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Impact of diagnostic terminology on parental attitudes toward concussion and brain injury

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Abstract

Although some have argued that the terms concussion and mild traumatic brain injury (mTBI) should not be used interchangeably, any differences between the diagnoses are subtle. In this study, we recruited 98 individuals through Amazon Mechanical Turk who self-identified as having children between the ages of 13 and 18 (inclusive). Participants were asked questions about a hypothetical injury to their child, related to symptoms, participation in school and physical activity, and recovery prognosis. Roughly half ($n = 51$) were asked these questions in reference to a “concussion”, and the remainder ($n = 47$) were asked questions in reference to an “mTBI.” Overall no significant differences were observed in terms of symptoms and prognosis, however, participants asked about an mTBI were more likely to expect activity restrictions (in both school and sports) than individuals asked about a concussion, $F(6, 89) = 3.1467$. This suggests an interesting dissociation between perceptions of injury severity, and attitudes toward participation. In addition, after adjusting the p-values to control for multiple comparison bias, an injury classified as an mTBI was also considered more likely than an injury classified as a concussion to: take more than a week to recover [$F(1,96) = 5.66, p = 0.040$]; result in symptoms that persisted for several months [$F(1, 96) = 5.69, p = 0.040$]; and present with feelings of sadness or depression [$F(1,96) = 5.27, p = 0.040$].

Keywords

concussion, mild traumatic brain injury, adolescent, parent, perceptions

Summary for Lay Audience

Despite the increasing similarities that exist between the terms concussion and mild traumatic brain injury (mTBI), some argue that these diagnoses should not be used interchangeably. For the purpose of this study we recruited 98 individuals through Amazon Mechanical Turk (an online crowdsourcing platform), who self-identified as the parent of at least one child between the ages of 13 and 18 years old. Participants received one of two versions of a survey that provided them with a hypothetical diagnosis for their child of either “concussion” or “mTBI.” Participants were then asked to complete 29 questions concerning their child’s expected symptoms, participation in school and physical activity, and expected recovery. Overall, no significant differences were found in terms of expected symptoms or recovery between those parents who received a diagnosis of concussion for their child and those who received a diagnosis of mTBI for their child. However, participants asked about an mTBI were more likely to expect activity restrictions (in both school and physical activity) than individuals asked about a concussion. This suggests an interesting disconnect between parents’ perceptions of injury severity, and attitudes towards their child’s participation. In addition, an injury classified as an mTBI was also considered more likely than an injury classified as a concussion to: take more than a week to recover; result in symptoms that persisted for several months; and present with feelings of sadness or depression.

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Chapter 1

1.1 Introduction

Approximately 1.7 million traumatic brain injuries (TBIs) occur each year, most of which are classified as mild (Faul, Xu, Wald, & Coronado, 2010). Within the literature, these “mild” brain injuries are sometimes referred to as mild traumatic brain injuries (mTBIs), and sometimes referred to as concussions (McCrory et al., 2017). Regardless of the terminology used, these injuries typically occur when an individual receives a blow to the head or body, with enough force to cause a jarring motion of the brain. This acceleration and/or deceleration motion can cause transient neurological symptoms that may ultimately result in serious physical, social and/or emotional implications (McCrory et al., 2017). Therefore, it is important that appropriate steps are taken during the post-injury management process to promote full recovery.

Unfortunately, there is some equivocation as to the definition of “concussion” and the definition of “mTBI” – and this may lead to confusion among clinicians and patients alike. Although the terms concussion and mTBI are often used interchangeably, it has been suggested that individuals may respond to these two terms differently (DeMatteo et al., 2010; Sullivan, Edmed, & Kempe, 2014; Weber & Edwards, 2010). It is plausible, therefore, that a lack of clarity surrounding concussion terminology may pose a challenge to clinicians, in that it may make it difficult for patients to fully understand the diagnosis that has been communicated to them. Thus, the purpose of this thesis is to examine possible differences in perceptions as to the severity, prognosis, and likely treatments associated with both of these terms.

1.2 Concussion versus mTBI

1.2.1 Concussion

A concussion is defined as “a traumatic brain injury induced by biomechanical forces” (McCrory et al., 2017, p. 2). According to the Centers for Disease Control and Prevention (2017), concussions are usually described as “mild” traumatic brain injuries, but the effects can still be severe and long-lasting. Individuals who sustain a concussion may experience temporary impairment in neurological function (which may or may not include loss of consciousness) following any application of force to the head or body, provided that the force is transmitted to the brain during the injury. The most commonly reported post-concussion symptoms include headache, emotional lability, dizziness, nausea and balance difficulties (McCrory et al., 2017). The majority of individuals can expect symptoms to subside within 10-14 days following injury. Some individuals may, however, experience symptoms that persist months or years past the 10-14 day timeframe (McCrory et al., 2017).

1.2.2 Mild traumatic brain injury

A mild traumatic brain injury is defined as “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon, Schwab, Wright, & Maas, 2010, p. 1637). According to Carroll et al. (2004, p. 115) a diagnosis of mTBI would be applied when an individual displays the following criteria:

- (1) *One or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, post-traumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities such as focal signs, seizure, and intracranial lesion not requiring surgery.*

(2) Glasgow Coma Scale score of 13–15 after 30 minutes post-injury or later upon presentation for healthcare

After sustaining an mTBI, individuals may experience a variety of somatic, cognitive, and affective (emotional) symptoms. For the majority, symptoms will resolve within a few weeks. However, for some these symptoms may persist for several months or even years following injury (Prince & Bruhns, 2017).

1.2.3 Concussion and mTBI: the same or different?

Given the similarities that exist between the definitions provided above it is apparent that these two terms, mTBI and concussion, reflect a similar injury. Most obvious is the relation between the mechanisms of injury, as both concussion and mTBI result from an external force being applied to the body causing the head to undergo a sudden acceleration and/or deceleration motion (McCrorry et al., 2017; Menon, Schwab, Wright, & Maas, 2010). However, their similarity is further pronounced when examining the events following injury (See Table 1).

Firstly, it is important to note that neither diagnosis requires an individual to lose consciousness, which is typically assessed using the Glasgow Coma Scale (GCS). The GCS is a standardized tool that was developed in 1974 by Graham Teasdale and Bryan Jennett for the purpose of measuring an individual's level of consciousness to better assist with the prognosis and management of head injuries (Teasdale & Jennett, 1976). Once a head injury has occurred, the scale monitors said individual's responsiveness to visual (1-4 points), verbal (1-5 points) and motor (1-6 points) information and will then provide a score between 3 and 15 (Teasdale & Jennett, 1976). A score falling between 3 and 8 reflects the presence of a "severe" head injury, a score between 9 and 12 would be considered "moderate," and a score between 13 and 15 is often

associated with an individual who has sustained a “mild” head injury (Rimel, Giordani, Barth, & Jane, 1982). Both an mTBI and concussion are considered to be on the mild end of the severity spectrum, and thus fall within a range of 13 and 15 (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004; Clark & Guskiewicz, 2016).

