

Early Activity Levels and Family Function in mTBI Recovery
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I. Introduction

Mild traumatic brain injuries (mTBIs), commonly known as concussions, are a major public health concern affecting an estimated 3.8 million people annually.^{1,2} The inflammatory processes following mTBIs take time to unfold³ and affect multiple systems.⁴⁻⁶ Research in animal models suggests that neurochemical and metabolic cascades that occur following an mTBI may leave the brain vulnerable to ongoing or worsening injury for an unknown period of time.⁷⁻⁹ Although the generalizability of these studies to humans may be limited, many theorize that sustained increases in physical or cognitive activity during the acute stages of the mTBI recovery process could impede recovery and potentially cause more damage.^{4,7} Studies indicate that children and adolescents who sustain mTBIs may be at an even greater risk for these adverse sequelae.^{3,10} Beyond the injury itself, environmental and behavioral factors have also been shown to be associated with post-mTBI recovery processes.¹¹⁻¹³ For example, higher levels of parental and family stress have been shown to be associated with higher symptom levels in the early stages of recovery.¹¹ From a behavioral standpoint, studies indicate that activity levels in the initial days following the injury may be associated with the severity of symptoms and timing of symptom resolution.^{12,13} To date, the evolving roles that family environment and early activity levels may play in recovery trajectories remain poorly understood. The overall goal of this study was to prospectively investigate the family functioning and activity levels in the initial days and weeks following mTBI to more clearly elucidate the influence these factors may have on the recovery processes children and adolescents experience. Findings from this study are expected to lead to new and more targeted monitoring and treatment recommendations to help re-integrate a child back into pre-injury activity participation.

II. Executive Summary

Background

MTBIs have a high incidence rate for youth.^{2,14} One recent study reported that 1 out of every 160 patients treated across 30 different pediatric emergency departments in the U.S. from 2007-2009 received a primary diagnosis of mTBI,¹⁴ resulting in a direct cost of over \$100 million annually for these visits. The incidence and cost burden of mTBIs, however, is likely much greater due to significant underreporting and the large number of injuries that are not treated at emergency departments.^{15,16}

Animal models suggest that mTBIs trigger changes in the permeability of brain cell walls causing an altered chemical balance.^{3,7,17,18} Consequently, the cell mitochondria

become impaired and ineffective in producing adequate energy for proper cell functioning. Additionally, the metabolic demands of brain cells increase after mTBI further exacerbating a mismatch between cellular energy production and consumption.^{3,19} Because exercise and cognitive challenges also increase energy needs, it is theorized that early engagement in cognitive and physical activities following mTBI could further exacerbate this metabolic mismatch.^{3,13,18} Although the direct generalizability of the results of these animal studies to humans remains unclear, increases in cognitive and physical activity have been clinically noted to worsen symptoms.¹³ In any case, it is commonly presumed that the brain is vulnerable to ongoing or worsening injury following mTBI,⁷⁻⁹ and that premature return to cognitive and physical activities while the brain is in this vulnerable state can lead to protracted symptoms and even death.^{9,10,20}

Although the pathophysiological recovery processes following mTBI remain unclear, mounting evidence indicates that mTBIs can lead to life-altering effects on a person's physical, mental, emotional, and social health in the short-term.^{18,21} They are also associated with potential complications including depression,²² chronic traumatic encephalopathy,²³ and persistent motor control deficits in the long-term.^{24,25} Head trauma during youth may profoundly compromise development and future abilities.²¹ In addition, evidence suggests that young brains, in particular, may be vulnerable to the rare but catastrophic occurrence of second impact syndrome (rapid malignant brain swelling with a second mTBI that occurs before full recovery from a prior mTBI).^{20,26} With the increased recognition of these potential dangers associated with pediatric mTBIs, the media coverage regarding mTBIs has surged over the last 5-10 years. In this same window of time, every state in the U.S., including the state of Ohio, has enacted legislation for concussions with state-specific requirements regarding when youth athletes are permitted to return-to-play following an mTBI. Thus, mTBIs can be scary and burdensome for young patients and their families, and familial concerns regarding adjustment and recovery following mTBI are to be expected.

