

Navigating Uncertainty: Exploring Parents Knowledge of Concussion Management and  
Neuropsychological Baseline Testing

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## ABSTRACT

### Navigating Uncertainty: Exploring Parents Knowledge of Concussion Management and Neuropsychological Baseline Testing

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Past research on parents' knowledge of concussion has shown that they understand the severity and consequences associated with the injury but have existing gaps in their knowledge for its management. This is a cause for concern due to the critical role parents play in their child's management process. This present study sought to address this area of concern with semi-structured focus groups to gain an insight on parents' perceptions and experiences with concussion management and an alternative method of care - neuropsychological baseline testing. What emerged from the focus groups was the core theme of navigating uncertainty. This theme encompassed the participants perceptions and experiences with having to take on the role of managing their child's concussion without a complete understanding of the management process. It incorporated aspects of injury diagnosis, methods of management, communication among stakeholders within the sporting community, the influence of concussion policy and parents' perceptions of neuropsychological baseline testing in the management process. A model was constructed to display the factors that influenced and guided parents' engagement with neuropsychological baseline testing.

**Keywords:** Concussion, management, diagnosis, uncertainty, communication, neuropsychological baseline testing

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**List of Abbreviations**

SRC- Sport-Related Concussion

NBT- Neuropsychological Baseline Testing

## Introduction

Concussion has emerged as one of the more problematic and detrimental injuries plaguing athletes at all ages and skill levels (McCrory et al., 2017). Sport related concussion (SRC) has garnered a lot of attention at the youth and adolescent aged level because of the high occurrence rates and the known long-term consequences that can affect the young athlete who is still going through development (Pinto et al., 2012; Marar, McIlvain & Fields, 2012). Past research has shown Canadians sustain 94,000 concussion and other related brain injuries per year with many being a result from sport, while the United States has reported 1.6 to 3.8 million sport-related brain injuries including concussion yearly (Langlois, Rutland-Brown & Wald, 2006). To address the concerns associated with SRC, efforts have shifted to the prevention and management of the injury. Prevention encompasses primary prevention which are implemented to reduce exposure and occurrences (e.g., educational programs and rule changes). Secondary prevention (management) focuses on assisting the athlete in their recovery post injury through engagement with policies like return to play protocols and support through health care providers (McCrory et al., 2017; Tator, 2013).

These efforts to reduce and manage concussion extend past the athlete and into the role of the parent. Parents play an important part in an athlete's engagement with sport which can include their recovery from any potential sporting related injuries like concussion. Currently, research has shown that parents have an understanding of the severity of concussion but lack knowledge surrounding its management (Black, Yeates, Babul, Nettel-Aguirre and Emery, 2020; Rice and Curtis, 2019). No research has examined where or why these gaps in knowledge exist, which is a concern due to how important their role within the concussion management process can be. The lack of knowledge means that parents are actively having to make decisions

involving their child's SRC management without a clear understanding of how to manage the injury. Consequently, their uncertainties could be one of the driving factors leading to parents' engagement with suboptimal methods of management. Neuropsychological baseline testing (NBT) is one of these methods that parents, and members of the sporting community are engaging with as possible support for the management process. NBT is an alternative tool that attempts to analyze an individual's cognitive state to try and assist in the identification and management process of a concussion injury (McCrory et al., 2017; Webb and Zimmer, 2014). The tool is comprised of an initial assessment that occurs prior to the start of the season to establish a baseline and after any suspected concussion to try and identify cognitive decline (Zimmer, 2014). This test is a decision taken upon a team or individual players themselves to try and provide additional support for the management process. Currently, the test is not mandatory to take but associations like York Region Football League, Greater Toronto Hockey League and Windsor Minor Football Association offer partnerships with clinics that deliver NBT (York Regional Football Association, 2022; Windsor Minor Football Association, 2022; Greater Toronto Hockey League, 2016). While the tool itself is marketed as a method to support concussion management, it has not been approved for use in a clinical setting or shown to be a reliable or effective measure for monitoring SRC during the return to play or school process (McCrory et al., 2017). This is alarming due to the structure and security the test may appear to provide. Parents could be unknowingly relying on an unproven method of care which could be detrimental to their child's recovery. It is important to note that there is also a lack of theory looking at parents' involvement in this process. The lack of a structured understanding inhibits both research and practice involving the parents' role in concussion management.

The current thesis sought to address these concerns by utilizing the qualitative method informed by Protection Motivation Theory (Rogers, 1983) to provide an in-depth examination of

parent's experience with concussion, their understanding of its management and their beliefs surrounding the use of NBT. To provide background, I will provide an overview of concussion injury and introduce primary prevention strategies which include educational programs, legislation and rules that have been implemented to prevent SRC. Then I will discuss secondary behaviours that include Return to Play, paper and pencil SRC assessments and NBT. Finally, we will provide a critical commentary of NBT and discuss the role of the parent in concussion management before introducing the present study.

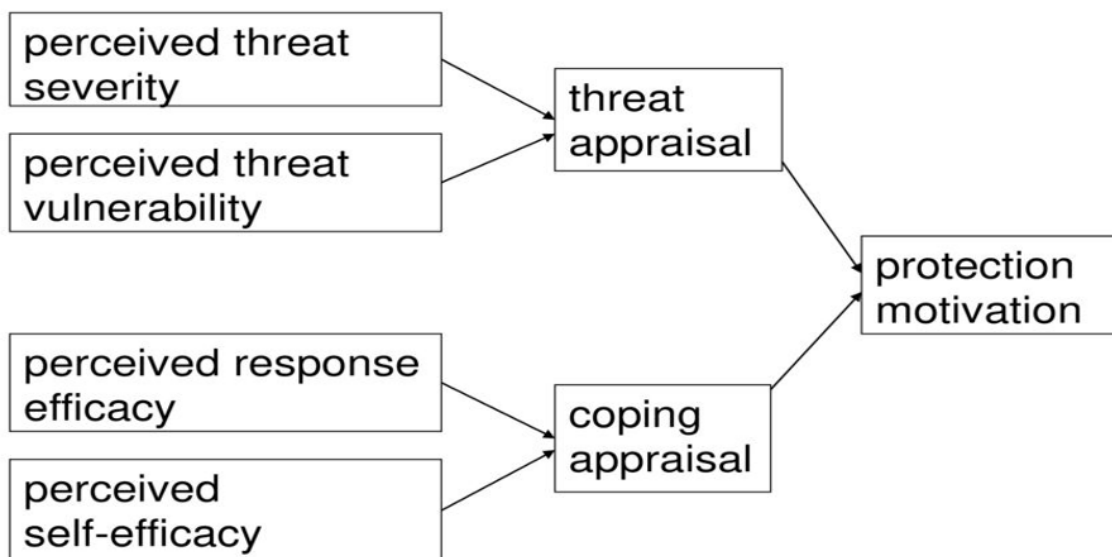
### **Overview of Concussion Injury**

Concussion injury is defined by the 5<sup>th</sup> international conference on concussion in sport (2017), "as a complex pathophysiological disruption to the brain caused by biomechanical forces either by a direct blow to the head, face, neck, or body where the energy is then transferred to the head" (p. 839). The effects of concussion can cause functional disturbances rather than structural injuries meaning that the implications of concussion injury are cognitive in nature and do not commonly display physical changes to the brain (McCrory et al., 2017; Lau, Kontos, Collins, Mucha and Lovell, 2011; Zamarripa et al., 2017). Since the effects are not structural, concussion injury cannot be identified by neuroimaging (ex., CT scan) and relies heavily on the self-reporting of the individual who experienced the injury (McCrory et al., 2017; Kutcher and Giza, 2014). The most common symptoms associated with concussion are headache, drowsiness, fatigue, and cognitive decline (Fazio, Lovell, Pardini & Collins, 2007). Typically, the recovery period for a concussion is between 7-10 days but within youth and adolescent athletes, it has been reported that 10% of affected athletes take much longer than 10 days to recover and return to sport (McCrory et al., 2017).

## **Protection Motivation Theory**

The Protection Motivation Theory has been commonly used within research on health and rehabilitation to examine how the effects of an individual's perception of a health threat could lead to possible behavioural change. Within the Protection Motivation Theory, the fear of a health threat is used to explain the cognitive processes behind behavioural change through an individual's threat and coping appraisals (Rogers, 1983). The Protection Motivation Theory (figure 1) consists of four elements that make up these threat and coping appraisals. Within the threat appraisal, there is vulnerability and severity of the health threat in question. Vulnerability relates to the likelihood of an individual experiencing a health risk, while the severity is their views on how detrimental the consequences of the health risk could be. Threat appraisal relates to primary prevention because it takes into consideration the beliefs and perceptions an individual has toward the potential of sustaining a health threat. Methods of primary prevention such as awareness and education can influence this area of the model by reducing or amplifying an individual's fear of sustaining an injury like concussion. Coping appraisal contains both self-efficacy and response efficacy which are used to measure an individual's perception of a self-protective behaviour. Self-efficacy relates to an individual's ability to accomplish the recommended self-protective behaviour successfully and response efficacy is the belief an individual has in the effectiveness of the proposed protective behaviour (Norman et al., 2005). Coping appraisal relates to secondary prevention do to the beliefs surrounding engagement with possible treatment methods to reduce the effects of a health threat. Once an individual has experienced an injury, their beliefs and understanding for a management tool, like NBT, and their views toward successfully engaging with the measure could lead to their pursuit for alternative methods of care to try and manage it. we can see response efficacy occurring through an individual's view on current return to play protocols and management methods and self-

efficacy being their belief that either their child or they as parents could be able to engage with these protocols and external management methods with success.



*Figure 1.* The Protection Motivation Theory (Rogers, 1975)

Recently, The Protection Motivation Theory has been investigated as a possible screening tool for helping to predict adherence to rehabilitation among people experiencing chronic lower back pain (Owen et al., 2022). Owen et al. (2022) examined the effects of Protection Motivation Theory to screen for adherence to treatment. They reported that the patients' perceptions of rehabilitation appeared to predict their attendance behaviours for treatment. So, the patients that did not believe they could fully recover were likely to miss more appointments than those that believed they could benefit from their treatment. The Protection Motivation Theory has also been found to influence perceptions toward the severity of an injury and the need to seek treatment. Basset and Prapavessis (2011) examine the effects of the Protection Motivation Theory through an intervention on 71 people with ankle sprains. Their findings concluded that participants who were exposed to the Protection Motivation Theory intervention had significantly higher scores on severity, vulnerability and response efficacy for their injury compared to the other participants

who did not. These results suggest that providing information shaped through Protection Motivation Theory enhanced the patients' beliefs toward their injury and treatment. The implementation of Protection Motivation Theory into preventative care has also shown the ability to modify perceptions of a perceived health threat. Maleki, Daniali, Shahnazi and Hassanzadeh (2022) found that exposure to an educational intervention for skin cancer prevention had a positive effect on adolescent aged students' engagement with preventative management (i.e., wearing sunblock, wearing sunglasses). When relating these studies to concussion injury, it is clear that the implementation of Protection Motivation Theory could help explain an individual's perceptions for the severity and vulnerability of concussion, their views of current return to play protocols and management methods and how they feel these methods could benefit their child.

## **Primary Prevention**

### *Educational programs*

Educational programs have been developed to encourage wide-spread evidence-based information about SRC and its consequences to stakeholders in the sporting community. The goal of these programs is to raise awareness for the severity of SRC and to in-form those who may be unaware of the difficulties and long-term consequences that can be a result of the injury (Waltzman, Hoffman, Donnell, Bell and Sarmiento, 2020). In Canada and the United States, two programs have seen mass adoption - the "HeadsUp" campaign and Parachute Canada's concussion program. HeadsUp was launched by the US Centers for Disease Control and Prevention (CDC) in 2003 to help educate the community about the risk associated with concussion injury (Waltzman et al., 2020; Feiss, Lutz, Reiche, Moody and Pangelinan, 2020). Since being introduced, evaluations of the campaign have examined the effects it has had on knowledge and attitudes surrounding concussion among healthcare providers, youth coaches and

parents (Waltzman et al., 2020). A study conducted by Sarmiento, Mitchiko, Klein and Wong (2010) evaluated the tool kits designed by the campaign through 1009 high school coaches that ordered them. They found that 38% of coaches were actively changing how they dealt with SRC among their athletes through preventative methods like emphasizing technique and proper safety equipment. Half of their sample also reported having a clearer understanding on the dangers of SRC after reviewing the materials in the tool kit. Similarly, Rice and Curtis (2019) evaluated the “HeadsUp” campaigns educational initiative for parents and found it to be a benefit to parents’ knowledge for concussion injury. Their study was an intervention that evaluated 140 parents who had children registered in clubs’ sports knowledge of concussion pre and post administration of the program. They found parents knowledge for concussion improved slightly following the administration of the intervention with examples being a better understanding of determining if their child could return to sport (50.7% to 64.3%), awareness for second impact syndrome (59.3% to 86.4%) and concussion being a critical issue (68.5% to 85%). It is important to note that parents continued to displayed gaps in knowledge for concussion management post-intervention which they deemed to be concerning. They highlighted that parents continued to be unsure if concussions were preventable (42.9%), if imaging could diagnose concussion (78%) and a lack of understanding of concussion signs and symptoms despite receiving education (78%-85% depending on the symptoms).

The amalgamation of four Canadian health platforms in 2012 (Safe Communities Canada, Safe Kids Canada, SMARTRISK and ThinkFirst Canada) led to the creation of Parachute Canada’s, “ThinkFirst” SRC educational program. This program was evaluated by several researchers. First, Cook, Cusimano, Tator and Chipman (2003) examined the changes in knowledge and behaviour among youth hockey players that completed the SRC program. Their results found that these athletes were able to retain the knowledge obtained from the program up



to three months post administration and that there was a decrease in dangerous play (e.g., high-risk penalties) as well (Cook et al., 2003). Research performed by Vassilyadi et al. (2009) examined the efficacy of the “ThinkFirst” program by examining knowledge acquisition in middle school students (grade seven and eight). They reported that following the completion of the program, all students involved saw an increase in knowledge retention. Students also self-reported that their decision-making and participation in risky behaviours were altered due to the information acquired through the program. Following the amalgamation into Parachute Canada, limited research has been performed on the validity and efficacy of their SRC education program or the implications it has on the sporting community (e.g., athletes, coaches and parents). They have continued to adapt with new developments relating with concussion management. They are actively suggesting that all energy that would be directed toward neuropsychological baseline testing should instead be focused on following the already existing return to play protocols either instilled by their program or within local sporting leagues.

### *Rule changes in sport*

Rule changes have and continue to be implemented to combat the high rate of injury and SRC occurrence in contact and collision sport. Two strategies currently being implemented are rules to reduce contact, particularly to the head and rules regarding fair play among competitors. Leagues and organizations have developed strict approaches surrounding contact to the head to reduce possible incidences of SRC. Such rule changes have been prevalent in youth hockey in both the United States and Canada primarily targeting body checking (Emery et al., 2020; Black, Hagel, Palacios-Derflingher, Schneider and Emery, 2017; Emery et al., 2010). Prior to the introduction of the rule removing body checking from Pee wee (11-12 years old) aged hockey players, Emery et al. (2010) examined the differences in concussion rates from Pee wee hockey players in leagues that permitted bodychecking (Alberta, Canada) and leagues that did not

(Quebec, Canada). There was no difference in league rules between the provinces (excluding body checking) and all teams within the study were reported to be in the top 60% of their leagues. They reported a threefold higher incidence in all game-related injuries including concussion, severe concussion (10 days or more) and severe injury in the league that permitted body checking. Following the removal of body checking at the Pee wee level, Black et al. (2017) examined if the new rule reduced the risk of injury, including concussion, within this age group. They found a 50% reduction in injuries and a 64% reduction in concussion rates within the Pee wee age group. They estimated that 581 concussions were prevented per season since the removal of body checking at the Pee wee level.