An overlap can also be found between the expected symptoms of an mTBI and a concussion. Following an mTBI, individuals may experience physical, cognitive, and emotional effects. Some physical symptoms include headache, sleep difficulties, nausea, and visual disturbances. Cognitively, individuals may struggle with multitasking, attention, memory, and processing speed (Prince & Bruhns, 2017). Finally, feelings of anxiety, emotional lability, irritability, and depression are commonly reported following an mTBI (Mild Traumatic Brain Injury Committee, 1993). Likewise, common symptoms of concussion include balance and sleep difficulties, headaches, emotional lability, irritability, fatigue, and issues with cognitive tasks such as sustaining attention and multi-tasking (McCrory et al., 2017). Lastly, the symptoms experienced following a concussion, as well as those following an mTBI, are often transient, with only some individuals being impacted more long-term (McCrory et al., 2017; Prince & Bruhns, 2017). Thus, based on the symptoms alone one can imagine that it would be difficult to decipher whether a concussion or an mTBI has occurred.

Table 1. Comparison of mTBI and Concussion Injury Characteristics

Injury Characteristics	Diagnosis	
	Concussion	MTBI
Definition	“a traumatic brain injury induced by biomechanical forces” (McCrorry et al., 2017, p. 2)	“an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon et al., 2010, p. 1638).
Mechanism of Injury	“A direct blow to the head, face, neck or elsewhere on the body with an impulsive force transmitted to the head.” (McCrorry et al., 2017, p. 2)	One of the following: <ul style="list-style-type: none"> - The head being struck by an object - The head striking an object - The brain undergoing an acceleration/deceleration movement - A foreign body penetrating the brain - Forces generated from events such as a blast or explosion - Or other forces yet to be defined (Menon et al., 2010, p. 1638)
Clinical Symptoms	May or may not experience: <ul style="list-style-type: none"> - Headache - Feeling in a fog - Emotional lability - LOC - Gait unsteadiness - Irritability - Slowed reaction times - Sleep disturbances (McCrory et al., 2017)	May or may not experience: <ul style="list-style-type: none"> - LOC (<30mins) - Headache - Sleep disruptions - Dizziness - Nausea - Irritability - Emotional lability - Difficulties with multitasking, attention, or memory - Slow processing speed - Sensitivity to light or noise (Mild Traumatic Brain Injury Committee, 1993; Prince & Bruhns, 2017)
Recovery Time	- 10 to 14 days - Potential persistent symptoms (McCrory et al., 2017)	- Within a few days to a few weeks - Potential persistent symptoms (Ruff et al., 2009)
Recovery Protocol	- Prescribed rest - Gradual re-integration into activity (McCrory et al., 2017)	- Prescribed rest - Gradual re-integration into activity (Lumba-Brown et al., 2018)

Considering the similarities that exist between these injuries, differentiating between what constitutes a concussion and what constitutes an mTBI has been an ongoing challenge. At one point in time, concussion was considered to be different from mTBI, as it was said to only result in transient functional disturbances, while an mTBI was believed to encompass a broader injury, involving functional and/or structural impairments (McCrory et al., 2013). However, as neuroimaging technology continues to advance, this hypothesis has been called into question, as microstructural changes have been witnessed following a concussion, specifically in white matter regions of the brain (Sasaki et al., 2014).

One difference may be found, however, in the context in which these diagnoses are applied. According to Bodin et al. (2012), the term “concussion” is currently used more commonly within the sport medicine community, while the term mTBI tends to be more prevalent within other medical specialties. Perhaps this is due to the fact that general medical specialists may see more of the TBI spectrum including, mild, moderate and severe brain injuries, as opposed to a sport medicine specialist who typically would deal with injuries on the mild end of the brain injury spectrum. Nonetheless, the discrepancy between the use of these terms is disconcerting as it has been found that individuals may respond differently to the varying nomenclature. Currently, it appears that an injury classified as a concussion may be perceived by the general public as a more transient, or less severe injury, than one diagnosed as an mTBI (Weber & Edwards, 2010). This trend may even be true for some physicians. DeMatteo et al. (2010) found that children who were hospitalized for a mild head injury were more likely to receive a diagnosis of concussion (as opposed to an mTBI) from physicians if their GCS scores appeared mild, thus implying a lesser severity. The authors presume that a diagnosis of a

concussion may be less upsetting for parents to receive from physicians as opposed to a diagnosis of an mTBI.

The lack of uniformity between the use of these terms has clearly created a source of confusion for both clinicians (in determining which diagnosis to provide), and patients and caregivers (in identifying necessary recovery protocols following diagnosis). Given the similarity in injury characteristics for these diagnoses, we will use the term ‘concussion’ throughout the remainder of this thesis, when referring to a brain injury of this grade.

1.3 Adolescent concussion recovery protocols

The highest rate of concussion is among those under the age of 18 (Munro et al., 2015), which is particularly disconcerting as adolescents may be more vulnerable to the effects of these injuries (McCrory et al., 2017). Therefore, it is important that appropriate steps are taken during the post-injury management process.

The majority of individuals will achieve complete recovery from the effects of a concussion within 10-14 days. The adolescent population is, however, more sensitive to the effects of concussions, with symptoms frequently extending past the suggested 10-14 day recovery period (McCrory et al., 2017). Disruptions may occur within the adolescent’s physical, behavioural, and cognitive functioning which may lead to serious long term implications if not managed appropriately (Valovich Mcleod, Wagner, & Welch Bacon, 2017). Therefore, following a concussion, it is important to consider the timing (and pacing) of re-integration of the adolescent back into school and sport. The current consensus statement on concussion recommends a 24-48 hour period of rest, followed by a gradual re-integration with cognitive and physical activity (McCrory et al., 2017). Adolescents are typically re-integrated with their

activities of daily living through a Return to School protocol that consists of both Return to Learn (RTL) and Return to Play (RTP) guidelines. The RTL protocol is a 4-stage process that begins with symptom-free daily activities in the home environment then gradually increases cognitive tasks and re-integration into the classroom, as the adolescent moves between each stage (McCrory et al., 2017). Simultaneously, the adolescent may be engaging in an RTP protocol. Recreation-related concussions are becoming an increasing concern within the adolescent population (Coronado et al., 2015), therefore RTP protocols are essential in preventing premature return to activity and in reducing the risk of receiving a subsequent blow to the head that may lead to potentially catastrophic effects (Karlin, 2011). The RTP process can be completed in 6 stages while gradually increasing between steps from symptom-limited activity all the way to normal game play (McCrory et al., 2017). If the adolescent experiences concussion symptoms at any point during activity they must revert back to the previous stage of their RTP protocol (McCrory et al., 2017). Given the heterogeneity of injuries (and symptoms), concussion management must be customized to suit each adolescent's unique needs. Some may require additional assistance in their return to activity and therefore accommodations should be provided, particularly within the school environment (McCrory et al., 2017). Neglecting to follow appropriate recovery protocol by premature return to physical or cognitive activity may result in the exacerbation of symptoms and ultimately the prolongation of the recovery process (Carson et al., 2014; Master, Gioia, Leddy, & Grady, 2012).

1.4 The role of the parent

Adolescents are (typically) under parental care, and so it is the responsibility of the parent to ensure that their child receives the necessary medical assistance and to follow through with an appropriate recovery protocol. Following a concussion, the physician will communicate the

diagnoses to the adolescent, along with his or her parent, who will then monitor and reinforce the recovery protocol within the home environment (Guskiewicz et al., 2004). Support has been shown to be an important factor within the recovery and return to activity processes for adolescents who have sustained a concussion. Parents and other family members are one of the main sources of support and can act as a protective factor during the recovery process (Covassin et al., 2014). Proper support from a parent can also assist in grading return to activity (McGuckin, Law, McAuliffe, Rickwood, & Bruner, 2016). With the amount of influence and authority a parent holds over the adolescent recovery process it is important to understand their perceptions regarding concussion diagnoses. A parent's initial interpretation of the diagnosis is likely to be important in constructing judgements of injury severity, along with the level of importance ascribed to adhering to recovery protocols.

