as well as the recovery process. Ensuring that individuals receive accurate written information about TBIs following an Emergency Room TBI assessment may be a vital step in the recovery process, as many patients reportedly forget verbal discharge instructions (Hart et al., 2018). Ensuring that patients have research evidence to support any personal experience may guard against future misconceptions related to their injury and may aid in the overall recovery process.

Public Health Education

Although all of the data presented in this study is relevant in some way, certain information has a more direct effect on the daily lives of the general public. Focus should be given to information that can lead to mishandling of care, or potentially hinder recovery. This study shows that many individuals may not be able to differentiate between true and false symptoms of an mTBI, which could lead to an absence of care for a more serious problem (i.e., "Symptom x must be related to an mTBI, no need for further care."). Additionally, the results of this study highlight that many individuals do not understand how an mTBI is sustained, most clearly demonstrated by the fact that almost three quarters of the sample believed that you could lose consciousness secondary to a blow to the head and not sustain an mTBI. This is another fact that could lead to an absence of care. More broad implications and interventions are discussed below.

Although, education interventions on an individual level are important, the data suggests that overall, the general public could benefit from more accurate TBI information. In this study, individuals who reported higher than average accuracy levels for TBI portrayals in the media reported statistically lower levels of TBI knowledge accuracy; i.e., the more they believed the television, the less accurate their TBI knowledge, highlighting a need for individuals to receive more formal TBI education outside of entertainment sources. One major way that this could occur is by reducing the number of inaccurate portrayals of TBIs on television and in movies. For example, many action movies include an individual taking a significant blow to the head, being knocked unconscious, and then quickly getting up and appearing to feel fine for the rest of the movie. While it may be possible for action heroes to continue on after sustaining an mTBI, for most individuals this is not safe and certainly not

advised. However, most participants assumed that you can be knocked unconscious and experience no ill effects. If they believe what they see on television as accurate, individuals may be engage in risky activities when their brain is still physiologically trying to recover following an injury. This may also contribute to the "walk it off" bravado that several participants reported was espoused by witnesses to their injury.

Of note, there were differences in TBI accuracy based on gender identity. Looking only at participants who identified as cisgender men or women, men had lower rates of TBI accuracy. Knowing that this discrepancy was not related to overall rates of TBI diagnosis, this suggests that there may be a gap in education of males regarding TBI related information. Health literacy disparities related to common conditions should be a priority for researchers to better understand and intervene.

Strengths and Limitations

One strength of this study was that it combined questions from a variety of studies completed over a 30-year period. This allows for the assessment of a more comprehensive set of facts related to TBI. Additionally, while this study was comprised of participants predominately from the southern United States, there was some geographic variability among participants. Finally, the demographic background of this study shows some inclusion of historically underrepresented demographic groups. In our study, the ethnic background of the sample closely mirrors most recent U.S. Census data. Having a sample that more closely reflects ethnic diversity of the population as a whole increases generalizability of the results. Additionally, 1.8% participants in the study identified as non-binary/transgender/questioning. Although this is a good start (many previous studies cited did not include gender options other

than male/female), it likely is not an accurate representation of these populations in the U.S. Future studies should consider recruiting participants of traditionally under-represented backgrounds in order to increase representation and understanding about these individuals.

There are some limitations to the current study. The biggest limitation is that this study relied solely on self-report data. Though care was taken in item creation, in some cases participants may have misunderstood questions, misreported information, or engaged in biased or dishonest (i.e., looking up answers) responding.

Future Directions

This study provides data that can help guide future projects for researchers and clinicians. Future studies should address some of the limitations discussed in the previous section, such as including a more gender diverse sample. Future studies may also continue exploring possible sources of information further and specifically locate where information is obtained. Clarifying questions related to sources may assist with the interpretation of some of the discrepancies noted in the study.

Based on the data collected in this study, there is a need to educate individuals about TBI after they sustain their first injury. Future studies could explore the most effective methods for providing this information, such as handouts, videos, follow up appointments, or individualized training. Another possible intervention could explore how to correct misinformation regarding TBIs. Individuals who reported formal TBI training in this sample had the lowest rates of TBI accuracy, suggesting that retraining regarding TBI knowledge may be warranted. Educational interventions could be constructed based on the current literature regarding health misinformation. Overall, the results of this study suggest that there is a gap in

the health knowledge of many Americans regarding a relatively common injury, suggesting that action is needed to stop the spread of inaccurate and potentially dangerous health information.

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Tables

Table 1

Participant Demographics

Variable	
Age	*M* = 25.49 years *SD* = 10.70 *Range* = 17-74
Gender	**% (n)**
Female	64.3% (398)
Male	35.2% (218)
Non-binary	.2% (1)
Questioning	.2% (1)
Transgender	.2% (1)
Racial Identity	**% (n)**
American Indian/Alaska Native	1% (6)
Asian	6% (37)
Black/African American	9.4% (58)
Multi-racial	4.4% (27)
Native Hawaiian/Pacific Islander	1.8% (11)
White	76.6% (474)
Other	1% (6)
TBI History – Formal Medical Diagnosis	
Yes	169
No	445
TBI History – Self-Diagnosis	
Yes	320
No	296
Athletic Identity	*M* = 40.87 (SD = 30.9)

Table 2

Source of TBI knowledge

Source	**Percent of TBI Information Received**
Health professional	55.55
Other Education source (i.e. health class, college course)	45.50
Personal experience (themselves or loved one)	24.18
Television/movies	13.76
Professional training/research	12.04
Websites	10.54
Print Media	9.37
Formal TBI training/programming	8.78
Social media	8.69
Medical Providers on YouTube	3.59
Other	2.91
Other: YouTube	1.98

Table 3

Pearson Correlations of continuous variables associated with TBI knowledge accuracy

Factor	***r***	**Significance (two-tailed)**
Age	-.085	.035
Identity as an Athlete	-.126	.001
Confidence of TBI knowledge	.017	.336
Accuracy of TV/movie portrays	-.297	<.001

Table 4

Point-Biserial correlations between dichotomous variables and TBI

Factor	**r**	**Significance (two-tailed)**
Gender	.145	<.001
Intentional un-reporting of suspected TBI	-.094	.010
TBI Experience (regardless of diagnosis)	.057	.080
Formal TBI Diagnosis	-.093	.010
TBI Training	-.140	<.001