Rugby chose two separate strategies to try and reduce SRC. First, they implemented new penalties establishing a zero-tolerance policy for contact to the head (World Rugby, 2016). These infractions can be handed out by the match official and are broken down in to two separate categories with their own respective punishments. The first category is defined as a reckless tackle when a player tackles or attempts to tackle a player while knowing there could be risk of head contact but executes the action anyway. The second category is deemed as an accidental tackle where the tackle or attempted tackle makes accidental contact with the opposing players head. The punishment for these incidences are then calibrated based on which category the match official feels the incident falls under. Currently there is no research supporting the effects of this rule change. The second strategy is lowering the height of contact during a tackle. Current research examining the biomechanics of the tackle have shown that the tackle height can strongly affect the energy delivered to the head of the ball carrier (Tierney, Richter, Denvir and Simms, 2018). Tierney and Simms (2018) examined the effects of the height of the tackle in relation to head injuries in elite rugby union. They concluded that upper body front-on tackles, side-on upper body tackles and front-on high leg tackles had a higher risk percentage of leading to head

injuries while lower upper body tackles (mid-section to waist) and lower leg tackles had a lower risk percentage of leading to a head injury. With evidence showing the reduction of energy delivered to the head by lowering tackle heights, leagues such as Rugby England have implemented rule changes to modify the legal tackling height within their under 15's and under 18's age athletes (Rugby England, 2021). Contrary to these findings, Stokes et al. (2019) found concussion injury had increased in leagues that restricted the height for tackling. They examined two leagues during the 2018/19 season with The Championship retaining standard rugby laws for tackling and The Championship Cup integrated the new ruling for contact being below the armpit line. They found that contact to the neck and head was reduced by 30% in the league that integrated the new rule changes, but it did not have an influence on the incidence rate of concussions. In fact, the league integrating the rule change had more athletes that suffered from concussion than the league with the standard laws.

The second strategy of implementing fair play rules are to help promote sportsmanship while reducing aggressive play. One method of fair play introduced to reduce exposure to injury was implemented in high school hockey in Rhode Island which punished players with suspension when they exceeded 50 and 70 minutes in total penalties throughout the season and playoffs (Kriz et al., 2019). Kriz et al. (2019) examined the effect of this rule change over a 6-year span that incorporated 1762 varsity boys' hockey games. They reported a significant reduction in injuries including concussions as well as a reduction in match disqualification penalties. Fair play rules can also integrate fair play points systems to govern their sporting leagues. Within this system fair play points may be rewarded for sportsmanlike behaviour or forfeited if they exceed a predetermined number of penalties per game (Smith et al., 2016). Points earned and forfeited are then added or subtracted from the already existing point system awarded for wins and ties which effect the teams' standings for their league. The implementation

of this point system has shown to have a reduction in penalties and game suspensions in youth hockey (Marcotte and Smard, 1993, as referenced in Smith et al., 2016). Brunelle, Goulet and Arguin (2005) evaluated a similar fair play points system in 52 youth hockey teams (ages 14-15) in Quebec, Canada. They found that violent infractions and penalties were reduced, but there was no difference in injury rates when compared to leagues not implementing the points system.

### *Legislation*

The implementation of legislation in sport is a strong driving factor for awareness and prevention of further injury among youth and adolescent athletes. Currently there are two concussion laws in existence in North America. “Lystedt’s” Law was developed in Washington state, USA in 2009 following an incident where a young athlete named Zackery Lystedt returned to play in the same game that he suffered a SRC and later collapsed and experience a significant neurological injury leading to permanent brain damage (LaRoche, Nelson, Connelly, Walter and McCrea, 2015; Bompadre et al., 2014). The law entails three components, the first being an educational portion where athletes and parents must sign and return a concussion education form that provides them information on the injury, while the coaches must undergo mandatory education within their organization. Second, athletes must be removed from a game or practice if they are suspected of experiencing a SRC. Third, the athlete can only return to play if they have written permission from a licensed health care provider. Research performed by Bomparde et al. (2014) found that since the implementation of the law, there have been an increase in documented cases of SRC and an overall increase in average days removed from play. This could be due to the awareness the law provides and the mandatory permission required for an athlete to return to play healthy.

Passed in Ontario, Canada, “Rowan’s Law” is named after a young rugby player, Rowan Stringer, who passed away due to second impact syndrome. Second impact syndrome occurs

when an individual experiences a SRC and before the first SRC is fully recovered, they experience another impact (McLendon, Kralik, Grayson and Golomb, 2016). There is a low occurrence rate for known cases of Second impact syndrome but, the consequences of the injury are known to cause catastrophic neurological impairments that can be fatal (McLendon, Kralik, Grayson and Golomb, 2016). The design of this law reflects aspects of “Lystedts Law” with the mandatory removal from play and requires sporting organizations to deploy appropriate concussion education and return to play protocols. One stipulation that separates itself from “Lystedts Law” is that it avoids stating that medical clearance is required for athletes to return to play (McCradden and Cusimano, 2019). Currently, Rowans Law is the only active concussion legislation in Canada (Ontario), no similar laws have been enacted in any other province or territory.

## **Secondary Prevention**

### *Return to Play*

Following the diagnosis of a SRC, athletes progress through a series of stages implemented by sporting leagues and organizations before they can be deemed safe to return to play (McCrory et al., 2017). These sporting leagues and organizations have implemented return to play guidelines to make sure that athletes are undergoing appropriate steps in their management, thereby minimizing the chances of an athlete returning before they are fully healed. The structure of return to play is bidirectional and fluctuates based on the condition of the athlete. Athletes can move forward through the model toward return to play or retract to an earlier stage if symptoms were to re-appear. Return to play may differ from sport to sport based on the physical demands required of the athlete, but the general structure of return to play is constant throughout (May, Marshall, Burns, Popoli and Popikandriotis, 2014). Return to play protocols have been widely adopted by sport governing bodies.

The recommended return to play as stated by Parachute Canada should consist of six stages which incorporate four components. The first stages involve symptom-limiting activities that can begin after 24-48 hours post injury. This stage allows for light cognitive and physical activities (e.g., walking around the house). The second stage is engaging in light aerobic activity for 10-15 minutes which can be prolonged, and the intensity increased if symptoms do not re-appear. Weight and resistance training is not permitted in this stage. Stage three is sport-specific activities which could incorporate skating for hockey and running drills for soccer (Hockey Canada, 2021; Soccer Canada, 2018). The fourth stage is the introduction of drills with no contact while stage five is a complete return to contact in practice with the medical clearance of a physician. The final stage is a full return to sport. Each stage takes a minimum of 24 hours to complete, progressing to the next stage once symptoms resolve, regressing to the past stage if symptoms worsen and get re-evaluated if symptoms return following medical clearance (Parachute Canada, 2021).

### *Concussion Assessments*

Known as some of the earliest tools designed and implemented to help with detection and management of SRC, concussion assessments have been utilized for side-line measures, within NBT's and as supportive tools within clinical examinations (Dessy et al., 2017; McCrory et al., 2017). These types of tools rely on direct interactions between participants and the administrators of the test (e.g., trainers, clinicians) and include self-reported symptoms and the completion of verbal and visual examinations. The most used version of these assessments are the Standardized Concussion Assessment Tool, the King-Devick Oculomotor Test and the Post-Concussion Symptom Scale (Apple, Stran and Tross, 2020; Echemendia et al., 2017; Galetta et al., 2011). A summary for the concussion assessments is located in table 1.

Table 1

*Summary of Concussion Assessments*

Test	Contents	Advantages	Disadvantages
SCAT	<ul style="list-style-type: none"> <li>- (MQMA)</li> <li>- (GSC)</li> <li>- (SAC)</li> <li>-(mBESS)</li> <li>-Immediate on-field assessment</li> <li>-Cervical spine assessment</li> <li>-Immediate memory and delayed recall</li> <li>-neurological screening</li> </ul>	<ul style="list-style-type: none"> <li>-Tests a variety of concussion symptoms</li> </ul>	<ul style="list-style-type: none"> <li>-Not comprehensive enough to be used on its own</li> <li>-Cannot accurately assess athletes with learning disabilities</li> <li>-Not recommended for individual use</li> </ul>
K-D Test	<ul style="list-style-type: none"> <li>-One demonstration card</li> <li>-Three test cards with a series of single digit numbers</li> </ul>	<ul style="list-style-type: none"> <li>-Easy administration</li> <li>-Able to identify oculomotor dysfunction</li> </ul>	<ul style="list-style-type: none"> <li>-Not a comprehensive assessment</li> <li>-Does not assess common concussion symptoms</li> </ul>
PCSS	<ul style="list-style-type: none"> <li>- 21-item battery of SRC symptom scale (0 no symptom – 6 severe)</li> </ul>	<ul style="list-style-type: none"> <li>-Contains a large section dedicated to concussion-related symptoms tests</li> <li>-Found to show greater abnormalities in athletes with multiple concussions</li> </ul>	<ul style="list-style-type: none"> <li>-Self-reported questionnaire -its subjective nature leaves it open to variability in its results</li> <li>-Easy to falsify answers due to reliance on self-reporting</li> </ul>

**Note:** SCAT- Standardized Concussion Assessment Tool, MQMA- Maddocks Questions for Memory Assessment, GSC- Glasgow Coma Scale, SAC- Standardized Concussion Assessment, MBESS- Balance Error Scoring System, K-D Test- King Devick Oculomotor Test, PCSS- Post-Concussion Symptom Scale

**Standardized Concussion Assessment Tool.** The Standardized Concussion Assessment Tool was originally designed and published in 2004 by the Concussion in Sport Group to help promote standardization for SRC evaluation (McCrory et al., 2005). Since then, there have been three iterations of the tool with SCAT5 being the most recent which was introduced following the Fifth International Consensus Conference on Concussion in Sport (Echemendia et al., 2017; McCrory et al., 2017). The tool includes the Maddocks Questions for Memory Assessment, the Glasgow Coma Scale, a symptom evaluation, the Standardized Assessment of Concussion, Balance Error Scoring System an immediate or on-field assessment, a cervical spine assessment, a 10-word and 5-word list for the immediate memory and delayed recall components of the standardized assessment of concussion, a neurological screening, and a minimum time requirement of 10 minutes (Bruce et al., 2020; Echemendia et al., 2017). Previous research on the Standardized Concussion Assessment Tool has found that results may be influenced by the athlete's sex, concussion history, learning disabilities (e.g., Attention Deficit Hyperactive Disorder) and the type of sport they may play (contact vs non-contact) (Chin, Nelson, Barr, McCrory and McCrea, 2016). Recently, Hänninen et al. (2021) examined short-term test-retest reliability and although they found considerable individual variability on the Standardized Assessment of Concussion and Balance Error Scoring System, they reported moderate to high reliability for the overall test. Like other management methods, the Standardized Concussion Assessment Tool is not recommended to be used in isolation when examining and determining if a SRC has occurred (Dessy et al., 2017).

**King-Devick Oculomotor Test.** The King-Devick Oculomotor Test has been implemented into SRC management due to its abilities to identify oculomotor dysfunction which is common to an individual who has experienced a concussion (Heick, Bay and McLeod, 2018; Dessy et al., 2017). The test is made up of one demonstration card and three test cards with a



series of single digit numbers that participants are required to read aloud moving from the left to right side of the card (Dessy et al., 2017; Galetta et al., 2011; Galetta et al., 2011). The test itself takes two minutes or less to administer and the sum of the three test card time scores amount to the final score for the test while accounting for the number of errors made (Galetta et al., 2011). Galetta et al. (2011) examined the use case of the King-Devick Oculomotor Test for concussion screening through pre- and post-fight administration of the test on mixed-martial arts fighters and boxers (n=39). They found that post-fight scores were significantly worse (>5 seconds) for those that experienced significant head trauma during their match. Galetta et al. (2011) continued to pursue the effectiveness of SRC detection using the King-Devick Oculomotor Test and found similar findings in a sample of 219 collegiate athletes (e.g., football, women's, and men's soccer). Within this population, nine out of the ten athletes that experienced a SRC showed significantly worsening results from their baseline test.

**Post-Concussion Symptom Scale.** Known as a common assessment tool for SRC, the Post-Concussion Symptom Scale is a 21-item battery of SRC symptoms (e.g., nausea, fatigue) where the individual is asked to report on their symptoms by ranking perceived severity on a scale ranging from zero (being no symptoms) to six (severe) to try and evaluate their current condition (Apple, Stran and Tross, 2020; Dessy et al., 2017). The Post-Concussion Symptom Scale has been deemed an effective measure for being able to identify concussed athletes and has shown greater abnormalities in athletes that have had multiple concussions (Lovell et al., 2006; Echemendia et al., 2001; Collins et al., 1999). The limitations of the Post-Concussion Symptom Scale come from its reliance on participants self-reporting their symptoms which can have variable effects on the results of the test (Tjarks et al., 2013). For example, individuals engaging with this scale are known to provide limited symptoms to try and mislead the test administrator to return to play in a timely manner. Due to this limitation, it has been recommended that the test

not be used in an isolated manner but rather in conjunction with another assessment (Dessy et al., 2017).

### *Neuropsychological Baseline Testing*

Neuropsychological baseline testing (NBT) is an auxiliary tool that has been incorporated within the SRC management process to gauge an individual's cognitive state to assist in the return to play process (McCrory et al., 2017; Webbe and Zimmerm 2014). NBT goes past the limitations of pen and paper tests by providing complex computer-based assessments that are marketed to accurately measure an athlete's cognitive state. Like pen and paper tests, NBT is implemented in two phases. The first phase being a pre-season assessment where athletes are evaluated through a series of computer-based cognitive assessments to evaluate their normative cognitive abilities (baseline), while the second phase is the re-evaluation of the same assessments to see if an athlete has deviated from their norm if suspected of having a concussion. Originally, this type of assessment was designed to be implemented by trained neuropsychologists but has transitioned to a common management method used by allied-health professionals (e.g., physiotherapists, chiropractors) (Apple, stran & Tross, 2020; McCrory et al., 2017). Within the field of NBT, companies have emerged with their own product to try and support the SRC management process. Notably, there are five tests that appear most in the literature which are: Concussion Resolution Index, CogSport/AXON, Automated Neuropsychological Assessment Metric, Highmark EQ Brain Performance and the Immediate Post-Concussion Assessment and Cognitive Testing. A summary of the neuropsychological baseline tests is located in table 2.