1.5 Impact of diagnostic terminology on injury perceptions

Currently, there is a great deal of uncertainty surrounding concussions. This confusion may stem from the abundance of nomenclature used to describe this type of injury. McKinlay, Bishop, and McLellan (2011) explored the general public's perceptions toward different brain injury diagnoses, along with their understanding of the term concussion. Interestingly, the authors found that of their 103 participants, 29 acknowledged that they had experienced a concussion firsthand, but over half (58.6%) of the 29 participants claimed that they did not have a head or brain injury (McKinlay, Bishop, & McLellan, 2011). This is particularly concerning as it suggests there may be misperceptions surrounding the term concussion and the injury it reflects.

Within the literature, however, there are inconsistent findings as to the influence of concussion terminology on injury perceptions. For example, Kempe, Sullivan, & Edmed (2013) found the term concussion to cause individuals to perceive worse post-concussion symptoms than the term mTBI. The participants consisted of staff and students from Queensland University who were randomly assigned to one of two groups: a concussion group or an mTBI group. The participants received a vignette illustrating a motor vehicle accident that was followed up by two pages of discharge information. The only difference between the groups was the hypothetical diagnosis (concussion or mTBI) used within the discharge pamphlet. Finally, the participants were asked to complete several measures assessing post-concussion syndrome symptoms and expected illness perceptions. The results showed that the “concussion group” expected more post-concussion syndrome symptoms to be experienced than the “mTBI group,” despite the fact that there were no significant group differences between the diagnostic terminology on illness perceptions, for either recovery timelines or injury consequences (Kempe, Sullivan, & Edmed, 2013).

Interestingly, another study conducted by these authors displayed very different results. Sullivan, Edmed, & Kempe (2014) examined the influence different brain injury diagnoses had on perceptions of injury expectations and outcomes. The authors used a vignette method illustrating a motor vehicle accident and concluded with a diagnoses of one of four options: (i) mTBI, (ii) concussion, (iii) mild head injury, or (iv) no diagnosis. The results showed that the diagnoses had significant effect on undesirability of injury, illness perceptions and expected Post Traumatic Stress Disorder (PTSD) symptoms, with mTBI being higher, or perceived to be “worse” than concussion, in all three outcomes.

When conducting a subsequent study with a sample of athletes, however, the authors found no difference between the two terms (Edmed & Sullivan, 2015). In this study, the authors took a sample of 122 undergraduate students at Queensland University who played contact sports, to determine the influence of diagnostic terminology on concussion injury perceptions and expected symptoms. The participants were randomly assigned to one of three groups; a concussion group, an mTBI group and a control group. All participants were provide a vignette illustrating a sport-related mTBI and were then asked to complete several measures assessing expected symptoms, illness perceptions, and desirability of injury.

1.6 Impact of diagnostic terminology on recovery protocol perceptions

Current concussion recovery protocols include an initial period of complete rest followed by gradual re-integration into daily activities, such as school and sports. It is important that individuals do not return to activity prematurely, resulting in the exacerbation and/or prolongation of symptoms (McCrory et al., 2017). It has been shown, however, that the use of varying diagnostic terminology may influence the concussion recovery process, including the amount of time one takes before returning to activity.

DeMatteo et al. (2010) studied the association between a diagnosis of concussion with the timeframe of discharge and return to school for children who were admitted at a Canadian hospital. The results demonstrated a strong association between those children who received a diagnosis of concussion, and children that were discharged from hospital earlier, as well as those who returned to school sooner. DeMatteo et al. (2010) noted that a diagnosis of concussion may be perceived as less “alarming” than a diagnosis of mTBI. Similar results were reported by Weber and Edwards (2010). In this study, researchers sampled over 200 university athletes to

compare familiarity of three commonly used diagnostic terms; concussion, mTBI, and minor head injury. A questionnaire was distributed that consisted of three versions that differed only in the diagnostic terminology used. The questionnaire included 29 items assessing injury outcome expectations, 3 items examining familiarity, and concluded with an open ended question prompting the participants to list the single most important indicator of the term they received. The results suggested that the term mTBI was perceived more negatively and was less familiar to the participants than the terms concussion and mild head injury. The results also indicated that mTBIs may result in a longer recovery time compared to the other terms. According to participants, an mTBI may not result in complete recovery, leaving individuals with learning difficulties, depression-like symptoms and a higher susceptibility in acquiring another comparable injury (Weber & Edwards, 2010).

Finally, Kelly and Erdal (2017) surveyed a group of both athletes and nonathletes to determine how diagnostic terminology impacted return to play perceptions and anticipated symptoms. The participants received a vignette illustrating a motor vehicle accident that concluded with a hypothetical diagnosis of either mTBI or concussion. Participants were then asked to complete several measures that assessed anxiety, post-concussive symptoms, perceptions of illness and return to play decisions. The authors did not find a significant difference between the two terms on measures of anticipated symptomology, anxiety, or injury expectations. However, the participants who received a diagnosis of mTBI consistently allocated more days to post-injury rest, as well as a longer time frame before returning to play, than the group diagnosed with a concussion (Kelly & Erdal, 2017). This suggests that diagnostic terminology could potentially impact an individual's investment in their prescribed recovery protocol following injury.

1.7 Parent perceptions of diagnostic terminology

The initial diagnosis provided by a health care provider is important as it provides information on the injury that has occurred along with the steps to be followed for treatment. Likewise, the patient/caregiver's interpretations of a diagnosis are equally as important as they can potentially influence the judgements made toward the injury. As the number of concussions continues to rise, particularly in the adolescent population (Coronado et al., 2015), it is necessary to examine the initial perceptions that parents have toward concussions and their management. The parent population has been greatly overlooked in this area of research with only two studies having specifically addressed this issue at this time.

Gordon, Dooley, Fitzpatrick, Wren, and Wood (2010) explored the terms concussion, minor traumatic brain injury, and mTBI to assess whether parents believed these diagnoses to be equivalent, "better", or "worse." Parents who were accessing non-emergency healthcare for their children at a pediatric Emergency Department were given a questionnaire comparing the three terms. The questionnaire gave scenarios comparing two of the terms at a time to assess the equivalence. The majority of parents perceived the terms mTBI and concussion to be the equal in regard to injury severity. However, for those who perceived a difference between the terms, concussion was consistently considered to be "better" than an mTBI (Gordon, Dooley, Fitzpatrick, Wren, & Wood, 2010). Although this study does explore parental perceptions toward the severity of diagnostic terminology, it does not assess how their perceptions toward injury severity might impact their child's adherence to recovery protocol. In addition, the participants in this study were provided two terms at a time and were therefore aware of the objective of comparing the diagnoses. In reality, after an individual sustains an injury they typically receive only one diagnosis from their physician. Therefore, by directly comparing two diagnostic terms

this may not accurately reflect the perceptions one may have toward one diagnosis over the other when received individually.