Participants

Adolescents who sustained a physician-diagnosed mTBI, were within 7 days of injury, and were between the ages of 13 and 17 years of age were recruited from the community via electronic fliers, head injury clinics, and emergency departments across the Greater Cincinnati area. Mild TBI was defined using the American Congress of Rehabilitation Definition: A blow to the head or acceleration/deceleration movement of the head resulting in one or more of the following: *i.* loss of consciousness <30 minutes, *ii.*

amnesia, *iii.* any alteration in mental state at the time of the injury. Exclusion criteria included: participant or parent who did not speak or read English, evidence of more severe brain injury defined as post-resuscitation Glasgow Coma Scale (GCS) score below 13, or pre-existing neurologic impairment.

A total of 48 adolescents were screened during the recruitment process. Seven were found to be ineligible, 10 were not interested or unable to participate, and study staff were unable to schedule a visit within the short window post-injury for two participants. Upon closure of recruitment, 29 adolescents and a parent/guardian enrolled in the study. One parent and child dyad withdrew after the second week due to inability to comply with scheduled study assessments. The remaining 28 participants were comprised of 14 females (50%), 14 males (50%) with a mean age of $15.03 \pm SD$ of 1.34 years. The sample was comprised of 27 (97%) who identified as Non-Hispanic and 1 (3%) who identified as Hispanic, 23 (83%) who identified as White/Caucasian and 5 (17%) who identified as Black or African American.

Methodology

A repeated measures mixed-methods design was employed for the proposed research. Study data were collected and managed using REDCap electronic data capture tools²⁷ hosted at Cincinnati Children's Hospital Medical Center. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies that provides: 1) an intuitive user interface for data entry, 2) audit trails for tracking data manipulation and exports, and 3) other select features. On the day of enrollment, participants and their parents began a series of online REDCap surveys that were issued for the initial 30 days post-injury. These surveys consisted of self-report of symptoms, activity levels, recovery outlook, family dynamic questions and coping styles. The child participant was also fitted with a Fitbit activity tracker and instructed with how to properly wear, charge, and care for over the course of the study. At the conclusion of the 30 days, the child and parent returned for a follow-up interview regarding their recovery process and study procedures. These data were collected in alignment with the following aims:

Aim 1: Prospectively examine the associations between early post-mTBI activity levels and symptom severity and resolution.

For this aim, we used a triangulation of three forms of activity level assessments. These included: 1) the child's self-report of symptom responses to activity level in an online

survey format, 2) the parent's report of the child's symptom responses to activity level in an online survey format, and 3) the physiological trackers of activity levels built into FitBit HR activity trackers. Symptom severity and resolution were assessed using daily reports completed by the child and weekly reports completed by the parent via an online REDCap platform. We hypothesized that higher and lower activity levels are associated with higher symptom reports and longer time to resolution, while moderate activity levels will be associated with the lower symptom reports and faster symptom resolution.

Aim 2: Elucidate the influence of family functioning and reports of parental distress on symptom recovery.

Semi-structured follow-up interviews were conducted with each child participant and parent/guardian to evaluate the influence of family function and parental distress to generate a profile of the dynamics of family functioning and parental distress relative to a child's symptom severity and symptom resolution. The interviewer notes and verbatim transcripts were analyzed to identify themes regarding how family functioning affected and was affected by the child's injury and recovery process.

Aim 3: Develop a multivariate model of the physiological and family factors associated with recovery of symptoms and return-to-activities following mTBI.

To accomplish this aim, we plan use stepwise-regression analyses to develop multivariable models of the activity and family factors that are associated with symptom reports and timing of symptom resolution in the first 4 weeks following an mTBI. We hypothesize that the combination of activity levels, family functioning, and parental distress will significantly improve the amount of variance explained in symptom severity and the timing of symptom resolution.

An *a priori* power analysis was conducted to estimate the sample size needed to achieve 80% power with an alpha of 0.05 using the average effect size for activity levels to symptom pairings reported by Majerske et al.¹³ The analysis revealed that 23 children would be needed to achieve the desired power. We planned to enroll 30 participants to account for potential attrition. We ultimately enrolled 29 participants, and lost only one to attrition. Validation of the data has been performed for 26 of the participants, with final checks and validation of the remaining participants' data currently in progress. Statistical analysis of the data will take place in the upcoming months.