Table 2

*Summary of Neuropsychological Baseline Testing Assessments*

Test	Contents	Advantages	Disadvantages
CRI	<ul style="list-style-type: none"> <li>-Examines speed of information processed</li> <li>-Visual recognition</li> <li>-Reaction time</li> </ul>	<ul style="list-style-type: none"> <li>-High sensitivity and resistance to test-retest effects</li> </ul>	<ul style="list-style-type: none"> <li>-Not suitable for long-term management</li> <li>-Issues with false positive reading</li> <li>-Results begin to deteriorate at the 45- and 50-day mark post injury</li> </ul>
CogSport/AXON	<ul style="list-style-type: none"> <li>-Reaction time and accuracy to evaluate simple and complex attention</li> <li>-Short-term memory</li> <li>-Working memory</li> <li>-Incidental memory</li> <li>-Adaptive problem-solving</li> <li>-Spatial abilities</li> </ul>	<ul style="list-style-type: none"> <li>-Correlates well with paper and pencil concussion assessments</li> <li>-Currently marketed as a standalone measure</li> <li>-Results statistically analysed and provided in custom formatting</li> </ul>	<ul style="list-style-type: none"> <li>-Reported high variability in results</li> <li>-Not available to the general population</li> <li>-Most studies in support of this measure have been funded by the company that created it</li> </ul>
ANAM	<ul style="list-style-type: none"> <li>-Simple reaction time</li> <li>-Code substitution-learning</li> <li>-Procedural reaction time</li> <li>-Mathematical processing</li> <li>-Go/No-Go</li> </ul>	<ul style="list-style-type: none"> <li>-No advantages have been identified</li> </ul>	<ul style="list-style-type: none"> <li>-Low sensitivity for identifying concussion</li> <li>-No utility as an individual diagnostic of populations screening tool for neurocognitive dysfunction past ten days</li> </ul>
Highmark EQ Brain Performance	<ul style="list-style-type: none"> <li>-Balance assessment</li> <li>-Visual function</li> <li>-Cognitive function</li> <li>-Resiliency</li> </ul>	<ul style="list-style-type: none"> <li>-Balance assessment reported to perform like the K-D test</li> <li>-Cognitive function assessment reported to perform like the SCAT</li> </ul>	<ul style="list-style-type: none"> <li>-New test with extremely limited research supporting their claims</li> </ul>
ImpACT	<ul style="list-style-type: none"> <li>-Verbal memory</li> <li>-Reaction time</li> <li>-Visual-motor speed</li> <li>-Visual-memory composites</li> <li>-PCSS</li> </ul>	<ul style="list-style-type: none"> <li>-High sensitivity and specificity</li> <li>-Marketed as a standalone test</li> <li>-separate version for children</li> <li>-Used for long-term management</li> <li>-Factors in place to catch attempts to hide symptoms</li> </ul>	<ul style="list-style-type: none"> <li>-Research has shown it cannot be relied upon as a standalone measure</li> <li>-Components of the assessment have been found to be unreliable</li> <li>-Results can be influenced by age, gender, test setting and if the individual has a learning disability</li> </ul>

Note: CRI- Concussion Resolution Index, ANAM- Automated Neuropsychological Assessment Metric, ImpACT-Immediate Post-Concussion Assessment and Cognitive Testim PCSS- Post-Concussion Symptom Scale

**Concussion Resolution Index.** Designed by HeadMinder Inc., Concussion Resolution Index offers an assessment that is 20-25 minutes in length and is completed entirely online (Erlanger et al., 2001). Concussion Resolution Index was constructed to address concerns surrounding current assessment techniques - test-retest effects, time efficiency, cost, and practice effects. The test is comprised of measures examining speed of information processing, visual recognition, and reaction time (Apple, Stran and Tross, 2020). The Concussion Resolution Index also includes imbedded validity indicators to screen for chance responses and significantly decreased baseline test performances (Schatz and Zillmer, 2003). In past research the Concussion Resolution Index has shown to be quite sensitive in identifying SRC. Results from a study performed by Erlanger et al. (2001) reported a 77% identification rate (the research team did not state if there were no false positives) among concussed athletes throughout the test with complex reaction time accounting for the most sensitive sub-category successfully identifying even very mild SRC's (Erlanger et al., 2001). The test has shown to deteriorate in its identification of SRC at the 45- and 50-day mark after injury with 19% and 32% of participants reporting one or more false positives (Brolio et al., 2007).

**CogSport/AXON.** CogSport/AXON was designed and is currently marketed as a standalone measure to help in the management of SRC injury. Unlike other NBT's CogSport is not openly offered making it difficult for amateur sporting organization to utilize its services. Interestingly, the test holds a strong presence in elite sporting organizations outside of North America (e.g., South Africa and Australia) (Arrieux et al., 2016; James et al., 2020; Symons et al., 2020; Schatz and Zillmer, 2003). The test itself was constructed to measure reaction time and accuracy to evaluate simple and complex attention, short-term memory, working memory, new learning, incidental memory, adaptive problem solving, spatial abilities and continuous performance (Schatz and Zillmer, 2003; Cogstate, 1999). The test evaluates these components of

cognition through a series of tasks taking the form of playing cards either grouped or on their own. The company offers a variety of additional services such as allowing for the results to be delivered in a customized format and the ability to have the results run through additional statistical analysis (Schatz and Zillmer, 2003). The test was originally validated on a sample of 300 professional Australian rules football players across a wide range of ages and has provided evidence to be a reliable measure of cognitive function in rugby union players (MacDonald and Minahan, 2016; Makkissi et al., 2001). While current research provides support for the use of CogSport/AXON, it is important to note that most studies providing evidence for CogSport/AXON have been either conducted or commissioned by the owners of the test and have focused mainly on professional athletes (Symons et al., 2020). Like other NBT's, CogSport/AXON has reported inadequate evidence to support its inclusion within the clinical decision-making process for return to play (Symons et al., 2020).

**Automated Neuropsychological Assessment Metric.** The Automated Neuropsychological Assessment Metric was originally created by the United States Department of Defense program to measure cognitive effects from chemical weapons, environmental stressors, and medications (Randolph, McCrea and Barr, 2005). Within the test there are eight subsets which include: simple reaction time, code substitution-learning, procedural reaction time, mathematical processing, matching to sample, code substitution-delayed, simple reaction time 2, and go/no-go (Nelson et al., 2016). Since the test was designed specifically for the United States Department of Defense, many of the studies surrounding its use have been related to trauma experienced in the field of combat (Coldren et al., 2012). Few studies have looked to examine its use case within the sporting community. One study that examined the Automated Neuropsychological Assessment Metric among a sample of college football players found that few concussed participants were classified as impaired after being examined with the diagnostic

tool (Register-Mihalik et al., 2013). With such low levels of sensitivity for SRC detection, researchers have questioned the use case for Automated Neuropsychological Assessment Metric in the return to play process (Register-Mihalik et al., 2013). The inclusion of Automated Neuropsychological Assessment Metric within its original context of combat assessment has also been put into question because of its low sensitivity for concussion detection. Between January and April of 2009, Coldren et al. (2012) were deployed to Iraq to examine the validity of Automated Neuropsychological Assessment Metric for the diagnosis of concussion in the field of combat. They found that Automated Neuropsychological Assessment Metric had no utility as an individual diagnostic or population screening tool for neurocognitive dysfunction ten or more days following injury (Coldren et al., 2012).

**Highmark EQ Brain Performance.** Relatively new to the world of NBT, Highmark Interactive designed a multi-faceted brain assessment tool which incorporates balance, visual function, cognitive function, and resiliency (Mazza and Crane, 2018). Unlike other NBT's EQ Brain Performance includes a balance element that evaluates both the vestibular and proprioceptive systems. Within the visual function element of EQ Brain Performance, participants are required to scan left-to-right on the screen making deliberate swipes depending on the direction of arrows presented to them. During the cognitive function component, short term memory, delayed memory, concentration, executive function, and visual reaction time are analyzed through a series of developed games created to target these areas of interest. The gamification of this app appears to be a big selling point for its inclusion in the management process which could help reduce possible "sandbagging". "Sandbagging" is an attempt made by an athlete to purposefully score lower on an initial assessment which would help their ability to score relatively the same if they were to experience a concussion. It has been documented as a major problem that has a direct effect on the results of a baseline testing (Higgins, Caze and

Maerlender, 2018). The last component resiliency was included to measure participants mental well-being by examining the balance between stress and recovery. It is also important to note that Highmark attempts to establish a strong baseline through repetitive testing of the athletes.

There does not appear to be any peer-reviewed studies that examine the validity or reliability of this NBT. Instead, the creators have performed assessments comparing existing measures to those they have developed for their assessment. Their balance components were found to be equivalent to current balance measures (Sway Balance System), their visual function assessment was found to be equivalent to the King-Devick test while their cognitive function assessment reported similar findings to the Standardized Concussion Assessment Tool and Trail Making Test (Kis and Mochizuki, 2019). The purpose of their multi-metric game-based application is to create a structured testing network that can encompass a variety of cognitive functions. This will then help establish more information on the participant which they state will increase sensitivity for the identification and management process.

**Immediate Post-Concussion Assessment and Cognitive Test.** The Immediate Post-Concussion Assessment and Cognitive Test is a computerized assessment tool that can be implemented through a web-browser using keyboard reaction time instead of a mouse-button input (Dessy et al., 2017). The test is made up of six tasks: Word Memory, Design Memory, X's and O's, Symbol Match, Colour Match, Three Letters and the Post-Concussion Symptom Scale. These form four output scores of verbal memory, reaction time, visual-motor speed, and visual-memory composites (Nelson et al., 2016; Gardner, Shores, Batchelor and Honan, 2012; Broglio et al., 2006). The Immediate Post-Concussion Assessment and Cognitive Test was designed to be implemented prior to the start of a sporting season to establish the athletes normal cognitive state to allow for re-assessment post impact to help in the identification and management process of a SRC (Nelson et al., 2016).

Past research has shown the Immediate Post-Concussion Assessment and Cognitive Test to be sensitive to the acute effects of concussion, particularly in the few days following the initial injury (Iverson, Lovell and Collins, 2003). Specifically, Iverson et al. (2003) found that athletes who had experienced a SRC had a significant decline in performance within the categories of verbal memory and visual memory. Although, research examining the test-retest reliability of the Immediate Post-Concussion Assessment and Cognitive Test found visual memory and verbal memory to be rather unreliable compared to visual motor speed and reaction time that showed greater reliability (Resch et al., 2013). The Immediate Post-Concussion Assessment and Cognitive Test like the other NBT's, have been put into question due to variables that can influence the results of the test. The results have been shown to be influenced by age groups, genders, individual or group settings, learning disabilities and intentionally poor performance (Vaughan et al., 2014; Lichtenstein et al., 2014; Abeare et al., 2018; McClure et al., 2013; Higgins, Caze and Maerlender, 2018; Schatz and Glatts 2013; Wojtowicz et al., 2015). Currently, the Immediate Post-Concussion Assessment and Cognitive Test is the most widely adopted NBT within North America (Dessy et al., 2017). ImPACT Applications, Inc. has reported that as of 2017, their NBT was being used by 7,400 high schools and 1,000 colleges. The assessment has also been incorporated into many professional sporting leagues such as the National Basketball Association, Major League Baseball, and the National Football League (Schatz and Sandel, 2013).

### **Critical Commentary of NBT in Sport**

Neuropsychological assessment is a well-known metric that has been used for the purposes of scientific research and within occupational fields like psychiatry (Casaletto and Heaton, 2017). Its history as an assessment that can help detect cognitive deficits is what led to its adoption within the sporting community (Webbe and Zimmer, 2014). Research first examined



its applicability to sport in the early 1980's when Barth et al. (1983) became interested in examining the risks of concussion on college level football players. While his results showed its possibility for helping to identify concussed athletes, the test relied on pen and paper for its administration which was deemed too time consuming to be feasible (Webbe and Zimmer, 2014). Although, the possible benefit of its integration is what eventually led to the development of the first computerized NBT during the late 1990's (Maroon, Lovell, Norwig, Podell, Powell and Hartl, 2000). By computerizing the process, it allowed for greater convenience to administer the test in a timely fashion and to reach a larger audience (Webbe and Zimmer, 2014). Since then, companies (e.g., ImPACT Applications Inc.) have built and developed their own NBT assessments to try and create a tool that could be marketed to the sporting community (Webbe and Zimmerm 2014). While NBT was developed to contribute to the management of a SRC, research has continually questioned its ability to provide adequate support for the concussion management process (Symons et al., 2020; Abeare et al., 2018; Gardner, Shores, Batchelor and Honan, 2012; Randolph, McCrea and Barr, 2005). So far NBT continues to perform below requirements for its inclusion in a clinical setting while continually presenting low test re-test reliability (Talavage et al., 2014; Echemendia et al., 2014; Broglio et al., 2007). Even with such inadequacies, companies continue to produce and market the test as a way of effectively managing a SRC (Symons et al., 2020). The consequence of this continual marketing is the on-going adoption of the tool within the management process. To my knowledge, no published research has documented parents' perceptions toward the inclusion of NBT as a strategy for concussion management. This is a cause for concern due to the acceptance this test has seen within stakeholders in the sporting community. Knowing that evidence has shown the flaws this test produces, it is essential to gain the parents knowledge of why and if they believe this tool is relevant when it comes to managing a concussion.

## Parents Role in Concussion Management

Parents (regardless of their education and knowledge of concussion) play a critical role in their child's concussion management. They are relied upon for both identifying the injury and acting as the caregiver during the management process. (Rice and Curtis, 2019; Lin et al., 2015). Currently, parents have demonstrated an understanding of the ability to identify concussion and the importance of removal from play following the injury but are limited in their knowledge of its management (Black, Yeates, Babul, Nettel-Aguirre and Emery, 2020; Rice and Curtis, 2019; Kroshus, Stellino, Chrisman and Rivera, 2018; Turner et al., 2017; Weerdenburg, Schneeweiss and Koo 2016). This lack of understanding was noted by Hecimovich, Kingb and Maraisc (2016) that reported only 41% of their sample (n=1441) could recognize proper concussion management and return to play guidelines. They found that 79% of their sample had received first aid training but only 9% reported receiving specialized training for concussion. Similarly, Weerdenburg et al. (2016) found the same gaps in knowledge within a sample of 495 parents. They found that 91% of their sample would prevent their child from playing sport if they suspected a concussion but only 32% were familiar with return to play guidelines. Recently, Black et al. (2020) found that 82% of their parent sample (n= 786) reported receiving concussion education but only 58.6% had heard of return to play protocols. Both Weerdenburg et al. (2016) and Black et al. (2020) reported their participants receiving information on concussion from a wide range of sources that included newspaper, television, family physician/emergency room doctor, coaches, and trainers.

Parents appear to understand the severity of concussion but lack the knowledge and guidance to effectively engage with the management process. Without any support targeting the parent population, they are left in a difficult position of trying to adapt and educate themselves while actively managing their child's injury (Feiss, Lutz, Reiche, Moody and Pangelinan, 2020). Knowing parents are having to learn while they manage is a cause for concern due to the limited

research examining how their gaps in understanding may affect their ability to manage their child's injury. The severity of concussion and limited understanding for its management could be creating a high fear appraisal for concussion injury and leaving them confused for how to properly manage it. This can only be amplified by the relationship they have with their child. This existing uncertainty and the emotional investment, they have in their child's well-being could be what is causing their engagement with alternative methods of care like NBT.

### **Present Study**

Research on the parent population in sport has continually identified gaps in their knowledge of concussion management but currently little to no research has focused on examining how these gaps affect the parents experience and ability to process concussion management. My project sought to address this area of interest through a qualitative study examining parents' current knowledge of SRC and its management. Specifically, my project aimed to gain an insight on the way parents engaged with concussion management and how their understanding of the injury and its management affected this process. We were also interested in examining how their current understanding of concussion management could have affected their decision to engage with an alternative method of management - neuropsychological baseline testing (NBT). In discussing the findings, we will also bring relevant theory to bear on parents' involvement in concussion management.

The decision to utilize the qualitative method allowed this research to provide an in-depth and contextualized understanding of parents' experiences, beliefs and feelings towards concussion management and their perceptions of NBT. Past research has commonly used quantitative methods, which has been able to identify parents' gaps in understanding but has yet to provide adequate support for why these gaps exist or how they affect the experiences and decision-making processes of parents. By adopting a qualitative approach to my methodology,

we were able to provide parents with and without experience managing concussion and engaging with NBT an opportunity to express their lived experiences through active discussion within semi-structured focus groups.

## **Methods**

### **Design**

A qualitative design was chosen due to the exploratory nature of this study. This research design was optimal for allowing us as researchers to engage in an in-depth examination of the participants perceptions and lived experiences regarding concussion management and NBT. Ethics approval for the study was received from Trent University's Research Ethics Board in June 2020 (protocol #26630).

### **Sampling and Recruitment**

Purposive sampling was used to recruit participants through advertisements (Appendix A) posted on social media websites (e.g., Facebook and Instagram) and connections with administrators of local sporting organizations (e.g., minor hockey, rugby) via email. These advertisements asked for parents with children involved with contact and collision sports to participate in 90-minute focus groups with the incentive of a twenty-dollar gift card to Sportcheck. Ten participants were sought out to form two focus groups. Parents were excluded from the study if they were not over the age of 18 and if they did not have at least one child who had been registered in contact/collision sport. Recruitment occurred from October to December 2020.

### **Procedure**

Focus groups were chosen because of their ability to gain an insight of a community by allowing for a detailed discussion among a sample of the targeted population (O'Donnell, Lutfey, Marceau and McKinlay, 2007). The use of focus groups also allowed for dynamic

interaction which offered participants the opportunity to compare the similarities and differences between their experiences (Morgan, 1997). Before the focus groups commenced, all participants submitted a consent (appendix B) and demographics (appendix C) form through an online survey platform. Participants were then assigned to two focus groups. All focus groups occurred virtually and were recorded through Zoom conference calling (Zoom Video Communications Inc., 2016). At the start of the groups, participants were welcomed and consent for participation and recording were reviewed. After verbal confirmation was obtained from the participants, the members of the research team were then introduced with the student researcher being the moderator and supervisor acting in the role of note taker. The student researcher and supervisor debriefed following each focus group.