In addition, Raugust and Latter (2013) sought to determine the impact of diagnostic terminology on return to play decisions made by parents. The authors distributed three versions of an identical questionnaire only differing in the diagnosis given: (1) concussion, (2) mTBI; or (3) concussion, which is a form of mTBI. A sample of 1409 pediatric ice hockey parents were asked to respond to the questionnaire by providing the number of days they felt their child should rest before returning to play. The results demonstrated that the diagnostic terminology had a significant impact on the number of days parents allocated for their child's rest, with parents being consistently less cautious when receiving a diagnosis of "concussion" as opposed to a diagnosis of "mTBI" or a diagnosis of "concussion, a form of mTBI". Although this study does contribute a better understanding to the impact concussion terminology may have on parent's attitudes toward return to play and prescribed rest, it does not explore any other area of participation.

1.8 The present research

The present study aims to explore parent perceptions of a diagnosis of concussion versus mTBI. Specifically the authors will address parent perceptions of expected symptoms and expected recovery protocol for their adolescent following a hypothetical diagnosis of either concussion or mTBI. The participants will be randomly divided into two groups, a "concussion" group and an "mTBI" group and will then be directed to an online survey. The survey will consist of 29 items; 11 assessing severity perceptions and 18 that assess attitudes toward treatment. The participants will be asked to respond with their level of agreement to each

statement provided using a 5-point Likert scale ranging from “strongly disagree” to “strongly agree.” Similar to Kelly & Erdal’s (2017) study, each participant will only receive one diagnosis according to the group they are in so they may remain blind to the study’s purpose of comparing the terms. However, unlike the 2017 study the current authors will not only assess attitudes toward return to play, but also attitudes concerning their return to other various activities, including return to school, which has not yet been explored within the literature. Exploring parental perceptions of concussion terminology may allow for a better understanding of the recovery decision-making process for their adolescent following a concussion. This may also further inform clinicians in choosing how to communicate a diagnosis of concussion to their patient. Ultimately, this will ensure that individuals fully understand the severity of the injury that has occurred so that they may proceed with the appropriate recovery protocol.

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Chapter 2

2.1 Introduction

Approximately 70-90% of all treated traumatic brain injuries are considered mild, with the highest rate of these mild brain injuries, also known as concussions, occurring among individuals under the age of 18 (Cassidy et al., 2004). A concussion is caused when an external force is applied either directly to the head or indirectly to the body, causing the head to undergo a sudden acceleration and/or deceleration motion (McCrory et al., 2017). Commonly reported symptoms include headache, amnesia, fatigue, sleep disturbances, and emotional lability. The majority of individuals recover from a concussion within 10-14 days, but some individuals – particularly children and adolescents – have symptoms that persist well beyond the suggested recovery period. This is disconcerting, as adolescents are especially vulnerable to disruption of physical, cognitive, behavioural, and somatic functioning caused by concussions (McCrory et al., 2017). Therefore, in order to encourage a complete and safe recovery, individuals should be given a systematic recovery protocol to follow when returning to their former levels of participation (McCrory et al., 2017).

The Berlin consensus statement describes the most widely accepted recovery protocol, which recommends a brief 24-48 hour period of complete rest post-concussion, followed by a gradual re-integration into daily activities while remaining below the symptom exacerbation threshold (McCrory et al., 2017). Following a concussion, it is important to consider the timing (and pacing) of re-integration of an individual into school and sport. The period of prescribed rest is essential in allowing time for symptom recovery as well as for preventing premature return to activity that might put the individual at risk for subsequent injury, which may lead to catastrophic effects (McCrory et al., 2017). Thus, it is critical that concussed individuals (and

their caregivers) fully understand the diagnosis of concussion and how to proceed with its recovery.

Unfortunately, this may be more challenging given the ambiguity surrounding concussion terminology. One potential source of confusion is the inconsistent terminology that is used to describe such injuries. Within the literature, “concussion” and “mild traumatic brain injury (mTBI)” are often used interchangeably. An abundance of definitions can be found for both of these terms as experts have continuously worked to refine these definitions to most accurately reflect the injuries. Currently, the most widely accepted definition of concussion is a “traumatic brain injury induced by biomechanical forces” (McCrory et al., 2017, p. 2). Alternatively, mild traumatic brain injury reflects “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon, Schwab, Wright, & Maas, 2010, p. 1637). Clearly these terms reflect highly similar injuries, rendering it difficult for laypersons (or even non-specialist clinicians) to differentiate between the two. For example, both injuries occur due to an external force being applied to the body causing an acceleration and/or deceleration movement of the head (McCrory et al., 2017; Menon et al., 2010). Similar to concussion symptoms, common symptoms of an mTBI include headache, nausea, irritability, sleep disturbances, and difficulties with cognitive tasks such as attention and memory (Prince & Bruhns, 2017). In addition, neither injury requires an individual to lose consciousness (McCrory et al., 2017; Menon et al., 2010). In fact, when assessing level of consciousness following injury, both a concussion and an mTBI would be classified as a “mild” injury, with the individual receiving a score between 13-15 on the Glasgow Coma Scale (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004; Clark & Guskiewicz, 2016; Rimel, Giordani, Barth, & Jane, 1982). Lastly, both terms are described as transient injuries, meaning that symptoms are typically expected to

resolve anywhere within a few days to a couple weeks following injury, with only a portion of individuals experiencing persistent symptoms beyond this timeframe (McCrory et al., 2017; Ruff et al., 2009).

Despite the similarity of the injury characteristics for mTBI and concussion, some have cautioned against their interchangeable use, suggesting that it contributes to the lack of clarity surrounding concussion nomenclature (McCrory, 2001). Currently, the term “concussion” is used more commonly within the sport medicine community to describe a mild brain injury, while the term “mTBI” is more prevalent within other medical specialities (Bodin, Yeates, & Klamar, 2012). The inconsistent use of these diagnoses may create uncertainty regarding what each injury entails, what symptoms are to be expected, and what steps need to be taken following injury.

For example, a study conducted by DeMatteo et al. (2010) found that a diagnosis of concussion may be perceived as less “alarming” than a diagnosis of mTBI. DeMatteo et al. (2010) studied discharge and return to school time frames of children who were admitted to a Canadian hospital following a head injury. The authors found a strong association between those children who received a diagnosis of concussion, and children that were discharged from hospital earlier, as well as those who returned to school sooner. The authors suggested that health care providers may communicate a diagnosis of concussion (as opposed to an mTBI) as this may be less upsetting to parents, thus implying a lesser severity associated with a concussion diagnosis (DeMatteo et al., 2010). Another misperception concerning concussions was demonstrated by McKinlay, Bishop, & McLellan (2011) as they assessed the general public’s understanding of the term. The authors found that of the 29 participants within their study that acknowledged having experienced a concussion firsthand, over half claimed that they did not have a head or brain

injury (McKinlay, Bishop, & McLellan, 2011). Based on these results it is evident that there is a disconnect between the term concussion and the actual injury it entails.

There are, however, inconsistent findings within the current literature as to the impact that terminology might have on injury perceptions. For example, one study conducted by Kempe, Sullivan, and Edmed (2013) found the term “concussion” to be worse in expected post-concussion symptoms when compared to the term “mTBI.” Interestingly, a subsequent study conducted by the same authors assessed the influence different diagnoses had on undesirability of injury, illness perceptions, and Post Traumatic Stress Disorder symptoms, and found mTBI to be “worse” than concussion in all three outcomes (Sullivan, Edmed, & Kempe, 2014). A third study by Edmed and Sullivan (Edmed & Sullivan, 2015) demonstrated no difference between these two diagnoses in terms of expected symptoms or illness perceptions, further illustrating the equivocation surrounding the difference between these terms.