The first focus group had a run time of 98 minutes and 21 seconds, while the second focus group was 108 minutes and 4 seconds in length. Both focus groups were downloaded from the Zoom server and saved on a secured laptop. Both focus groups were transcribed verbatim by the primary investigator and all participants names were replaced with pseudonyms to maintain confidentiality. Focus groups were held in December 2020.

## **Materials**

**Semi-Structured Focus Groups.** The guide (appendix D) used to facilitate my focus groups was shaped by the principles of protection motivation theory (Rogers, 1975).

The focus groups began with a general question asking participants about what interested them in participating in the focus group before shifting into the first topic of questioning which was their current beliefs surrounding concussion injury. Within this section, questions looked to examine parents' beliefs about SRC and the sources of those beliefs (e.g., what past education have you received regarding SRC?) their perceptions on the severity of the injury (i.e., in your mind, what

are the consequences of SRC?) and what measures they viewed as an effective means of reducing the chances of SRC in children (i.e., rule changes, equipment).

Questions then shifted to the participants' experience with the SRC management process. This section was interested in understanding participants' confidence in the management process their child's SRC and what actions they may have taken to help in the recovery process. Questions also extended to their experiences dealing with medical professionals and what they would suggest for other parents who are experiencing the recovery process for the first time (i.e., what do you think might be helpful to provide a parent of young athletes to help them be able to manage a SRC?). Questions then focused on their experiences and thoughts on neuropsychological baseline testing.

### **Data Analysis**

Conventional content analysis was chosen for data analysis for two reasons. The first reason being that Conventional content analysis's principles embrace social phenomenon with limited background or developed theory which is relevant considering little is known about parents' perceptions toward NBT (Hsieh and Shannon, 2005). The second reason was due to my decision to allow participants to speak freely about their lived experiences. We chose to allow an open discussion among the participants because of the opportunity it provided to gain valuable information on parents' perceptions of concussion management and NBT. The analysis of the transcripts followed the guidelines of Hsieh and Shannon (2005) approach to Conventional content analysis.

The analysis started with multiple reads of the transcripts to achieve full immersion with the data. During these read throughs, initial impressions and comments were being noted and words that captured key thoughts were highlighted (Hsieh and Shannon, 2005). As this process continued, themes were developed from multiple key thoughts that emerged from the data. After

the themes and sub-themes for each focus group were formed, they were then compared to examine similarities and differences between the transcripts. During this process, my supervisor was actively providing his thoughts and opinions on the emerging themes. This discussion led to the final construction of a common theme deemed navigating uncertainty which incorporated categories of sub-themes relating to the participants experience with concussion management and NBT. Examples were then provided from the text to give context for the themes that formed navigating uncertainty.

### **Reflexivity**

By engaging with a qualitative research model, I am aware that the way in which I have interpreted my data could be influenced by my past experiences with concussion injury and its management. As a coach I have received training on the topic of concussion injury and return to play which notably did not include information on NBT. The information I received was in line with the concussion management I have witnessed as a coach where the athlete had to follow the steps laid out by the sporting organization which relies on the final say of a doctor. As a researcher, I have noticed little support within the literature for the inclusion of NBT in the management process despite its widespread use which has led to my possible bias against the measure. The research identifies the unreliability of the test, yet coaches and administrators seem to place faith in its results. With limited research supporting NBT and my own personal experience as a coach, I have begun to question the involvement of this measure in the sporting community. This curiosity for the tests continual use has led me to question how parents perceive this tool within the management process.

After identifying my current biases, I made efforts to ensure rigor was embedded in the analysis of the data. I began by having the focus group guide evaluated by third parties to ensure the questions were not leading and displayed a rather neutral stance. I then ensured the data was

captured and transcribed in an objective manner to accurately document the communication among the participants (Seale and Silverman, 1997). I obtained the data through a screen capturing software that recorded the audio for both of my focus groups which I immediately shared with my supervisor. I then transcribed the focus groups verbatim while openly sharing and reviewing the work with my supervisor. Throughout this process I continuously self-reflected on any biases I may have had during the analysis portion of the transcripts to ensure I was aware of the possible effects I could have had on the data. I also actively engaged my supervisor in the development of emerging themes and sub-themes to provide an additional perspective to help reduce any of my own biases which could have affected the data (Morrow, 2005). The themes were then evaluated by my supervisor, research lab and an external PhD candidate to ensure they were a representation of the data itself and were void of any potential biases I may have held toward NBT. The actions that I have taken to limit the presence of bias within the focus group guide, collection of the data and process surrounding data analysis helped increase the reliability and validity for the results found within this study.

## **Results**

### **Participants**

The sample consisted of five female and six male participants who currently have or had their children registered in contact or collision sports (i.e., hockey, soccer, gymnastics etc.) ranging from recreational to national level competition. The participants ranged in ages from 23-61 ( $M= 46.36$ ) years. The parents reported having one to three children enrolled in sports at a time with their children's ages ranging from 6-25 ( $M=15.68$ ) years old. There were six parents who had children suffer a SRC and three that had their children undergo NBT. The parents held many roles in their child's sporting career which included: spectator, coach, assistant coach, trainer, and league administrator. The parents were organized into two focus groups with the first



consisting of four mothers and the second consisting of five fathers, one mother and one guardian. A further break-down of the participants can be found in table 3.

Table 3

Demographic Information		Sports Enrolled in and Number of Children per Participant																		
		Gender	Age	Role of Coach	# of Children in sport	Hockey	Soccer	Baseball	Volleyball	Speedskating	Rowing	Ball Hockey	Synchro Swimming	Gymnastics	Rugby	Basketball	Track and field	Lacrosse	Football	Total Sports Enrolled In
Participants <sup>1</sup>																				
A1	F	47		3	X			X												2
A2*	F	52		2	X				X			X								3
A3*	F	48		2	X					X		X								3
A4*	F	43		2			X													1
B1	M	44	X	2		X													X	4
B2***	F	47	X	3						X									X	5
B3	M	23		1											X				X	1
B4*	M	61	X	3			X				X									3
B5*	M	45		3	X		X									X				5
B6****	M	53	X	2	X															1
B7**	M	39	X	2	X						X								X	3
Total		5	25	7	3	2	3	3	2	2	2	1	1	3	1	1	1	1	1	1

Note 1. Participants were given codes in replacement of their name to maintain confidentiality. The letter represents the focus group they were a part of, and the number is respective of their position in said focus group.

Note 2. Participants with a \* has had a child experience a sport-related concussion, \*\* has not had a child experience a sport-related concussion but has engaged with neuropsychological baseline testing, \*\*\* has had a child experience a sport-related concussion and neuropsychological baseline testing.

## **Navigating uncertainty**

Navigating uncertainty was the core theme that emerged from the data and encompassed the participants' efforts to manage their child's concussion in the face of uncertainty. The participants faced the dilemma of managing their child's concussion while knowing they possessed an incomplete understanding of the injury and its management process. This meant the participants had to learn and adapt while being presented with new and challenging experiences they were not prepared for. These efforts also extended past their role as the caregiver and into their position as a volunteer coach.

Navigating uncertainty contains five sub-themes, two reflecting an orientation towards greater uncertainty, two reflecting an orientation towards greater clarity and one reflecting ambivalence. The first sub-theme, "the absence of a definitive diagnosis generated uncertainty for their child's injury and how they were going to manage it" relates to the uncertainty the participants felt surrounding their child's concussion diagnosis and the methods they felt could benefit their child's management. The second sub-theme, "experience helped to reduce uncertainty" highlighted the importance experience with concussion injury had on providing the participants clarity for the complexities of the injury and the difficulties associated with its management process. The third sub-theme, "communication was a leading factor for uncertainty during the management process" discussed their discontent with their experiences communicating with stakeholders (e.g., children, coaches, and parents) in the sporting community regarding concussion management. The fourth sub-theme, "concussion policy in sport provides clarity for the role of the parent coach" related to the clarity concussion policy provided to the role of the parent coach within the concussion management process. The final sub-theme, "neuropsychological baseline testing provided information, but participants remained

uncertain about its reliability” relates to how the participants saw the benefits of engaging with an alternative measure of care to try and provide clarity to the management process but also had doubts due to the known flaws with the assessment. Themes are illustrated in figure 2.

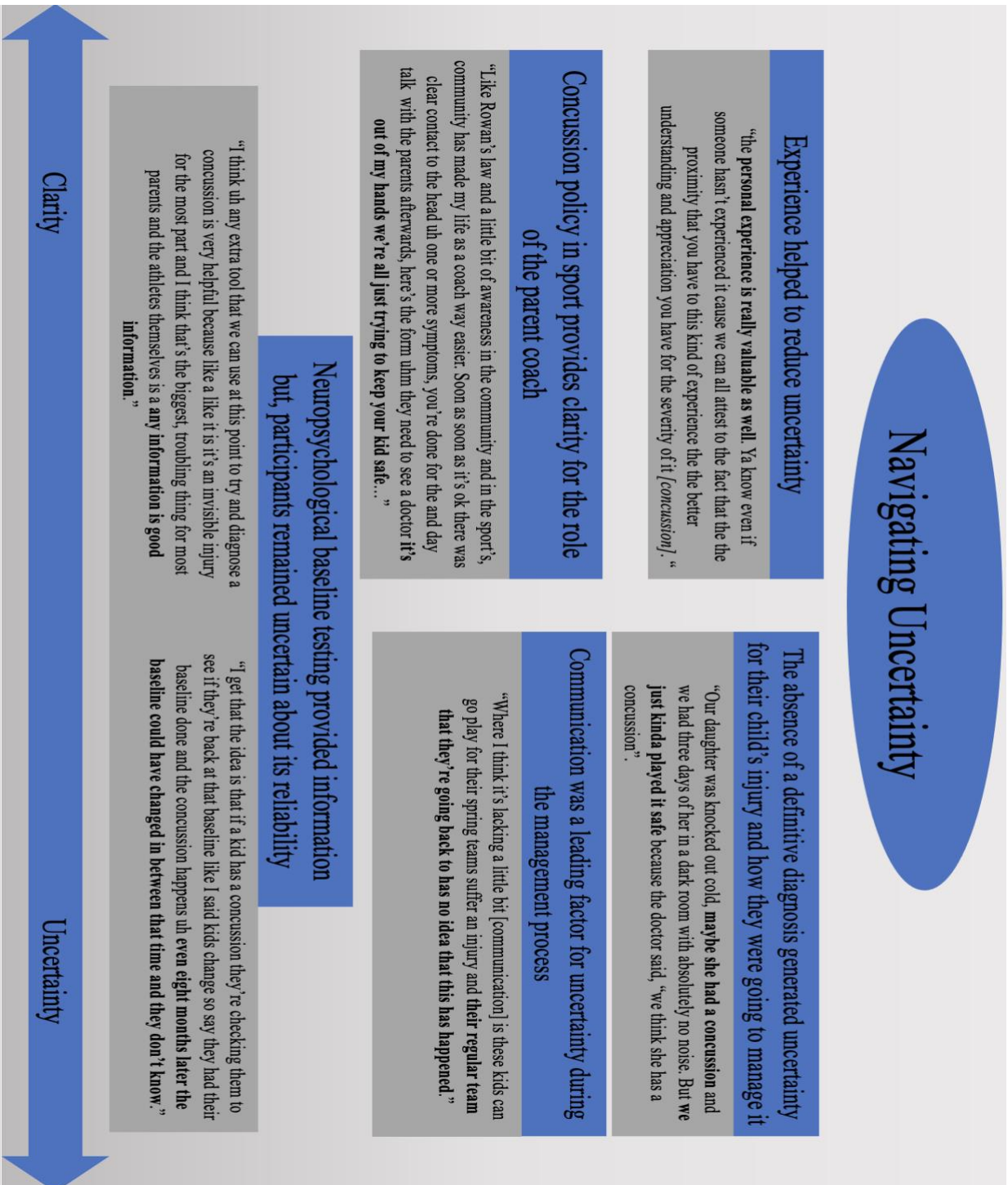


Figure 2. The existing themes that led to the construction of navigating uncertainty

**The absence of a definitive diagnosis generated uncertainty for their child's injury and how they were going to manage it.** The participants felt there was a lack of clarity in how to manage a concussion due to the absence of a definitive diagnosis. They attributed this diagnostic ambiguity to their interactions with emergency room physicians. The difference in experiences were present within A3 and A2's engagement with emergency rooms services within the same community. For A3, they had experienced no diagnosis and received minimal supportive materials for both her child's and husband's concussion, while A2 had a doctor who provided them with the diagnosis and supportive information they needed to aid in their management process.

(A3, pg. 34): So the fact that A2\*'s daughter was asked to come back to the doctor after three days, I mean that was great. We didn't unfortunately have that guidance I again think it's that lack of consistency right. Ya know some doctors are really focused and wanting to get ya know whether it's a definitive diagnosis or give them the information they need to um get better whereas others are kinda like well it might be so just so you can see what happens kind of thing.

(A2, pg. 36): Ya I I found they were really great and very caring, but I also find that not everybody is delivering the same message to everybody who comes through the door, so that's a little confusing. If you go to a different physician or different emergency room or clinic, you might get a different message.

For the participants who did not receive a definitive diagnosis, they were left without an understanding of what exactly their child had experienced. This uncertainty created a sense of doubt for how they were going to approach managing their child's injury.

(B5, pg. 30): I think when my son had his first concussion, it was a bit of a learning curve of does he have it, does he not have it and not fully understanding and I think the education isn't out there enough for a lot of people and I think going through it the first time it was kind of easing in [to managing the concussion].

Without knowing what exactly their child experienced, the participants had to learn and engage with methods of management they felt would benefit their child's recovery from a potential SRC. Mainly, these methods consisted of supervising and limiting their child(ren)'s daily

activities while relying on their child to express their symptoms to understand how they were feeling.

(A3, pg. 31): Lots of sleep, trying to minimize um media which in this day and time is really challenging. Um because I mean even school like they're using smart boards and they're using digital everything. We like, we let him lead the way in terms of/ we wanted him awake during the day just a little bit, he'd uhm we [just tried to help him move a little bit] say lets go for a walk or something and we just listened to his cues, if his head [was starting to hurt] he would go back to bed.

(A4, pg.32): I could say with his concussion that he had when he was playing from hockey when he was hit by from the puck he was in his room there was no stimulation, no school work I mean not a lot of anything. He didn't have a tv in his room, he had his cellphone but he on his own was unable to do it I didn't really manage it because he was he was just sleeping a lot and that was followed up with our doctor it was more letting him decide and he was ok.

The uncertainty in management led to three of the participants seeking out auxiliary health care providers to receive additional treatment for their child's injury. Only two of these participants felt their child benefitted from the added care, although the methods (i.e., craniosacral therapy, Virtual focus training) they pursued were not clinically recommended to treat a concussion (McCrorry et al., 2017). It appeared that these decisions were influenced by existing relationships they had with healthcare providers versus any form of evidence-supported intervention. Mainly these alternative methods pursued by the participants were attempts to provide some form of care to a management process they did not fully understand.

(B2, pg. 30): we have a friend who's a neuroscientist who works at the university and he was conducting studies with people who have suffered concussions, so we were able to get my kid in to that trial which was great. But he did a lot of work with umm with focusing training and almost like a it's almost like a video game ya know and that really helped him recover quite quickly.

(A3, pg.32): Um I had my um colleague um work do some craniosacral therapy on my son and uhm that seemed to put him over like he was feeling better but still not a hundred percent and that seemed to help him kinda get the last little bit of whatever, feel better ya. So that's a light touch/ she's actually an occupational therapist but a lot of massage therapists use that um form of treatment it's a bit lighter touch than a true massage and its um its been shown to be pretty helpful with concussion.

**Experience helped to reduce uncertainty.** Participants had reported either directly managing or vicariously witnessing the management of a SRC as a valuable learning experience that they could not gain through education alone. Their experiences provided them with an insight of the complexities associated with the injury and its management process.

(B2, Pg.35): the personal experience is really valuable as well. Ya know even if someone hasn't experienced it cause we can all attest to the fact that the the proximity that you have to this kind of experience the the better understanding and appreciation you have for the severity of it [*concussion*].

These complexities were described by the participants as factors that would not be commonly understood by those without experience managing the injury. The first factor was the deceptive nature of concussion when compared to other common sporting injuries. The participants noted that concussion does not have any immediate visual cues which would make it difficult for those without experience to understand the severity of the injury.

(B4, Pg. 12): I think the problem with concussions is is that a unlike a broken arm, there's there's no label that there's something wrong (..) and and people don't, and parent's and fellow athletes don't necessarily appreciate all of those symptoms that have been talked about so far.

The second factor was the effects concussion can have on an athlete's mental health. The ability for concussion to cause irregularities in an athlete's mood and behaviour needed to be experienced by being around the individual during the management process. Participants reported changes within members of their own social circle that affected their family life, profession, and schooling.

(B1, Pg., 39): Well the social emotional part of a concussion that people that haven't been around concussion's really don't know that it's just not physical, it's just not the fact that you have blurred vision or difficulty seeing with light and have headaches and all the rest, it's the social emotional bit like I had a friend that their son had a bad concussion and he literally became a different boy for six months he was he became very moody and very in bad moods.

(A2, Pg., 16): I have a friend who is in education as well and he played hockey in Europe as well and today as an adult he's had so many concussions he really can't function, and it's really effected his life. Now he has been monitored from the get-go and they can't seem to really help him feel better right now. So, it's pretty devastating for their children, for his profession his work and his wife have really been affected so, we've kind of learned a lot from that.

The participants did not feel they were able to gain an awareness for concussion through the current education provided in the sporting community. Their first criticism was with the flow of information being directed mainly to coaches and trainers instead of the parenting community. The parents felt they were not being provided with the educative support they needed even though they were the ones that had to manage their child's concussion.

(B5, Pg., 38): I think awareness overall is the big thing that needs to come out more for most parents. I know there's been a lot of awareness like lots of literature towards coaches and coaching staffs and trainers but the general population of parents, haven't been shown it as much of this information and I think getting it out there and the awareness to the parents so they can realize what concussions really are.

Their second criticism was with the organization and consistency of information that is already accessible for parents. They did not feel confident in choosing or following any specific option of care due to the lack of centralization surrounding opinions on concussion and methods used to manage it.

(B7, pg.,36): I wish there was just a one stop shop for this works and this is what we should be looking for but because like anything you just punch it in to the internet and and it's you know it's find the information that you're sort of looking for you're actually looking for and I guess what I'm trying to say is I just wish it was more cut and dry. There was more hey let's go to concussion.com let's go to concussion recovery.com, whatever it is instead of just joe's concussion recovery and Dr. you know this and therapy and there's just so many people that have, an opinion or information or have done research and sometimes it varies from person to person.

**Communication was a leading factor for uncertainty during the management process.** The participants were reliant on communicating with their children and other actors (e.g., children, coaches and league officials) within the sporting community to understand if their child or

athlete had experienced a concussion. Without clear communication, the participants were uncertain about the condition that their child or athletes would be in and how that would affect their decision to keep them in play. This sub-theme contains two dimensions the participants experienced in the role of parent and coach. The first being “parents were uncertain if their children were telling the truth about their symptoms” discussed the importance of open and honest conversations with their children about their condition. The second part “parent coaches were uncertain about the health status of their athletes due to problems with information exchange between sporting bodies” related to the parent/coach participants’ concerns of playing athletes that had not disclosed an injury they had experienced while participating on other sporting teams and in other third-party leagues.

*Parents were uncertain if their children were telling the truth about their symptoms*

The need to trust a young athlete about their condition worried parents because of the internal and external factors they believed could cause their child to not fully or accurately report their symptoms. A2 expressed concerns about their child possibly holding back information when discussing concussion management. They acknowledged their children as committed sport participants and knew that they would not like to miss games or practices, which can make it difficult when trying to manage or identify a concussion. Consistent with previous literature, young athletes believe that if they are honest about their symptoms, they could miss out on playing time which they view as a potential punishment (Schatz and Glatts, 2013). So, they might choose to withhold information to try and limit any opportunity that would keep them out of sport.

(A2, Pg, 13): And I know sometimes, uh a kid won't want to, they'll say their fine especially if a tournament is coming up because they are going to want to play so they won't say that they have a concussion or if I'm not feeling well so it that's a little tough if you're.. you're kid has to tell you depending even on the age. Uhm so that's, we found a bit tricky like our daughter would go full-tilt all the time and I'm not sure that some kids wanna miss.



The presence of this internal factor can keep a young athlete from being forthcoming, but social factors could also lead to the same result. A4 has experienced this firsthand with peers from her son's hockey team pressuring an injured player to try and play during an important game. The pressure A4 has experienced has been noted in previous literature on external factors causing young athletes to continue playing injured (e.g., Kroshus et al., 2015).

(A4, Pg.19): some kids might not be truthful, um (..) leading up to a tournament or something where they really want to play a certain game and I have experienced that firsthand with one of our teams. We had a peewee team who their key player was injured, and the entire team wanted that player to be there, but that player very obviously was injured, and it was the parents who actually stepped in and was like nope you can't play and it was a very important game for that team.

Alternatively, athletes could also be limited in providing information because of difficulties identifying and communicating what they have experienced as a potential SRC (Sye, Sullivan and McCrory, 2006). A3 discussed that when her child experienced a concussion, they did not have the ability to properly express their current condition.

(A3, Pg.37): Kids don't always have the right words either right. They don't have those like necessary skills, sometimes giving them like I gave him wording like there's pressure in your head, is there something sitting on your head, do you have a headache or do your eyes hurt. Like I gave him those things to kinda go through just again cause I know a lot of the weird symptoms that can happen with concussion.

Their child's decision to not report their symptoms was unintentional and originated from an inability to articulate how they currently felt at the time. It is also likely there is considerable denial on the part of the concussed athletes, believing what they want to be true (i.e., they don't have a concussion) to avoid the negative consequences of sitting out. The inability for the athlete to self-identify their symptoms appeared to be another factor hindering communication alongside internal and external factors.

*Parent coaches were uncertain about the health status of their athletes due to problems with information exchange between sporting bodies*

Four of the participants who identified as coaches expressed their displeasure about a lack of exchanging of information between sporting bodies. They were concerned that they may be playing athletes who did not disclose injuries they experienced while participating in other sports and third-party events (e.g., summer league tournaments). There appears to be a lack of information being exchanged that would allow for other sporting entities to be provided with the required injury reports needed to prevent an athlete from participating in another league/sport while they are injured. Without any supportive information, the participants were uncertain about the health status of their athletes knowing that they were being exposed to greater chances of injury through their engagement in multiple sports.

(B7, Pg. 19): Ya know we coach with the organization with the town we're in and then when spring and summer come we're all coaching these weekend tournaments, spring teams, summer teams, one day tournaments. Where I think it's lacking a little bit is these kids can go play for their spring teams suffer an injury and their regular team that they're going back to has no idea that this has happened.

The participants proposed the formation of a database that would address these concerns. A database would allow for mass collection of injury (e.g., concussion) reports across multiple sport organizations providing coaches with the information needed to identify injured athletes. This database could keep all interested parties informed of the overall health of their athletes minimizing the chances of exposure to further injury.

(B7, Pg.19): It's interesting to think of the idea that there might be some way of having an intra-sport database for kids who have suffered a head injury. Like if I coach a kid in a spring team but he's from another town and he suffers a head injury I can send him home or off the ice all I want but when he goes back to his regular team, there's no one there that might know that this has happened and hopefully his parent's ya know are looking out for his best interest. But unfortunately, that's not the reality in every case.

A database would also remove the burden from the athletes and parents to disclose any possible injury to their coaches. Since the injuries would be reported by the coach who witnessed it,

parents would not be put in a position where they would have to decide if the injury their child experienced was severe enough to report. B5 experienced an incident where a parent did not feel the need to report an injury (albeit not a concussion) which led to an injured athlete continuing to play and causing the injury to become severe.

(B5, Pg. 22): Where a player on my hockey team was also playing football and he had injured his arm in a football game and the parents never told me nothing about it. He came to play and then halfway through the game he's like op I went to take a shot and my wrist is killing me and we're like what's going on? And he's like oh it's fine or whatever and uh so we told the parent's after the game and the parents were like oh he was just in a football game the weekend before and he hur- or like two days before and he hurt his arm so low and behold he went for a x-ray and he had a broken wrist and we were told nothing about it and it was sort of, it's a tough situation for various sports coaching when you're not informed by the parent's.

The idea of introducing a cross-sport database was the participants way of trying to increase transparency for injury identification to reduce the likelihood of unknowingly playing an injured athlete.

**Concussion policy in sport provides clarity for the role of the parent coach.** Concussion policies like Rowan's Laws and Hockey Canada's concussion policy were viewed as a benefit by the participants who had experience within the role of volunteer coach because of the clarity (I.e., uncertainty reduction) it provided to the concussion management process. The inclusion of concussion policy gave these five participants a system they could engage with to help identify and guide injured athletes back to recovery while also working as a supplemental tool which provided awareness for concussion to the sporting community.

(B1, pg. 16): Like Rowan's law and a little bit of awareness in the community and in the sport's, community has made my life as a coach way easier. Soon as soon as it's ok there was clear contact to the head uh one or more symptoms, you're done for the day uhm talk fo- talk with the parents afterwards, here's the form uhm they need to see a doctor it's out of my hands we're all just trying to keep your kid safe. I think it's like the grey areas have been removed which I mean as long as we all sort of live to the letter of Rowan's law, the grey areas for a lot of the grey areas have been removed. So I feel, actually a lot more comfortable now than I did five, six years ago again I coach uhm football, rugby

and hockey and uhm they're people do get bumps and bruises and and knocks in the head and uh it's a reality.

Specifically, return-to-play policy provided the parent coaches with the opportunity to objectively engage with concussion management through a structured protocol. It simplified their role within the decision-making process by having a protocol that would identify and track the progression of an injured athlete. These concussion policies also alleviated pressure from the parent coach by now having a mandated guideline that could be referred to when being questioned by a parent or others on the decision to remove an athlete from play (B2, Pg. 17): “Then the coach or the medical professional can also point to that it's not about them making the decision.”. Concussion policy gave the parent coaches a sense of security knowing that parents and athletes had to abide by the policy to return to play.

(B5, pg. 16): I know another coach uh my wife actually coaches as well and a last year she had a player that was their trainer thought had a concussion they had to go to the doctor get the note signed, the doctor said that they had a concussion and then before they actually got the letter re-evaluated for the doctor to sign off, the parent was trying to force the coach to make the player play and my wife was like no she a that that a player cannot play until you get the doctors note signed and uh I think that's a good step for sure.

(B4, pg. 19): I think just the the paperwork and and Rowan's law has helped a lot as a speed skating coach cause one once I send in that report in on a concussion to our provincial body, that athlete isn't going into any races until they get another piece of paper back saying I've gotten the doctors note back on this kid.

### **Neuropsychological baseline testing provided information, but participants remained**

**uncertain about its reliability.** The inclusion of NBT generated conflicting opinions among the participants when discussing its involvement within the management process. They were aware of the uncertainties surrounding its results but also felt that its inclusion could provide clarity for the management process. This potential clarity is what led to the belief that including the test would be better than doing nothing at all.

(B5, Pg. 59): I think uh any extra tool that we can use at this point to try and diagnose a concussion is very helpful because like a like it is it's an invisible injury for the most part and I think that's the biggest, troubling thing for most parents and the athletes themselves is a any information is good information.

There were three levels of inclusion for NBT that participants identified which they believed provided clarity to the concussion management process. The first level of inclusion was formed through impulsive decisions that they believed could help manage their child's concussion. This included potentially engaging with measures they did not fully understand but were willing to include if there was a chance of the test possibly helping.

(A1, Pg. 55): I could see people doing it because ya know why not, is it helpful maybe, maybe not, but if it was included in as a team thing and the coach and trainer said or the league said this is what we're doing this year then I think people would be on board with it because ya know it's not, it's not a big deal it's not a cost not a hassle and maybe it will be helpful but we don't know right.

This level appeared to include parents that were overly concerned with the potential damage children could be doing to themselves and were willing to provide any possible support they could to help in the management process. This type of engagement with management methods appeared to transition into their beliefs surrounding preventative care as well. They felt that including any type of precaution, even those proven to be ineffective, could possibly help prevent the injury.

A2 pg. 22: I think that most coaches should check to see if a kid has their mouth guard in on the ice because mouth guard you don't have to wear a mouth guard now and I think that is just another precaution. Like put the mouth guard in like and I'll tell ya when you reach midget, there's not to many people putting that mouth guard in. It it could help.

The second level of inclusion was the ability for NBT to generate tangible evidence for SRC. This related to the visual results the test provides to parents and administrators to reflect on during the identification and management process. Although research has shown the results of NBT's lack reliability and should not be included in a clinical decision for return to play, its

ability to provide tangible results was enough for three participants to feel comfortable including it in the management process (McCrory et al., 2017).

(B1, pg.42): I think in theory it's a great idea that we have something measurable and tangible because concussions are so fuzzy for us to have something measurable to say your score was x beforehand and it's now um x minus 10 you're not up to where you were cognitively beforehand. So I think that to have some- to make an effort to have something measurable is um is beneficial.

The third level of inclusion was the belief that NBT could work as a way of spreading concussion education and awareness. Due to the test requiring continual engagement, parents and athletes would have to keep revisiting the assessment either yearly or after a suspected concussion which would provide reinforcement for the importance of concussion injury and management.

(B2, Pg. 55): But I think it it's important to have that information the concrete information umm ya imbedded somewhere uh but it also highlights/ it gets people talking right it also calls on people to take responsibility and be involved and understand what ya know it's like in coaching where we're expecting our coaches to have a criminal record check and and they have to go through some sort of process right to be tracked to be part of the part of the community..... Like it fun- it functions as an education, it functions as an awareness.

The justification for NBT relied on how the participants viewed the applicability of the test itself and the severity of SRC. On all levels of inclusion participants felt the management process could benefit from NBT, but how it could benefit differed based on how they envisioned the involvement of the test.

The participants also had significant reservations about the inclusion of NBT in the concussion management process. They understood that accurately recording and comparing children's scores months apart would not be an effective way for identifying or managing a SRC. Having the existing gap in testing during the developmental years of a child's life would make the pre-season assessment void if the injury were to occurs months later. They would then be left to deal with a SRC and no test to help with the management process.

(A1, pg. 46): even if you have a baseline and I get that the idea is that if a kid has a concussion they're checking them to see if they're back at that baseline like I said kids change so say they had their baseline done and the concussion happens uh even eight months later the baseline could have changed in between that time and they don't know.

The participants also found it difficult to justify the inclusion of NBT when their organizations, which already have extensive return-to-play protocols, did not require it. The additional cost and time required to participate in NBT was not appealing to participants who found it to be redundant when there is already existing return to play policies which are mandated in youth sport.

(A1, Pg. 46): So why not just treat the concussion and make sure it's gone and make sure they're better before letting them go back and making sure that they're passing all their new whatever milestones or getting better um they would have to do that regardless of if they had a baseline so it's kind of like what's the point other than sounds like it's a chiropractor money grab.

The main concern for participants was treating the SRC and they did not feel that NBT's lack of reliability, accuracy and further cost warranted the inclusion in their existing protocols. The fact that NBT did not provide any form of prevention also increased their doubts for the inclusion of NBT in the management process (A1, pg., 57): *"it's not going to prevent anything [concussion]"*. The idea of targeting treatment for the injury directly and following the already pre-set guidelines was deemed as a more effective management method than pursuing a costly auxiliary test.