Most concerning, however, is the influence that terminology may have on recovery protocols. Weber and Edwards (2010) sampled over 200 university athletes to compare familiarity of three commonly used diagnostic terms; “concussion”, “mTBI”, and “minor head injury”. The results demonstrated that out of all three terms, mTBI was perceived more negatively and was less familiar to the participants. An mTBI was also associated with a longer recovery time with participants more likely to consider an mTBI to not result in complete recovery, leaving individuals with learning difficulties, depression-like symptoms and a higher susceptibility in acquiring another comparable injury (Weber & Edwards, 2010).

Kelly and Erdal (2017) directly compared the terms “concussion” and “mTBI” to determine their impact on return to play perceptions and anticipated symptoms. Although the authors did not find a significant difference between the two diagnoses in regard to expected

symptomology, those who received a diagnosis of mTBI consistently allocated more days to post-injury rest, as well as a longer time frame before returning to play, than the group diagnosed with a concussion (Kelly & Erdal, 2017). This suggests that diagnostic terminology could potentially impact an individual's investment in their prescribed recovery protocol following injury.

Clearly, there remains significant uncertainty as to the impact that different diagnoses may have on individual interpretations of brain injuries, and recovery therefrom. One population in particular that has been overlooked in this area of research are parents. When dealing with concussions in children and adolescents, the role of the parent is especially important, due to their authority over the treatment process. It has been shown that parents hold the strongest influence over their child's decision to seek health care services (Wahlin & Deane, 2012). Thus, considering the significant role that parents play it is essential that their attitudes toward concussion diagnoses, along with the recovery process, are better understood.

To date, only two studies have specifically addressed parent perceptions of concussion terminology. Gordon, Dooley, Fitzpatrick, Wren, & Wood (2010) explored the terms concussion, minor traumatic brain injury, and mTBI to assess whether parents believed these diagnoses to be equivalent, "better", or "worse." The majority of parents perceived the terms mTBI and concussion to be equal in regards to injury severity. However, for those who perceived a difference between the terms, concussion was consistently considered to be "better" than mTBI (Gordon, Dooley, Fitzpatrick, Wren, & Wood, 2010). Although this study does explore parental perceptions on the severity of diagnostic terminology, it does not assess how these terms may impact parents' attitudes toward their child's expected symptoms, ability to participate, and return to activities following injury.

A subsequent study conducted by Raugust and Latter (2013) assessed the influence of concussion terminology on parental attitudes toward their child's recovery, specifically concerning the days of rest they would allocate for their child before returning to play. The authors compared three diagnoses: "concussion"; "mTBI"; and "concussion, a form of mTBI". The results indicated that parents were significantly less cautious when allocating days of rest following injury when provided a diagnosis of "concussion" as opposed to "mTBI" or "concussion, a form of mTBI" (Raugust & Latter, 2013). Although this study does explore the impact concussion terminology has on parent's return to play and rest expectations, similar to Gordon et al. (2010), they failed to address other areas of adolescent participation. After an adolescent has sustained a concussion there are a variety of activities that the child is expected to return to within the school, sport and social environments. Therefore, exclusion of some areas of participation makes it difficult to fully understand the impact that terminology might have on the recovery process. The foregoing suggests that it may be fruitful to further explore parental perceptions toward concussion terminology, and to ultimately understand how these perceptions may influence their adolescent's adherence to recovery protocol.

Therefore, the aim of the current study was to explore parents' attitudes toward concussion terminology and how a diagnosis of a concussion versus a diagnosis of an mTBI may alter their interpretations toward their adolescents injury and, subsequently, their return to activity. The current researchers sought to explore the following question: do parents change their attitudes toward the requirements of treatment when given a diagnosis of concussion, as opposed to a diagnosis of mTBI?

2.2 Methods

2.2.1 Participants

All participants were recruited through Amazon Mechanical Turk (mTurk), with no specification as to the geographical location of the individuals. In an attempt to ensure that our population consisted entirely of parents, we specified that individuals were to be “verified parents” within the mTurk system. We similarly required that individuals be qualified as “Masters” within the mTurk system. The Masters Qualification in mTurk is used by the system to identify individuals who have been identified as having performed at a consistently high level of performance in previously completed tasks. MTurk engages in continual monitoring and reassessment of individuals to ensure that performance continues to be high. Individuals were also required to be fluent in English, in order to participate in the task. We recruited 98 parents (52 females, 45 males, 1 missing value) aged 26 to 59 (mean = 39.26, SD = 5.96) who self-reported having at least one child between the ages of 13 to 18. The majority of participants (n = 50) reported having a 4 year degree, but some reported having a graduate or professional degree (n = 21), some college (n = 13), or a 2 year degree (n = 7). Seven of the participants reported that high school was their highest level of education. None of these demographic characteristics differed significantly between groups.

2.2.2 Procedure

After screening for parental status, the participants were randomly assigned to one of two groups, concussion (n= 51) or mTBI (n= 47). All participants were then directed to a brief survey consisting of 29 questions; 11 assessing injury severity perceptions and 18 that assessed their attitudes toward treatment. These questions are presented in Table 2.1. Each participant received the same set of survey questions with the only difference between the two groups being the

diagnosis used. The mTBI group were assigned to a survey that used the term “mTBI” to describe a hypothetical injury, while the concussion group received a survey using the term “concussion” to describe the injury. Participants were asked to select their level of agreement to each survey item using a five point Likert scale, ranging from “strongly disagree” to “strongly agree.” The aim of this survey was to collect information concerning: (a) differential perceptions of the severity of mTBI versus concussion; (b) differential perceptions as to the required treatment for each of these diagnoses; and (c) self-reported estimates of an individual’s likelihood of adherence to treatment protocols within each of these diagnoses.

2.2.3 Statistical Analysis

Wherever possible, multiple comparison bias was managed using multivariate analyses (MANOVA) prior to calculating univariate statistics (Hummel & Sligo, 1971), and in the case where the multivariate effect was non-significant, no adjustment was made to the per-comparison alpha of any subsequent univariate analyses. Within families of comparison where the multivariate effect was non-significant, error was controlled by managing the false discovery rate within the set of comparisons, using methods described by Benjamini and Hochberg (1995). The questionnaire was subdivided into 4 sections, that formed the families of comparisons used in this study: (1) attitudes toward symptoms and recovery time; (2) attitudes toward participation; (3) attitudes toward next-day action; and (4) attitudes toward next-week action. All analyses were conducted within R (R Core Team, 2019). Some analyses were conducted using the `psych` (Revelle, 2018) and `data.table` (Dowle & Srinivason, 2019) packages.