Participants were also concerned with the ability for young athletes to purposefully score lower on a NBT to try and return to play faster. B3 expressed these concerns with NBT as a strategy because of the way young athletes could work the system knowing that the scores they provide would allow them to try and pass the test if they were to succumb to a SRC. By doing so, they are circumventing the tangible results NBT claims to provide during the identification and management process.

(B3, Pg.40): But there's sometimes situations where people low ball it on purpose so that when they go to baseline testing afterwards they say ok well you're not that much different even though we saw this so technically using this term we cannot like officially say there's something wrong with you.

B4 supported B3's claims discussing how the assessment may become vulnerable to 'gaming' when providing the young athletes with information on how the test is supposed to fit into the SRC management process. They believed that once the athletes are provided with the information on how the process around the assessment is supposed to work, athletes would purposefully use that knowledge to try and underperform their test to guarantee a result that would allow them to return to play.

(B4, Pg. 43): They sandbag it. Cause when you educate them, which you need to educate them, they they figure out well.. I need to do poorly on this test to guarantee that myself I can get back to competition if I do get a concussion.

The idea of young athletes purposefully scoring lower was not a matter of *if* but rather *when* they would try to cheat the test. B4 felt that athletes within his own sporting program would try to score lower based on his ongoing interactions with them in a sporting context (B4, Pg. 43): "*Well I know I know some speed skaters that would put a fix in on the test*". B2 supported B4's claim from experiences that she had witnessing young athletes complete NBT. (B2, Pg, 44): "*I've seen kids game it for sure*". Participants, including those who did not hold coaching roles, knew that some youth athletes would continually try and alter their scores to return to play faster. The chance that a player may be able to circumvent the assessment added further doubt and uncertainties for its inclusion in their league's current return to play protocols. Knowing that they already had a structure in place that required time away from play and a final sign off by a physician made them question the purpose of including an assessment that would not benefit the management process.



## Discussion

The goal of this project was to better understand parents' knowledge, beliefs and practices surrounding SRC management and how they perceived NBT as an assessment for concussion injury. We approached this goal by utilizing focus groups to provide parents/guardians of children in sport an opportunity to express their opinions and lived experiences surrounding concussion management and NBT. Uncertainty emerged as a core theme that encompassed the participants perceptions of concussion management and NBT. This uncertainty was compounded by a lack of, and variability in information for concussion diagnosis, management strategies and communication with their children and sport organizations. Experience with concussion and the enactment of return to play policies helped to alleviate uncertainty. NBT was attractive because it provided a degree of "scientific" assurance in identifying concussion and supporting management efforts. At the same time, parents recognized the limitation in NBT in terms of its reliability and validity as an assessment tool.

### Navigating Uncertainty

#### **The absence of a definitive diagnosis generated uncertainty for their child's injury and how they were going to manage it**

The participants described managing a concussion as a stressful and demanding process. They reported having to learn as they managed, noting limited support through education materials on concussion management and a lack of diagnosis for their child's injury. Like the participants, research on parent populations in sport have shown an understanding of the severity for concussion injury but continually identify gaps in knowledge for its management (Kim and Connaughton, 2021; Rice and Curtis 2019). This could be due to a greater presence of education materials that focus on coaches and athletic trainers instead of the parent population. A systematic review performed by Feiss, Lutz, Reiche, Moody and Pangelinan (2020) on the effectiveness of concussion education programs on coaches and parents found that no programs

were specifically designed to target parents of youth athletes. Despite the central role of parents in managing SRC, they reported that the only program that had any offerings for parents was the CDC HEADS UP campaign. They offered a fact sheet on the signs and symptoms of concussion and its management and an online module too. These offerings did not focus on how to manage a concussion but rather provided awareness for the severity of the injury and how to identify it (Feiss et al., 2020; Rice and Curtis, 2019). These findings on education have implications to parents' perceptions and level of engagement with concussion management when examined through the principles of the Protection Motivation Theory (Rogers, 1975). It is evident that education is influencing parents perceived threat severity and vulnerability of concussion but is not providing enough support to modify their perceived response efficacy and self-efficacy for its management. This is leading to their raised concerns about the severity and likelihood of the injury but is leaving parents uncertain on what methods to choose and if they feel these management methods could benefit their child's recovery.

While there is minimal information to support the role of the parent in concussion management, research has shown that psychoeducational interventions have been effective in helping caregivers manage their child's SRC (Kamba and Plourde, 2022). So, the problem does not appear to be the awareness for concussion but rather the limited education and support reaching parents to assist in managing their child's injury. Without dedicated programs to educate parents of young athletes, they are left having to obtain information on concussion management from their physician, an emergency room doctor, alternate health care providers, television, internet or from their child's coach and athletic trainer (Weerdenburg et al., 2016; Hunt et al., 2018). The wide-spread sources of information were one of the problems the participants had with concussion management. Without a consistent source of information, parents were left having to pursue education as they were managing their child's concussion

which only complicated the treatment of an already complex injury. While research has focused on parents' awareness and knowledge for concussion, it may be necessary to focus attention on developing a consistent point of education to help parents through managing their child's injury.

When discussing the process of taking their child to the emergency room for evaluation, only one parent reported a satisfactory experience surrounding diagnosis by the emergency room doctor. For the others, they were left unsatisfied by a lack of diagnosis/clarity of injury and potential information that could have helped them manage their child's SRC. The lack of diagnosis has been previously reported by Boutis et al. (2015) who found that emergency room doctors were diagnosing concussion less often relative to the standards outlined in the Zurich international consensus guidelines. Within these guidelines a concussion could be defined as a non-structural, direct, or indirect head injury with evidence of brain injury and one or more signs and symptoms of brain dysfunction (McCrory et al., 2013). Of the 495 children's cases that they examined, only 200 were diagnosed as concussion by the emergency room doctors while 443 of the cases met the criteria for the Zurich consensus statement. Diagnosing a SRC is not an easy process considering there is no definitive test and symptoms could take days to develop (Zamarripa et al., 2017; Kutcher and Giza, 2014). This leaves emergency room doctors to rely on signs and symptoms that they see during an initial assessment which may not, at that moment, lead to a diagnosis of a SRC.

Knowing the difficulties associated with diagnosing a concussion, it is important to understand what the participants might have expected when they visited the emergency room for a suspected SRC. A study conducted by Zamarripa et al. 2016, examined parents' expectations and beliefs surrounding diagnosis in an emergency room setting and found that parents were expecting more than what the emergency room doctors could provide. For the parents willing to take their child to the emergency room for a concussion, they were likely to expect

comprehensive and definitive care, including imaging, a definitive diagnosis, a timeline for return to activity and a signed return to play form (Zamarripa et al., 2016). What is possible from the emergency room doctor is a review of the patients SRC history and previous conditions (e.g., learning disorders, migraines, mood disorders), collecting additional data from any witnesses of the injury, ruling out any severe injuries that may need imaging (e.g., cervical spine injury) and the administration of an age-appropriate symptom inventory (e.g., SCAT5) (Ellis et al., 2019).

While the participants may view the lack of diagnosis for concussion as a fault on the part of the health care provider, there is only so much they can do during the initial assessment and without time for symptoms to develop. The implications of the delayed diagnosis furthers the uncertainty of parent's knowledge for their child's injury and contributes to any perceptions they may already have toward medical professionals. Without a definitive diagnosis parents are required to begin treating what they may suspect to be a concussion while being uncertain for how to approach its management.

### **Experience helped to reduce uncertainty**

Experience with concussion was noted by the participants as essential for developing an understanding and appreciation for concussion and the difficulties associated with managing the injury. Being in close contact to the management process provided an effective learning experience for the participants which they were not able to obtain from education alone. The need for experience described by the participants shared commonalities with Kolb's (1984) theory of experiential learning.

Within this theory, there are four stages that an individual cycles through when presented with a new experience. The first being concrete experience which involves being exposed to a new experience or approaching an old experience in a new way. The second stage is reflective observation where an individual interprets their personal experience and understanding to reflect

on what the new experience means to them. The third stage of the theory is abstract conceptualization which occurs when the learner develops new ideas and concepts from their observation of the experience. The final stage is active experimentation where the individual applies the new concepts and ideas that they have developed to change their decision making and solve any potential problems (Kolb, 1984).

The first two stages of experiential learning relate to apprehending experiences while the next two relate to transforming the experience. Grasping an experience is the process an individual goes through while they are reflecting on an experience to gain a better understanding of what has occurred. Transforming the experience is the process in which an individual develops and constructs ideas that could modify the way they experience a social phenomenon.

The theory of experiential learning can help account for the two described learning experiences detailed by the participants. Since the theory does not have a particular starting point, participants can enter and exit the stages depending on where they are within their experience (Kolb and Kolb, 2005). This relates to parent's experience with SRC because of the ability for concussion management to provide a learning opportunity for those in proximity to the injury. Those with direct experiences would be able to modify their perceptions through their own lived experiences and be able to adapt the methods they use to manage SRC. Those with an indirect experience would benefit from the opportunity to witness the injury and develop new ideas and concepts about the severity of concussion. By having experience with concussion, the participants were able to reduce their uncertainties for its management by developing new perceptions for concussion which would place them in a better position to manage a concussion if it were to occur. The benefits of experience have been reported in Carrol, Lis, Weiser and Torti's (2016) qualitative study on participants perceptions of recovery following a musculoskeletal injury. Their participants described their past experiences with their injury

helping to provide an understanding of the severity and consequences associated with the injury and also felt these experiences helped to provide the framework for what management and rehabilitation would look like.

The importance of experience was relied upon heavily by the participants because of the variability in educational materials that were provided by health care providers (e.g., emergency room doctors) during the management process of their child's injury. The gap in education received was exhibited among the participants when two stated receiving an overwhelming amount of educational material while the rest of our sample were displeased with the little to no information, they were presented during their trip to the emergency room. Their displeasure has been noted in past research evaluating information provided to parents who have visited the emergency room for their child's injury. In a systematic review of discharge communication practices in pediatric emergency care, Curran et al. (2019) found that most of the information provided to parents was through passive dissemination strategies (e.g., pamphlets). This method of supplying educational materials is ineffective because of its reliance's on a one-time distribution with no further follow up or opportunity for interaction. The absence of interaction is a limiting factor when relating to a person's ability to process and develop through the model of experiential learning. Specifically, it would influence the first two stages of the model impacting an individual's ability to capture the experience with the support of appropriate educative materials. For the participants, the majority were presented with little to no information which left the participants having to rely on their own experience and knowledge of concussion to help manage their child's injury.

### **Communication was a leading factor for uncertainty during the management process**

Although deemed a critical part of the concussion management process, the participants viewed communication being a limiting factor among stakeholders (e.g., athletes, coaches,

sporting entities) in the sporting community. With six of the participants having their children experience a concussion and five having experience in the role of volunteer coach we were able to gain their insight on how they viewed communication effecting the concussion management process. Two channels of communication emerged from the participants discussions. The first being communication between parent and child while the second was problems with knowledge transfer between sporting bodies.

*Parents were uncertain if their children were telling the truth about their symptoms*

Consistent with previous literature, participants were aware of the heavy reliance on self-reporting to identify a SRC and expressed their concerns regarding young athletes being honest and transparent about their symptoms (McCrorry et al., 2017). The inability to know for sure that their children were informing them of the truth in an accurate way left the participants uncertain about if their children were being open about how they felt. The concerns voiced by the participants are a common occurrence in youth athletics (Kroshus et al., 2015; Cusimano et al., 2017 Kaut, DePompei, Kerr and Congeni, 2003). In particular, the three concerns that participants noted were withholding information to play, external pressure coming from other teammates and the inability to voice their symptoms from a lack of education surrounding concussion injury. The first two concerns appear to be intentional acts made by the youth athlete to avoid detection while the third is more of an unintentional act coming from a lack of understanding.

Research has found that a high number of athletes are willing to avoid disclosing their SRC symptoms to stay in play. Research performed by Wallace et al. (2017) found that 55% of their sample would not disclose their suspected SRC with the main reason being to avoid the loss of playing time while, Chrisman, Quitiquit and Rivara (2013) reported that 66% of their sample continued to play through concussion because of the fear of being removed from play. The

decision seems to be completely driven by the young athlete themselves due to their concerns of losing playing time from reporting their suspected concussion.

The second intentional act of non-disclosure came from external pressures created by teammates, parents, and coaches in the sporting community. The externalized pressure was examined by Kroshus et al. (2015) who reported of the 328 collegiate athletes surveyed, 26.5% of them experienced pressures to remain in play from teammates, coaches and parents. External pressure is a common trait in competitive sport and is believed to be caused by a sporting culture that reacts negatively to injury disclosure (Cusimano et al., 2017). The negative culture surrounding symptom reporting continues to be a cause for concern and has previously been identified as a hinderance on the effectiveness of sport legislation such as Rowan's Law (McCradden and Cusimano, 2019).

The third concern was the fear of athletes failing to recognize their symptoms through a lack of understanding surrounding SRC (Sye, Sullivan and McCrory, 2006; Kaut et al., 2003). Unlike other sport-related injuries, SRC has a range of complex signs and symptoms that can occur hours up to days following the initial incident. The delayed onset and other known explanations (e.g., dehydration) could lead to athletes questioning if what they experienced was a SRC and if it was serious enough to report (Cusimano et al., 2017). Past research on collegiate athletes performed by Kaut et al. (2003) found that nearly 32% of their sample size reported experiencing a blow to the head that led to subsequent symptoms of SRC but continued to play due to the inability to self-identify their symptoms as a concussion. Similar finding were documented by Cusimano et al. (2017) who interviewed 31 minor hockey athletes and found that underreporting of SRC was partially caused by the inability to recognize their own symptoms.



*Parent coaches were uncertain about the health status of their athletes due to problems with information exchange between sporting bodies*

Participants with experience in the role of coach were worried of potentially playing an injured athlete because of a lack of knowledge surrounding the health status of the athlete in question. Without a network dedicated to tracking reported injuries of youth and adolescent athletes, coaches are reliant on self-declaration by the player or the parent to keep the athlete from play. The need for self-declaration relates to the communication element of the coach-parent-athlete relationships within the athletic triangle (Lisinskiene, Lochbaum, May and Huml, 2019; Holden et al., 2015; Smoll, Cumming and Smith, 2011; Hellstedt, 1987).

The athletic triangle consists of the coach, parent and athlete and is one of the main social systems found within youth sport. Within this triangle, each member is responsible for their own role to ensure the sporting experience is a success (Holden et al., 2015). If there are disruptions within the dyads present in the triangle, there can be consequence that could negatively impact the youth athletes experience. One of the participants experienced disruption to the triangle when they continued to play an injured athlete due to the parent failing to disclose the injury that occurred while their child participated in a different sport. This failure to disclose led to a minor injury becoming severe through continual play past the point where the athlete should have been removed for evaluation. The decision to withhold information on the part of the parent could also be from their decision to assume more of a professional model for their child (Smoll, Cumming and Smith, 2011). This occurs when parents set unobtainable goals for their children who are still developing both physically and mentally in a youth sporting environment. They can push for and engage in behaviours that can put their child at risk of injury such as withholding information from their child's coach to keep their child in play.

The formation of a database to track cross-sporting injuries was discussed by the participants as a viable option to help keep coaches up to date with the health status of their athletes and to prevent parents from avoiding reporting their child's injury. While no current network exists within youth sport, cross-sector collaboration is continually used in the world of business between organizations to share knowledge and encourage transparency while working toward a common goal (Weber, Haugh, Göbel and Leonardy, 2021). A similar model could be applied to youth and adolescent sport which would see all coaches, teams and organizations having the ability to both report and monitor the status of their athletes. By addressing an injury through a collaborative database across sports and leagues, coaches would not have to rely on the self-declaration from the parent and child which would limit the opportunities for them to play an injured athlete.

The researcher on this project has had personal experience with problems associated with knowledge transfer between sporting bodies. As a rowing coach, I am aware that my athletes participate within multiple sports especially during the winter months. Recently, I noticed an athlete within my group who was acting differently during my training session and upon further questioning with said athlete, it came to my attention that he sustained what his trainer believed to be a concussion in his hockey game during the previous night. After removing the athlete from my session, I informed him that to continue training I would need to know that he had been cleared of any possible injury. Later that week I was informed that he did sustain a concussion. He then proceeded to have a prolonged recovery which kept him out of sport for a month. Without my knowledge on the topic of concussion and my rapport with the athlete, I would not have been able to identify and remove the athlete from play. Without a system in place to help track and identify injured athletes, there are opportunities that will continue to occur where coaches are unknowingly playing injured athletes.