Table 2.1. Survey Questions (each scored using a 5-point Likert scale ranging from “Strongly Disagree” to “Strongly Agree”)

If my child received a [Concussion / mTBI], he or she:

1. may experience a loss of consciousness
2. would likely recover in about a week
3. would likely take more than a week to recover
4. may experience symptoms for several months after the injury
5. may experience feelings of sadness or depression

[Concussion / mTBI] is likely to result in an impairment that would:

6. prevent my child from attending school for a day
7. prevent my child from attending school for a week or more
8. prevent my child from participating in physical education class
9. prevent my child from participating in recreation-league sports
10. prevent my child from participating in competitive-level sports
11. require an academic accommodation for my child (e.g., writing tests in a separate room)

If my child received a [Concussion / mTBI], the next day I would:

12. notify my child’s school, teachers, and/or coaches of the injury
13. keep my child home from school
14. restrict my child’s “screen time” (e.g., television, phone, tablet, computer)
15. restrict activities that require sustained attention (e.g., reading, writing, homework)
16. restrict my child’s exposure to bright lights
17. restrict my child’s exposure to loud noises
18. ask to have him or her excused from physical education class
19. not allow him or her to participate in recreation-league sports
20. not allow him or her to participate in competitive-level sports

If my child received a [Concussion / mTBI] a week ago, and was still experiencing symptoms (e.g., headache), I would:

21. seek medical attention for my child
22. keep my child home from school
23. restrict my child’s “screen time” (e.g., television, phone, tablet, computer)
24. restrict activities that require sustained attention (e.g., reading, writing, homework)
25. restrict my child’s exposure to bright lights
26. restrict my child’s exposure to loud noises
27. ask to have him or her excused from physical education class
28. not allow him or her to participate in recreation-league sports
29. not allow him or her to participate in competitive-level sports

2.3 Results

2.3.1 *Attitudes toward Symptoms and Recovery Time*

Multivariate and univariate tests of the 5 items within this family of comparisons are presented in Table 2.2. The multivariate test of the items assessing attitudes toward symptoms was non-significant, $F(5,92) = 1.74, p = 0.13$. Participants did, however, indicate that they considered it likely that an injury classified as an mTBI (as compared to an injury classified as a concussion) would be more likely to: take more than a week to recover [$F(1,96) = 5.66, p = 0.040^1$]; result in symptoms that persisted for several months [$F(1, 96) = 5.69, p = 0.040^1$]; and present with feelings of sadness or depression [$F(1,96) = 5.27, p = 0.040^1$].

2.3.2 *Attitudes toward Participation*

Multivariate and univariate tests of the 6 items within this family of comparisons are presented in Table 2.3. The multivariate test of the items assessing attitudes toward participation was statistically significant, $F(6,89) = 3.15, p = 0.0076$. The participants indicated that they considered an injury classified as an mTBI (as compared to an injury classified as a concussion), to be more likely to: prevent their child from returning to school for a week or more [$F(1,94) = 11.09, p = 0.0012$]; prevent their child from returning to physical education class [$F(1,94) = 7.77, p = 0.0064$]; prevent their child from participating in recreation-league sports [$F(1,94) = 5.41, p = 0.022$] or competitive-league sports [$F(1,94) = 7.73, p = 0.0066$]; and to require an academic accommodation following injury [$F(1,94) = 3.94, p = 0.05$]. However, there was no significant difference indicated between an mTBI and concussion when asked if the diagnosis would prevent their child from returning to school for a day [$F(1,94) = 0.22, p = 0.64$].

¹ p-value adjusted using the FDR method described by Benjamini and Hochberg (1995)

Table 2.2. Differences between “concussion” and “mTBI” groups’ attitudes toward symptoms and recovery time

Item	Concussion		mTBI		F(1,96)	p	p _{adj}	η^2_{partial}
	Mean	SD	Mean	SD				
may experience a loss of consciousness	3.98	1.19	4.26	0.74	1.85	0.18	0.22	0.019
would likely recover in about a week	3.49	1.27	3.17	1.27	1.55	0.22	0.22	0.016
would likely take more than a week to recover	2.98	1.27	3.57	1.19	5.66	0.019	0.040*	0.056
may experience symptoms for several months after the injury	3.25	1.21	3.83	1.17	5.69	0.019	0.040*	0.056
may experience feelings of sadness or depression	3.43	1.14	3.91	0.93	5.27	0.024	0.040*	0.052

Note: Multivariate effect was non-significant, $F(5,92) = 1.7368$, $p = 0.134$. Univariate p-values adjusted using the FDR method described by Benjamini and Hochberg (1995).

Table 2.3. Differences between “concussion” and “mTBI” groups’ attitudes toward participation

Item	Concussion		mTBI		F(1,94)	p	η^2_{partial}
	Mean	SD	Mean	SD			
prevent my child from attending school for a day	3.90	1.10	4.06	1.13	0.22	0.64	0.0021
prevent my child from returning to school for a week or more	2.90	1.32	3.79	1.25	11.087	0.0012	0.105
prevent my child from participating in physical education class	3.69	1.10	4.26	0.74	7.77	0.0064	0.076
prevent my child from participating in recreation-league sports	3.94	1.03	4.34	0.70	5.41	0.022	0.054
prevent my child from participating in competitive-level sports	3.78	1.23	4.38	0.85	7.73	0.0066	0.076
require an academic accommodation for my child (e.g., writing tests in a separate room)	2.69	1.34	3.21	1.21	3.94	0.050	0.040

Note: Multivariate effect was significant, $F(6,89) = 3.1467$, $p = 0.007618$

2.3.3 *Attitudes toward Next-day Activity*

Multivariate and univariate tests of the 9 items within this family of comparisons are presented in Table 2.4. The multivariate test of the items assessing attitudes toward next day activity was non-significant, $F(9,84) = 1.44$, $p = 0.18$. None of the univariate comparisons were statistically significant after adjusting for multiple comparison bias.

2.3.4 *Attitudes toward Next-week Activity*

Multivariate and univariate tests of the 9 items within this family of comparisons are presented in Table 2.5. The multivariate test of the items assessing attitudes toward next week activity was non-significant, $F(9,87) = 0.93$, $p = 0.50$. None of the univariate comparisons were statistically significant after adjusting for multiple comparison bias.

Table 2.4. Differences between “concussion” and “mTBI” groups’ attitudes toward next day activity

Item	Concussion		mTBI		F(1,92)	p	p _{adj}	η^2_{partial}
	Mean	SD	Mean	SD				
notify my child’s school, teachers, and/or coaches of the injury	4.33	0.82	4.57	0.74	2.50	0.12	0.35	0.026
keep my child home from school	3.94	1.21	4.17	1.07	1.18	0.28	0.40	0.013
restrict my child’s “screen time” (e.g., television, phone, tablet, computer)	3.76	1.24	4.17	1.01	2.77	0.099	0.35	0.029
restrict activities that require sustained attention (e.g., reading, writing, homework)	3.73	1.20	3.91	1.16	0.71	0.40	0.45	0.0077
restrict my child’s exposure to bright lights	3.94	1.05	3.87	1.35	0.071	0.79	0.79	0.00078
restrict my child’s exposure to loud noises	4.00	0.95	4.28	1.02	1.49	0.22	0.40	0.016
ask to have him or her excused from physical education class	4.18	1.14	4.39	0.95	1.052	0.31	0.40	0.011
not allow him or her to participate in recreation-league sports	4.14	1.17	4.45	0.80	1.84	0.18	0.40	0.020
not allow him or her to participate in competitive-level sports	3.94	1.32	4.49	0.78	5.11	0.026	0.23	0.053

Note: Multivariate effect was non-significant, $F(9,84) = 1.4418$, $p = 0.1837$

Table 2.5. Differences between “concussion” and “mTBI” groups’ attitudes toward next week activity