## **Concussion policy in sport provides clarity for the role of the parent coach**

Concussion policies like Rowan's Law were met with praise by the participants because of the benefits they have provided to their role in the identification and management process of a SRC. Specifically, the participants who volunteered in the role of coach experienced direct benefits from the return to play protocols these policies introduced. By having access to mandated guidelines, participants were able to partially remove themselves from the decision-making process. Protocols reduced what they deemed to be the 'grey area' allowing for their decisions to be supported by a formal guide. However, protocols did not stop parents from trying to return their child to sport earlier than allowed. The pressures coaches experience from a parent to return their child early could be occurring based on two factors. The first being a lack of knowledge surrounding return to play protocols while the second is knowingly trying to return an athlete to play before they are cleared.

Gaps in knowledge have been identified among parents understanding of return to play protocols. Hecimovicha et al. (2016) who performed a study on parent and athlete knowledge of concussion found of the 1441 parents sampled, a high percentage (90%) understood that athletes should be removed from play following a suspected concussion, but just under half of those parents (41%) recognized proper concussion management and return to play guidelines. They accounted the lack of understanding to limited educational programs specifically targeting proper return to play and concussion management. Similarly, Black et al. (2020) reported findings of low knowledge on return to play and concussion management among 786 youth hockey parents. Notably, 15-20% of their participants reporting that they did not consult a physician for assessment or clearance to return to play and 19% stated they would not actively seek care from a physician for concussion management or guidance on return to play.

The decision on the part of the parent to pressure an athlete to continue to play injured could be attributed to their efforts to circumvent concussion protocols (Kroshus et al., 2015). Their avoidance could originate from their own belief that they may know what is best for their child which may go against their child's coach's decision to remove them from play. Past research by Knight and Harwood (2009) examined parent-related stressors among 70 British tennis coaches and found through the interview process that parents can develop their own poor perceptions of a coach. They act on these perceptions through efforts to undermine the coach's decision by taking what they believe to be necessary action, or by questioning the coaches every move. This type of behaviour may also be a part of a retaliatory effort against the increase in policy as described by McCradden and Cusimano (2019). Through their commentary on the implementation of Rowan's Law, they noted that imbedded cultural issues may be hindering the effectiveness of policy implementation. These issues include suppressing injuries to stay in play on the part of the athlete, but it may also extend to parents' efforts to evade protocols by not disclosing an injury or trying to return a child to play before they are cleared. While the participants may be experiencing the benefits of policy within their role as coach, lapses in understanding of return to play protocols and underlying beliefs about playing through injury could be limiting the effectiveness of keeping injured athletes from play.

### **Neuropsychological baseline testing provided information but, participants remained uncertain about its reliability**

Participants were open to accepting any product or tool that *had the potential to* benefit concussion management because of the limited support and treatment options that are currently available. The need to engage with alternative measures appeared to originate through their limited understanding surrounding concussion and its management which relates to the theory proposed by Herbert Simon (1957) deemed bounded rationality. Bounded rationality states that not one person has unlimited knowledge but rather they are restricted to the knowledge they do

and do not have, their ability or inability to evoke that knowledge when it is relevant, to work out potential consequences, to cope with uncertainty and to decide among their many wants (Simon, 1999). Bounded rationality also relates to my core theme of navigating uncertainty in that it helps explain how the participants may have decided to cope with their uncertainties surrounding concussion management. An example of this would be their willingness to engage with alternative methods of care like NBT. Participants noted that NBT helped to ease their uncertainties for concussion management by working as an educative tool for the sporting community while also providing speculative objectivity to the SRC management process.

Participants viewed NBT as a potential way to distributed SRC education to stakeholders in the sporting community. When compared to current SRC education methods such as pamphlets and brochures that rely on passive dissemination through one-time administration, NBT works as an intervention that requires engagement by the parent, coach, and young athlete (Curran et al., 2019; Taylor and Hamdy, 2013; Meriam, 2001). If these stakeholders choose to follow up with the assessment it will continue to provide them with opportunities to reinforce their knowledge for concussion injury. If they choose to engage with it once, it is still providing another element of exposure to SRC education which the participants felt parents, coaches and athletes could continue to benefit from (Kroshus, Babkes Stellino, Chirsman and Rivara, 2018). Participants also felt they benefited from the objective information NBT provides to a rather subjectively dominated identification and management process. Participants appreciated the idea that they could see tangible evidence that could suggest whether their child had or had not sustained a SRC and if they were healthy enough to return to play. The factors the participants addressed related to their bounded understanding of concussion and its management. NBT appears to be providing an informative element to the management process they have already identify as needing improvement, while the tangible results are helping to compensate for the

absence of a definitive diagnosis. It seems that NBT providers are capitalizing on the complexities associated with concussion by marketing their test to provide what is currently absent in concussion management.

While participants were optimistic about the support provided by NBT, they had concerns surrounding its implementation into the management process. They discussed three issues they had with the NBT that questioned its reliability and feasibility as a tool that could be used to help a child recover from concussion. The first issue related to its reliability and validity as a measure that could be used to treat young athletes. Participants also noted that only one assessment at the beginning of the year would not be enough to accurately measure their child later in the season due to the developmental changes their child would go through over the course of the year. These changes would lead to their initial assessment being void which would counter-act the benefits of engaging with a pre-season assessment in hopes of detecting a possible SRC. This issue has been documented among a popular NBT known as the Immediate Post-Concussion and Cognitive Test. Past research examining the Immediate Post-Concussion and Cognitive Test have found high base fail rates from embedded validity indicators incorrectly triggering for youth athletes experiencing neuronal maturation while going through puberty (Abeare, Messa, Zuccato, Merker and Erdodi, 2018). Research has also found the results of the test to be affected based on hours of slept before the assessment, if it was performed in groups rather than individually and that male athletes report higher rates of invalid performance when compared to female athletes (McClure et al., 2014; Schatz et al., 2012). Even though participants may feel comfort in the objective element of NBT, the uncertainty surrounding the results it produces keeps it from being an essential part of the SRC management process (McCrorry et al., 2017; Randolph, McCrea and Barr, 2005).

The second issue related to the already existing return to play protocols implemented in youth sporting organizations which led to the participants questioning the purpose of including NBT. They noted that these protocols, regardless of the presence of NBT, would have to be followed properly and a physician would have to sign off on the child's status before they could return to play. The absence of NBT in the return to play protocol is not out of the ordinary considering that SRC can be identified and successfully managed without it (McCroory et al., 2017; Echemendia et al., 2012; Randolph et al., 2005). Parachute Canada have also supported the absence of NBT in the return to play process. They recommend that energy that would be placed into searching for NBT facilitators should shift to actively encouraging organizations to develop processes that focus on recognizing and removing athletes with suspected SRC from play (Parachute Canada, 2018).

The third issue was the ability for a young athlete to cheat the initial assessment by purposely sabotaging their scores to set a lower standard if they were to be re-assessed following a suspected concussion. Participants questioned the honesty surrounding young athletes participating in NBT noting that they knew and have witnessed athletes that would go out of their way to try and cheat the test. The act of purposely scoring lower on the initial NBT assessment has been coined as "sandbagging" and is a serious concern among youth and adolescent athletes (Higgins, Caze and Maerlender, 2018; Schatz and Glatts, 2013; Erdal, 2012). To try and combat suboptimal performance, tests such as the Immediate Post-Concussion and Cognitive Test have tried placing invalidity indicators within their test to try and remove the intentionally low scores. Past research has found that these embedded detectors miss approximately 20% of people who are intentionally trying to sandbag the test (Gaudet and Weyandt, 2017). Knowing that athletes could influence the outcome of their results only led to the participants further questioning its involvement in the management process.

From the participants beliefs surrounding the use case of NBT, I have constructed a model that depicts their process of engagement with the assessment. (Figure 3). The model begins with an evaluation of fear for concussion that is constructed from their past education and experience with the injury and is modified by their current relationship with the athlete. This was present within the participants who had knowledge of the severity of concussion and experience through proximity with its management but experienced a greater valuation of fear when the consequences of the injury were associated with their child or a close family friend. The element of fear appraisal can be related to the Protection Motivation Theory because of its connection to the beliefs surrounding perceived threat severity and perceived threat vulnerability which would influence an individual's possible engagement with seeking protective behaviours (Rogers, 1975). Following this fear appraisal for concussion, three paths emerged. The first two paths are associated with factors that influenced their certainty surrounding their possible engagement with NBT. These factors were diagnosis of injury, possible management strategies and communication among stakeholders (i.e., emergency room doctors, coaches, children) in the sporting community. Parents who were uncertain about diagnosis, management and communication were likely to engage with NBT as a method to cope with concussion injury. Parents who demonstrated certainty for diagnosis, management and communication were likely to not engage with NBT based on their current understanding of concussion injury and its management process. Interestingly, it appeared that existing policies had a modifying effect on parents' certainty for concussion management. Such policies like return to play protocols and Rowan's Law provided clarity to the management process for parents who had access to this information. These pathways also relate to the perceived response efficacy and perceived self-efficacy components of the Protection Motivation Theory. Based on their current views of concussion management, diagnosis and communication, the participants are evaluating if



engaging with an alternative method of care would be beneficial to the management process and if they feel they could engage with this assessment successfully. The third path of the model was from their fear evaluation to engagement with NBT. These parents did not rely on whether they were certain about diagnosis, concussion management or communication but rather their pre-conceived fear for concussion injury was enough to include any measure based on the premise that ‘anything is better than doing nothing at all’.

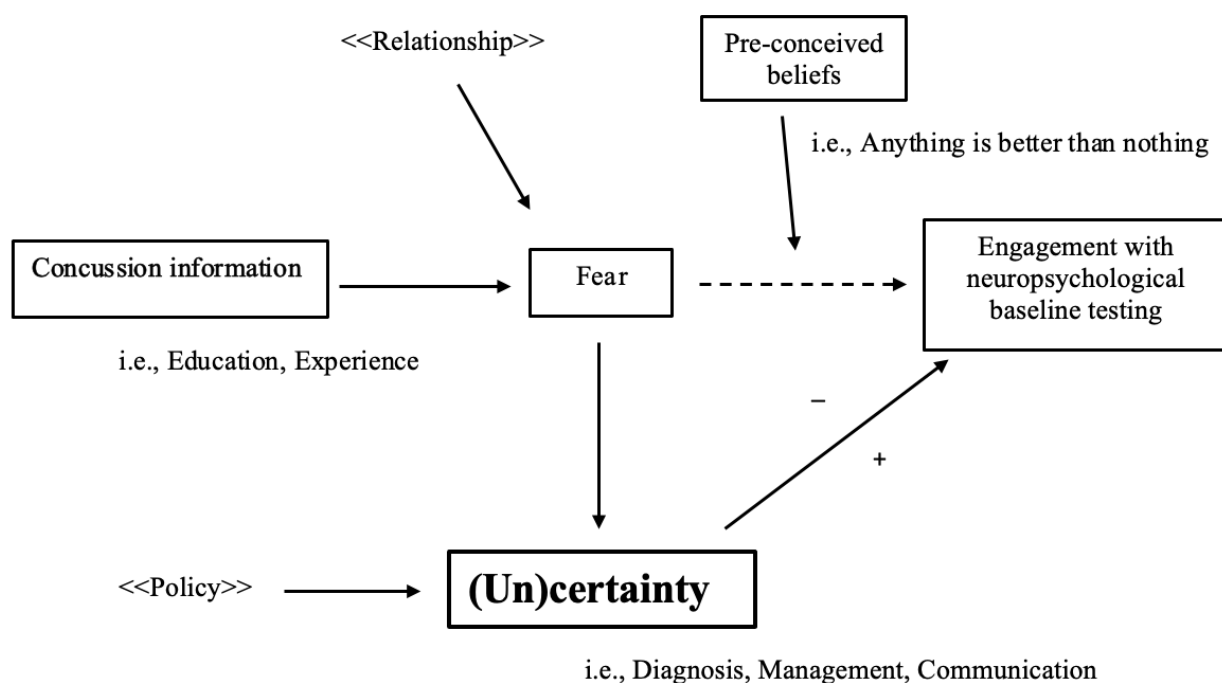


Figure 3. Model illustrating the paths to engagement with neuropsychological baseline testing.

### Beyond Uncertainty: Implications for Policy and Practice

Participants attributed their uncertainties for concussion management to minimal access to education, the absences of a definitive diagnosis and difficulties with communication among members in the sporting community. Participants with involvement in the sporting community (i.e., trainer, coach) were able to obtain education on concussion management but for the general

parent population, there are no targeted interventions to support them through this process. Currently, leagues are providing outlets for education to parents in the form of documentation such as Rowan's Law or through joint efforts with medical centres or charities like the Greater Toronto Hockey League has with Holland and Bloorview and the Ontario Minor Hockey Association has with Parachute Canada (Ontario Minor Hockey Association, 2019; Greater Toronto Hockey League, 2015). These efforts to provide education through accessible documentation do not appear to be benefitting the parent in the way they are currently being delivered. Attention needs to shift to a more targeted approach which could include implementing psychoeducation interventions which have previously been reported as an effective way to educate caregivers on the concussion management process (Kamba and Plourde, 2022). Notably, parents' beliefs surrounding the minimal support they are currently receiving could help explain their interests with including alternate measures of care like NBT. While having their own doubts about the measure, they justified its inclusion because of its educational element and the tangible results the test could provide. Their engagement could also be explained by their emotional response to their child possibly experiencing a concussion. This response could be driven by their believed severity and likelihood for the injury occurring and their reservations surrounding diagnosis, communication and education. These factors could lead them to cope emotionally through engagement with alternative methods of care like NBT that would help to reduce their anxiety (i.e., doing something is better than doing nothing). Moving forward parents need to be targeted with effective methods of support to help alleviate their uncertainties for concussion management and possible engagement with NBT to cope with their emotions.

Participants who volunteer in the role of coach worry about and have experienced situations where they have played an injured athlete. While negative cultural issues and lack of knowledge may be driving athletes and parents to withhold such information to keep their child

in sport, there is no method or system in place that could help deter these situations from occurring. The possible development and inclusion of a cross-sporting network could help limit these avoidance behaviours by allowing for coaches to report and monitor the status of athletes through an open network of communication. The system could take the shape of existing protocols such as the blue card process instituted within Ontario by Rugby Canada and Rugby Ontario (Rugby Ontario, 2022). The blue card process is initiated by a blue card being assessed by a match official to a player suspected of a concussion. That player is then reported to the leagues administration which then forwards that information to the athlete's club signalling the athletes possible concussion status. The athlete will then be flagged and removed from play until they are cleared of a suspected concussion or have received written clearance from a medical professional and have met the return to play requirements set out by World Rugby and Rugby Ontario. A cross-sporting network could build off this premise in that once flagged by a referee, match official or even schoolteacher, the status of the athlete would then be sent to the current league or schools administration which would then trigger a multi-sport wide notice on the health status of the athlete. This would help reduce the reliance on self-declaration on the part of the parent and athlete and keep coaches up to date with the health statuses of their athletes.

### **Strengths and Limitations**

The ability to sample parents with varying levels of experience dealing with SRC and NBT provided an opportunity for a balanced discussion and was seen as a strength for this study. The inclusion of parents with experience in the role of coach was also a strength of this study because of the insight they provided on concussion and its management from their role within the sporting community. A limitation of this study was that the small sample size was made up of volunteers who were interested in participating and discussing this topic. There is a chance that they do not share the same perceptions on concussion management as parents who may try to

circumvent concussion protocols. Nonetheless, these willing participants provided their insight on the barriers to concussions management that they encountered which were communication, diagnosis and methods of treatment. These identified barriers would be especially important for under-motivated individuals due to the possible effects it could have on their attitude surrounding concussion management and identification. Moving forward, attention needs to be given to understanding the attitudes of under-motivated individuals and developing possible methods of support to try and effectively reach this community. Another strength of this study was its use of Conventional Content Analysis which allowed for naturally forming themes to emerge from the data. Specifically, this provided us with the opportunity to inductively examine participants beliefs on concussion management and NBT. To my knowledge, this is the first study to examine parent's perceptions toward NBT as a management tool.

### **Future Research**

Within my focus groups there was a considerable amount of uncertainty surrounding concussion management. Consequently, these uncertainties led to some of the participants believing alternative methods of care like NBT could be appropriate in the management process. Moving forward I would like to propose a series of testable hypotheses based on my constructed model to examine the effects leading to engagement with NBT. I will also be proposing the potential construction of a cross-sporting database to track the health status of youth athletes.

I will first hypothesize that education on concussion diagnosis, management and awareness of policy will reduce uncertainty and lead to a decrease in engagement with NBT. Within my focus groups we observed that parents who were knowledgeable on the factors that influenced certainty for the process of concussion management had greater confidence in their decision-making which led to a reduction in engagement with NBT. Also, parents who had exposure to concussion policy appeared to have reduced levels of uncertainty due to their

awareness for existing protocols like return to play in their respective leagues. This hypothesis could be tested through the theory of Bounded Rationality (Simon, 1957). By implementing Bounded Rationality, one could examine the effects of implementing education or policy on an individual's ability to work out potential consequences associated with concussion management and their ability to cope with uncertainty.

The second hypothesis I will be proposing is that greater fear and uncertainty associated with concussion and its management will lead to engagement with NBT. Participants were fearful of the consequences associated with concussion injury but those that were uncertain about diagnosis, management and communication were more likely to engage with NBT as a way of providing clarity to the management process. The theory of Experiential Learning could be an effective theory to apply to this hypothesis because of the effect experience had on an individual's decisions to engage with alternative methods of care (Kolb, 1984). It would be important to understand the difference experience can have on the management process and how those who did not have experience with management may decide to pursue alternative measures of care.

The last hypothesis I will be proposing is that parents with a high fear evaluation for concussion, regardless of their certainties for concussion management will choose to engage with NBT. The participants felt there was not enough support currently available to help manage a concussion. This appeared to increase their fears associated with sustaining the injury which led to their adoption of the belief that including any possible measure had the potential to benefit the concussion management process. The Protection Motivation Theory could be implemented to test this hypothesis due to the effects perceived threat severity and vulnerability can have on an individual's decision to engage with a protective health behaviour (Rogers, 1975). If they hold a

high fear appraisal for concussion, they may believe that any method of management could be a possible way to benefit the management process.

An interest for future research within cross-sporting communication networks was generated through the participants discussions over their concerns of playing injured athletes. The participants were aware of the multitude of sports that their children and the athletes they coach participate in over the course of the year and knew that it was not currently possible to track the health status of these athletes accurately. Currently, they are reliant on self-declaration on the part of the parent or athlete for injury disclosure which participants knew was not a reliable way of obtaining possible injury reports. To address these concerns, I will be hypothesizing that the inclusion of a cross-sporting network to track the health status of athletes will reduce the uncertainties parent coaches currently have with playing injured athletes. This could be done through the implementation of participatory action research to work alongside multiple sporting leagues within the same community. Through active engagement with coaches and sporting boards, there is the potential to create an injury detection network which could provide clarity for the health status of athletes among volunteer coaches.

### **Conclusion**

This current thesis has expanded the understanding of the gaps in parents' knowledge for concussion management and their perceptions toward NBT. My study has also provided an opportunity to see how parents who volunteer in the role of coach perceive concussion identification and management. The main finding from my project was the existing uncertainties parents have toward concussion management. The participants identified these uncertainties being caused by a lack of guidance and support, insufficient communication, minimal access to education, and an absence of a definitive diagnosis for concussion injury. These uncertainties also appeared to be the driving factors for engagement with alternative measures of care like

NBT. To address these uncertainties, future research needs to be guided toward developing and providing parents with aids that can help address any questions or concerns they may have for the management process. These aids may take the form of an intervention or an educational tool that they can view and engage with prior to the start of a sporting season or upon their initial visit to a health care provider. Uncertainties surrounding concussion management were also prevalent within parents who volunteer in the role of coach. As a coach, they were concerned about the possibility of playing an injured athlete due to the child or parent failing to disclose the athlete's current health status. Currently no system exists which can track and monitor the health status of an athlete across different sporting leagues and teams. The implementation or presence of a cross-sporting network would limit the likelihood of playing an injured athlete and remove the reliance for injury declaration from the parent and child. The findings from this thesis can be used to highlight the need to develop educational platforms to assist parents during the management process of a concussion and to bring attention to the potential construction of a cross sporting network to support coaches in youth sport.

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## Appendix A: Advertisement

90 Minutes Total  
**20\$ gift card**

## Parent's Perceptions of Sport-related Concussion and Neuropsychological Baseline Testing

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*Purpose*

There is little known about parents' perceptions of sport-related concussion and neuropsychological baseline testing. The goal of our focus group is to gain an insight from you, the parent, on your views and experiences dealing with these topics.

*Inclusion Criteria*

We are looking for parents who have had or currently have children registered in competitive contact/collision sports. A few examples are hockey, rugby, basketball, football and soccer. Participation is not limited to parents who have had a child experience a sport-related concussion or have gone through neuropsychological baseline testing. That being said, experience with sport-related concussion and neuropsychological testing will be prioritized for our focus group.

*Process*

If you choose to participate, you will be emailed a consent form and will be asked to provide some information prior to the start of the focus group. You will then receive a link to a meeting which will take place online through zoom. During the focus group you will be asked a series of questions in regard to your experiences and knowledge on the topic. After the completion of the focus group you will receive your compensation. If at any point you become uncomfortable answering any of the questions or would like to leave, you will receive your compensation penalty free and your decision will be respected.

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### Contact Information

Matthew Hagopian  
 Psychology MSc Candidate  
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 Department of Psychology  
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## Appendix B: Consent Form

**Parents Perceptions Towards Sport Related Concussion and Neuropsychological Baseline Testing**

**Purpose:** The interest of this focus group is to examine your perceptions and experiences dealing with sport related concussion and neuropsychological baseline testing. The information gained from this focus group will help in furthering our understanding on how parents perceive the injury itself and why parents would explore neuropsychological testing as a way to manage a sport-related concussion. These focus groups will be conducted as part of a project to fulfill my requirements for my graduate degree and will be overseen by my supervisor Dr. Fergal O'Hagan.

**Time Commitment:** 90 minutes

**Compensation:** \$20 Gift card

**Potential Risks:** There is a minimal level of risk associated with participating in this focus group. You may be asked about your past experiences with concussion injury. If you or your child(ren) have experienced concussion injury, this may bring back some unpleasant memories. With this in mind, you are allowed to leave the focus group at any time as well as refrain from answering a question if you do not feel comfortable answering. There will be no penalties associated with leaving the focus group and you will still receive your compensation if you choose to do so. Your participation is voluntary, and we appreciate your contributions.

**Foreseeable Benefits:** Participating in focus groups has many benefits including the unique and rare opportunity to tell your personal story. Even if you do not feel any personal benefit yourself, you may gain benefit from knowing you are contributing to the community to which you belong i.e. parents of children at risk for concussion through their participation in contact sport.

**Consent:** By consenting for this study, you are giving permission to the researchers to be able to record the focus group. The focus group will be recorded through Zoom. If you choose not to consent to this focus group, your decision will be respected, and you will be removed from the roster for the focus group.

**Confidentiality:** You Are free to share information, including personal identifying information, to the extent you feel comfortable. After the data is collected and prior to analysis, your personal information will be removed and there will be no identifiable information attached to your responses. We are taking all the measures in our control to ensure your information remains confidential and your participation remains anonymous. Nonetheless, we cannot guarantee that other participants may share information that you disclose. We encourage all participants to respect the confidentiality and anonymity of others and not share information outside of the focus group

**Data Storage:** All data will be stored by means of a secured file on a password protected computer owned by the master's student candidate and a backup copy will be saved on the supervisor Dr. Fergal O'Hagan's computer as well. All personal identification will be removed

prior to data analysis and all audio data will be destroyed after it has been transcribed. Transcribed data will be kept for five years, then destroyed.

**Use of Information:** The information from the focus groups will be used in reports, a student's masters thesis, presentations, and publications.

**Thank you in advance for your participation.**

I, \_\_\_\_\_ (*please insert your name*) have read the attached Letter of Information for Recruitment and I agree to participate in this study in a focus group process under the following conditions.

- 1 I understand that my participation is voluntary, there are no obligations to participate, and I can withdraw from the study at any point up until the data has been anonymized.
- 2 I understand that I can withdraw from the study by not attending the focus group or contacting Matthew Hagopian.
- 3 I understand that once my focus group interview has been transcribed because there is no identifying information, your responses cannot be removed from the study.
- 4 I understand that there is minimal risk associated with participating in this study.
- 5 I agree to be voice recorded during the focus group.
- 6 I understand that the focus group recordings will be destroyed once they have been transcribed.
- 7 I understand that I can contact Matthew Hagopian ([matthewhagopian@trentu.ca](mailto:matthewhagopian@trentu.ca)) or his supervisor, Dr. Fergal O'Hagan ([fergalohagan@trentu.ca](mailto:fergalohagan@trentu.ca)) with questions regarding this project. For further inquiry, I can contact Jamie Muckle in the Trent Research office at [jmuckle@trentu.ca](mailto:jmuckle@trentu.ca) or by his phone number 705-748-1011 ext. 7896.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Email: \_\_\_\_\_

Date: \_\_\_\_\_

Contact Information

Matthew Hagopian ([matthewhagopian@trentu.ca](mailto:matthewhagopian@trentu.ca))

Participants can contact Jamie Muckle regarding questions relating to the Ethics policies at Trent University: [jmuckle@trentu.ca](mailto:jmuckle@trentu.ca).

This project has been reviewed and approved by the Trent Research Board #26281 on 17/06/2020.

## Appendix C: Demographic Information

## Parent Demographic Form

Thank you for participating in this study. Below are a few questions that we would like you to answer prior to your engagement in the focus group. If you are uncomfortable answering any of the listed questions, we would like you to remember that this study is voluntary, and you do not need to answer any questions that make you feel uncomfortable.

Gender: \_\_\_\_\_

Age: \_\_\_\_\_

Number of children in sport: \_\_\_\_\_

Ages of children involved in sport: \_\_\_\_\_

What sports do your children play: \_\_\_\_\_

What level of sport do they play? (i.e. A, AA, AAA) \_\_\_\_\_

Have any of your children ever sustained a concussion? (Yes/ No)

If yes, please describe?

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Have any of your children ever gone through neuropsychological baseline testing? (Yes/ No)

If yes, how many times was it administered?

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## Appendix D: Focus Group Protocol

### Focus Group Protocol

#### Part I- Introduction

Good morning and thank you for participating in our focus group today. We are looking forward to discussing your perceptions and hearing your stories about sport-related concussion and neuropsychological baseline testing. We are also interested in discussing the passages that were emailed to you along with the zoom link.

I will be asking you questions about your knowledge in regard to concussion injury, your past experience dealing with concussion injury in regard to your children and also questions pertaining to concussion management. I would like to remind you that this focus group will be recorded so we would like to ask you to speak clearly and to respect other participants by not trying to talk over them. Please refrain from using gestures and nodding with your head and instead verbalize your responses so they can be detected on our tape recorder. Your responses will also be recorded by Dr. O'Hagan who will be taking the role of the Recorder, is everyone OK with that?

At this time, I would like to remind you that all personal information you give us from your identity to your responses will remain anonymous during data analysis. We would like to ask you at this time to maintain confidentiality of other participants by not sharing information outside of the focus group. Is everyone OK with that? I would like to remind you at this time that your participation in this focus group is completely voluntary and we appreciate you giving us your time. At any point during the focus group if you feel uncomfortable or would not like to continue, you are free to withdraw and will receive your compensation.

#### Part II- Overview

There is currently a lack of information in the research community that looks at how you, the parent, perceive sport-related concussion and the way in which it is managed. This seems to be troubling considering that you are the ones who are most involved in your child's recovery from this injury. Knowing that there is little understanding on parents' perceptions of this process, this focus group looks to gather the opinions from those who have gone through the process of having a child experience a sport-related concussion or have known someone that has. The questions that will be asked during this focus group look to target three main areas of interest. We would like to gain an understanding on how you perceive a sport-related concussion, your experience with sport-related concussion and your views on how they are managed. We appreciate your participation in this group and remember, please speak clearly and try not to talk over others. Thanks.

#### Part III- Questioning

##### Opening Question

- 1) Let us open up our discussion by having everyone talk about why they were interested in participating in this study?



- a. Could I invite someone to get us started?

### Concussion Knowledge

- 1) What do you know about sport related concussion?
  - a. What past education have you received in regard to sport-related concussion?  
Where did you receive this education?
  
- 2) (Perceived severity) In your mind, what are the consequences of sport-related concussion?
  - a. Short-term
  - b. Long-term
  - c. Do you think the consequences are more severe within children?
  
- 3) (Perceived occurrence) Is concussion a likely injury for children and youth in sports?
  - a. (Perceived occurrence) Do you think that the more involved a child is in sport, the risk of sustaining a concussion becomes greater?
  
- 4) (Response efficacy) What measures are effective in reducing the chance of an athlete sustaining a concussion?
  - a. Rules?
  - b. Equipment?
  - c. Skills?

### Concussion Experience and Management

- 1) Do you have any personal experiences dealing with a sport-related concussion in regard to your child?
  - a. How confident do you feel about identifying concussion? What actions did you take to help identify the concussion?
  
  - b. What types of management methods did you employ to help with your child's recovery from sport-related concussion?
  
  - c. What do you think might be helpful to provide a parent of young athletes to help them be able to manage a concussion?
    - a. What do you feel could have benefitted your child more looking back on the recovery stage?

- b. Is there anything you wish you knew prior to helping your child recover from a sport-related concussion?
  
- d. What did you learn that you did not know prior to your child sustaining a sport-related concussion?
  
- 2) How was your experience dealing with medical professionals during your child's recovery?
  
- 3) What measures do you view to be effective in managing your child's concussion?

#### Baseline Testing and Passages

- 4) A type of management process that has been gaining popularity is neuropsychological baseline testing, do you have any thoughts on this tool?
  - a. Have you ever used the service of baseline testing to help manage your child's sport related concussion?
    - i. Why or why not? Was it mandatory? If not, why did you pursue it?
    - ii. Who provided it?
    - iii. Who paid for it?
    - iv. When was it administered?
    - v. How was it administered? Rink? Clinic? Home?
  - b. Do you believe it is a tool that could help manage a sport-related concussion?

At this time, I would like to discuss the passages that we sent you along with the zoom link (10 minutes to review if need be)

- 1) Were the passages easy to comprehend?
  
- 2) Did these passages make you think about your current beliefs of neuropsychological baseline testing?
  
- 3) Do you feel like you were able to gain a better perspective from the media passages?
  
- 4) What did you take away from these passages?

I would like to thank you at this time for your participation in our focus group. If anyone has anything they would like to add to our discussion, please feel free to do it now.

## Appendix E: Follow Up Form

Dear Participant,

I would like to thank you for your participation in this study. We are grateful for your contribution and we would like you to know that we value the information that you have provided. Moving forward, the data that you have provided will contribute to the development of a questionnaire concerning sport concussion that will be administered in the near future to other parents.

All data provided to us will remain confidential and actions will be taken to remove any identifying characteristics before the data is analyzed. All data will be deleted once transcribed and all transcriptions will be destroyed 5 years after the conclusion of this project. Please remember all questions and responses said during this focus group need to remain confidential to protect everyone's privacy.

If you are interested in learning about the results of this study please contact me, and I will email you the information pertaining to this study once it is complete. If you have any further questions, feel free to contact me or my supervisor, Dr. Fergal O'Hagan (fergalohagan@trentu.ca).

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