Item	Concussion		mTBI		F(1,95)	p	p _{adj}	η^2_{partial}
	Mean	SD	Mean	SD				
seek medical attention for my child	4.49	0.90	4.51	0.86	0.0035	0.95	0.95	4.04
keep my child home from school	4.02	1.16	4.30	0.88	1.50	0.22	0.40	0.016
restrict my child’s “screen time” (e.g., television, phone, tablet, computer)	3.92	1.09	4.21	1.04	1.80	0.18	0.40	0.019
restrict activities that require sustained attention (e.g., reading, writing, homework)	3.88	1.14	4.19	0.95	2.10	0.15	0.40	0.022
restrict my child’s exposure to bright lights	3.92	1.11	4.13	1.19	0.64	0.42	0.55	0.0067
restrict my child’s exposure to loud noises	4.04	0.98	4.21	1.12	0.65	0.42	0.55	0.0068
ask to have him or her excused from physical education class	4.31	0.93	4.40	0.88	0.12	0.72	0.82	0.0013
not allow him or her to participate in recreation-league sports	4.35	1.04	4.62	0.77	1.89	0.17	0.40	0.019
not allow him or her to participate in competitive-level sports	4.32	0.98	4.60	0.68	2.57	0.11	0.40	0.026

Note: Multivariate effect was non-significant, $F(9,87) = 0.93233$, $p = 0.5015$

2.4 Discussion

The purpose of this study was to investigate the influence that commonly used diagnostic terms, “concussion” and “mTBI”, had on parental perceptions of injury expectations and attitudes toward recovery protocol for their child. No significant difference was found between the two terms concerning the participants attitudes toward next day or next week activity for their adolescent. Likewise, the results indicated no difference between the concussion and mTBI groups when assessing their attitudes toward symptoms. However, an injury classified as an mTBI was perceived to be more likely than an injury classified as a concussion to take more than a week to recover, to result in symptoms that persisted for several months, and to present with feelings of sadness or depression. Although there was little variation between the groups on expected activity and symptomology, a significant difference was found when assessing participants attitudes toward adolescent participation. Participants indicated that they were more likely to prevent their child from returning to school for a week or more and were more likely to prevent their child from returning to physical education class, as well as extracurricular sporting activities when receiving a diagnosis of an mTBI as opposed to a diagnosis of concussion. In addition, parents considering a diagnosis of mTBI were more likely to believe that their child would require an academic accommodation, than parents considering a diagnosis of concussion.

The results indicate that the parents within this sample had a decent grasp on the expected symptoms following a concussive injury. Perhaps this is due to the push for better concussion education over the more recent years. However, when assessing attitudes toward recovery protocol these findings agree with the findings of DeMatteo et al. (2010), who suggested that a diagnosis of mTBI may be perceived as more alarming than a diagnosis of concussion. The

results of the present study suggest that parents receiving a diagnosis of mTBI may be more cautious in allowing their child to participate in various school and sport activities, than they would if their child had received a diagnosis of concussion. This aligns with existing literature that suggests that terminology has an impact on the perceptions of the course of recovery (Kelly & Erdal, 2017; Raugust & Latter, 2013).

The results of this study suggest that it might be fruitful to choose one universal term to describe and diagnose a brain injury of this magnitude. Some may argue the term “mTBI” to be the most plausible diagnosis as it promotes a more cautious approach to recovery (Kelly & Erdal, 2017; Weber & Edwards, 2010). Perhaps this caution is due to a lack of familiarity with the term, or due to the word “traumatic” being embedded within, causing individuals to be more gracious in their period of rest before returning to activity. However, this unfamiliarity may also be a cause for concern as an injury classified as an mTBI may be more upsetting and uncomfortable for parents to receive (DeMatteo et al., 2010). In contrast, the use of the term “concussion” has grown in recent years, and thus has become a more familiar term to the general public (Weber & Edwards, 2010). Concussion may be a more comfortable diagnosis for parents to receive as it successfully communicates the transient nature of the injury at hand (McCrary, 2001). However, the results of this study suggest that this may encourage individuals to underestimate recovery time, which may lead to premature participation. Additionally, there still appears to be some uncertainty surrounding the term concussion and the injury it entails (McKinley, Bishop, & McLellan, 2011).

Regardless of which term is used, it is evident that there is a need for more education on the nature of these injuries, particularly among parents. Better education may foster awareness of what to expect following a concussion (or an mTBI), the appropriate steps to take toward

recovery, and the probability of persistent symptoms that are often seen within the adolescent population. Although the course of recovery shows substantial individual differences, parents should be aware of the general steps to return to activity. This information should extend past athletics and into the schools, as return to activity also includes the adolescent's return to the classroom and social environment following injury. Parents should be informed of the impact that these injuries may have various areas of participation, so that they can make better informed decisions as to the steps to take toward recovery for their child.

Similarly, physicians should be aware of the impact that varying terminology can have on perceptions toward recovery and thus should be careful in communicating their diagnosis to their patients and caregivers. It is the responsibility of the physician to ensure that their patient and/or caregiver fully understand the diagnosis that has been provided to them and are confident in their next steps toward treatment.

2.4.1 Limitations

A key characteristic of the participants in this study (i.e., parenthood) relies on self-report. Despite our use of advanced qualifications within our sampling methodology (in mTurk), it is possible that individuals may have misrepresented their parent status within the survey, or to mTurk. It is similarly possible that individuals may have misrepresented themselves as being the parent of at least one child between the ages of 13 and 18.

This research also relies on self-reported information, within an online questionnaire. It is possible that individuals may have responded randomly to questions within the survey – or that they responded in a socially desirable fashion that did not accurately reflect their beliefs or opinions. It is difficult to monitor or prevent response biases of this sort, when asking questions

of the sort used in this study, but we attempted to minimize the influence of this limitation by restricting our participants to the pool of “masters qualified” individuals on mTurk.

Finally, this study did not take into consideration first-hand experience with a concussion or mTBI. Therefore, it is difficult to say if the participants familiarity with the terms and/or injury themselves had any impact on their perceptions toward the diagnoses.

2.4.2 Conclusions

Much work remains to be done concerning attitudes toward concussion terminology, particularly within the parent population. Until now the literature has solely focused on the impact terminology has on parent’s return to play decisions. It is important to continue to explore the influence of terminology on other areas of participation, such as return to school, to better understand parents’ decision making process concerning their adolescent’s recovery.

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Chapter 3

3.1 Discussion

Although concussion research has grown in recent years, the current literature lacks a full understanding of the impact that terminology has on the recovery process for these types of injuries. The terms concussion and mild traumatic brain injury (mTBI) are often used interchangeably within the literature to describe a brain injury of mild magnitude. Although these terms appear to reflect a similar injury they have been shown to be perceived differently. This study assessed parental perceptions of the term “concussion” versus the term “mTBI” in regard to injury expectations and expected recovery for their child. In order to accomplish this, 98 parents that self-reported having a child between the ages of 13-18 completed an online survey. The purpose of the survey was to assess the parental attitudes toward their adolescent’s expected symptoms, ability to participate, and return to activity following a diagnosis of either concussion or mTBI. The parents were asked to respond with their level of agreeance to each of the 29 items within the survey using a 5-point Likert scale ranging from “Strongly Disagree” to “Strongly Agree.” Each participant received only one diagnosis to ensure that they were unaware of the exact purpose of the study.

The results of this study demonstrated that parents were somewhat familiar with the symptoms to be expected following a concussion and/or an mTBI. No significant differences were found between a concussion and an mTBI in terms of symptomology and return to next day or next week activity. The participants did, however, indicate that they considered it likely that an injury classified as an mTBI (as compared to an injury classified as a concussion) would be more likely to: take more than a week to recover; result in symptoms that persisted for several months; and present with feelings of sadness or depression. This suggests that although parents

are aware of the symptoms associated with these types of injuries they still perceive mTBI to be more severe and long lasting.

Furthermore, the results of this study did demonstrate a significant difference between the term concussion and the term mTBI when assessing attitudes of participants toward their adolescents' participation following injury. For example, parents who received the mTBI diagnosis, as opposed to the concussion diagnosis, were more likely to: prevent their child from returning to school for a week or more; prevent their child from returning to physical education class; prevent their child from participating in recreation-league or competitive-league sports; and require an academic accommodation for their child.

The results of the current study support existing findings within the literature, insofar as they suggest that minimal differences exist between the two diagnoses in regards to perceptions of symptoms, but also suggest that a diagnosis of mTBI is perceived as a more severe injury, requiring a more cautious return to participation in various activities than a diagnosis of concussion (Kelly & Erdal, 2017). Unfortunately, at this time there is limited literature exploring concussion terminology and its impact on injury and/or recovery perceptions. The current study is the first to not only assess the impact of terminology perceptions on return to play, but also return to learn, which is equally important during the recovery process. Following a concussion it has been shown that symptoms such as increased difficulty focusing on tasks, decreased comprehension, and disruption of cognitive recall, may be detrimental to an adolescent's ability to effectively attend school and complete homework (Karlin, 2011). If a diagnosis is perceived by parents to be a less severe injury this may result in premature return to activities for their child, leading to the exacerbation of symptoms. Conversely, it is also important that adolescents are not completely removed from their activities for a prolonged period of time, as much of the

psychosocial development of this age group occurs in these settings (Karlin, 2011). Thus, a careful balance must be met based on the individual adolescent's injury and needs in order to promote a successful and safe return to all activities.

3.2 Lessons Learned

Although the current study was relatively successful in assessing parental perceptions of concussion terminology, there is always room for improvement. If I were to complete the study again there are a few minor changes I would suggest.

To begin, one area that I believe is often overlooked in this area of research is the impact of concussions on the adolescent's social activities. The current survey includes questions regarding the parent's attitudes toward their child's return to various school and sport activities. However, it fails to explore perceptions toward their child returning to their normal social lives following injury (e.g., attending a sleepover with friends). After sustaining a concussion, return to activity can be complex, impacting multiple areas of an adolescent's life (Valovich McLeod, Wagner, & Bacon, 2017). The presence of symptoms following injury has been shown to restrict their ability to participate in normal daily activities. Consequently, social interactions often suffer, which may lead to the worsening of existing symptoms, such as irritability and depression (Iadevaia, Roiger, & Zwart, 2015; Valovich McLeod et al., 2017). Therefore, in order to receive a more complete picture of the impact terminology has on attitudes toward recovery, it may be beneficial to consider the social environment, in addition to school and sport environments.

In addition, the current survey does not consider parental familiarity with the terms concussion or mTBI. In a future version of this survey, I would be inclined to include a question that addresses any first-hand experience the participants might have with these injuries. It is plausible that if a participant was exposed to these injuries prior to the study, they might have

some knowledge concerning what these injuries entail, the different terminology and/or the appropriate recovery protocol. Ultimately, if the parent themselves, or someone they know, has sustained a concussion (or mTBI), this might impact their perceptions toward the terms and thus should be taken into consideration when interpreting the results.

3.3 Future Directions

There is yet to be a consensus as to which term should be used to diagnose a concussive injury. The term mTBI may be an obvious choice as it promotes a more cautious return to activity ensuring that the adolescent does not return to school or sports too soon (Kelly & Erdal, 2017; Weber & Edwards, 2010). However, mTBI has also been shown to be a less familiar and more alarming diagnosis for parents to receive (DeMatteo et al., 2010), which perhaps may lead to an unnecessarily prolonged period of rest based out of fear. On the contrary, concussion has become a more familiar term over the more recent years with the its' growing popularity within both the research and media realms. However, Sharp and Jenkins (2015) argue that the term concussion lacks diagnostic precision and promotes a lazy diagnostic approach by physicians, leading the patient and/or caregiver to assume the injury will resolve spontaneously without any extra precautions. Ultimately, more work needs to be done in order to better understand the perceptions toward these terms and the impact they have on the recovery process, particularly in the parent population. More specifically, research should focus on the impact these terms may have on parents attitudes toward their adolescent's ability to participate within the school, sport, and social settings following injury. Perhaps once these perceptions are fully understood it might be fruitful to select one term to be used to describe an injury of this magnitude, whether it be "concussion", "mTBI", or another term altogether.

Regardless of the chosen terminology, there is a current need for more education surrounding these injuries. Increasing awareness of the different terminology used to describe mild brain injuries, such as concussion and mTBI, might provide patients and caregivers a better understanding of these diagnoses and the injuries they reflect. More importantly, physicians should be made aware of the different perceptions these terms might evoke so that they can make better informed decisions when choosing which diagnosis to communicate to their patient and/or caregiver. When communicating said diagnosis, physicians should always ensure that they thoroughly explain what the injury entails, the symptoms that are to be expected, as well as the steps to be taken toward recovery. This ensures that the patient and/or caregiver has all the necessary information to make informed decisions over the course of the recovery process.

Education surrounding these injuries should also be implemented within the school and sport settings. Information should be provided concerning what these injuries entail and the appropriate steps that should be taken toward recovery. Although a concussion (or an mTBI) typically reflects a transient injury that may spontaneously resolve with rest, persistent symptoms are not uncommon, particularly within the pediatric population (McCrory et al., 2017). In light of this, a patient-centred, individualized approach to recovery should be utilized in order to reduce the risk of premature return to activity, while still ensuring that the adolescent is not completely removed from their activities for a prolonged period of time. Parents, coaches, teachers, and adolescents should all be made aware of current recovery protocols so that they are better equipped to handle these injuries at home, on the field, and within the classroom.

3.4 Conclusion

Despite their interchangeable use, the terms concussion and mTBI appear to evoke different perceptions in parents concerning their adolescent's expected recovery. An mTBI has

been found to be perceived as a more severe diagnosis to parents, requiring a longer period of time before their child returns to their various activities. However, there is still a considerable amount of research that needs to be done in order to better understand the impact terminology has on attitudes toward concussion recovery for the parent population. Likewise, there is a need for more education focusing on the different terminology and the injuries they reflect to ensure that patients and their caregivers have the knowledge to make better informed decisions concerning the recovery process.

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Appendix A: Ethics Certificate



Date: 22 November 2018

To: Dr. Andrew Johnson

Project ID: 111581

Study Title: Parental self-reports of adherence to return to activity protocols

Application Type: NMREB Initial Application

Review Type: Delegated

Full Board Reporting Date: December 7 2018

Date Approval Issued: 22/Nov/2018

REB Approval Expiry Date: 22/Nov/2019

Dear Dr. Andrew Johnson

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
LOI, Concussion, 20181115	Implied Consent/Assent	15/Nov/2018	v2
LOI, mTBI, 20181115	Implied Consent/Assent	15/Nov/2018	v2
MTurk	Recruitment Materials	15/Nov/2018	v1
Survey, 20180921	Online Survey	21/Sep/2018	v1
Survey, 20181115	Online Survey	15/Nov/2018	v2

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

██████████ Research Ethics Officer on behalf of ██████████, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

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