Conclusion

This study provides novel information about the social and behavioral recovery processes and trajectories in the first month after pediatric mTBI. Preliminary analyses of the data indicate many participants continued to experience symptoms above their pre-injury levels for 3-4 weeks post-injury. Over the course of the month, a majority of participants reported a steady decline in overall symptoms, however, the decline in the symptoms was often not linear, with spikes in reported symptoms often corresponding with spikes in activity and cognitive levels.

A variety of themes emerged regarding family dynamics and social interactions relative to the recovery process. Children who had fairly slow recovery processes, with parents who worked and had smaller support networks tended to express higher levels of family burden. In many cases, the siblings of the injured child did not seem to play much of a role, with several exceptions. In several cases, the child reported their siblings to be quite helpful in the recovery process by helping to get them homework or bring things to them while they rested. One parent emphasized that as the injury dragged on, they began to fear the uninjured sibling may feel neglected. So they made a collective effort as a family to make sure the sibling understood the injury as well as got one-on-one attention as well. Several parents noted the key role the coordinating physician played in helping aid in their comfort level with how their child was recovering. They felt particularly comforted when the physician appeared to be communicating well with other clinicians associated with the child's care (e.g., physical therapist, headache specialist).

Collectively, the data from this study provide a rich and deep look into the patient and family experiences with the recovery processes after pediatric mTBI. In the upcoming months, we intend to perform more robust statistical analyses of the data and continue to analyze the interview transcripts to develop a conceptual model for patient and family profiles.

III. Information/Qualifications – principal and all co-investigators

Principal Investigator: Catherine Quatman-Yates, PT, DPT, PhD, is a physical therapist and researcher with expertise in the areas of post-mTBI assessment and rehabilitation with children and adolescents following mTBI. Dr. Quatman-Yates' prior work has focused on refining post-mTBI physiological and postural control techniques in children and adolescents, which has resulted in numerous pilot studies supporting the

work for this application and several manuscripts published and in-press relative to this population. Her work in this area has also received national attention including being honored with the APTA Sports Section's Excellence in Research Award in 2014 and recognition as a finalist for the same award in 2015. Dr. Quatman-Yates is currently PI on a project which utilizes a similar design of physiological assessments to study children experienced persistent post-concussion symptoms. Her prior research and clinical work has enabled her to develop strong collaborations with the other members of this research team. This history of collaboration will be integral to the implementation of the work proposed in this application.

Co-investigator: Jason Hugentobler, PT, DPT, SCS, CSCS, is a physical therapist who currently focuses on identifying postural control deficits with clinical testing tools, prognostic factors for recovery, physical therapy management, and determining safe return to play guidelines for athletes following concussion. He has completed a sports physical therapy residency program at Cincinnati Children's with an area of focus on concussion evaluation and management. He has completed a Point of Care Scholar (POCS) program at Cincinnati Children's to improve clinical practice guidelines regarding the management of patients with concussion and has served as co-author for a number of Dr. Quatman-Yates manuscripts. His academic, clinical and research experience within the area of concussion assessment and management will be essential for completion of the proposed project.

Co-Investigator: Brad Kurowski, MD, MS, is a rehabilitation medicine physician with subspecialty certification in brain injury medicine and pediatric rehabilitation medicine. His prior research has focused on two broad areas: 1) better understanding individual, injury-related, and socio-environmental factors associated with recovery after traumatic brain injury (TBI) and 2) improving evidence-based management of TBI of all severities using novel treatment approaches and clinical trial design methodology. As a rehabilitation physician, he is interested in how medical, behavioral, and physical therapy, and other interventions, individually and in combination, can be used to facilitate recovery after brain injury. Dr. Kurowski has over 25 peer-reviewed publications and has been invited to give numerous national and international presentations. He has also worked on several collaborative projects with the Dr. Quatman-Yates and other co-investigators Drs. Wade and Gubanich. From a clinical standpoint, he has been forging the development of a multidisciplinary head injury clinic. Through this work, he has developed collaborations

with several sports physical therapists (Quatman-Yates and Hugentobler) to implement a clinical rehabilitation protocol for children with prolonged post-concussion symptoms. Dr. Kurowski's prior research and clinical work has enabled him to develop clinical and research collaborations that span multiple fields (pediatric neuroimaging, clinical trial implementation and analysis, emergency medicine, sports medicine/sports physical therapy, and physical medicine and rehabilitation). These collaborations will be integral to the implementation of this pilot project and the development of larger studies. Dr. Kurowski has the research skills, clinical expertise, and has developed the necessary collaborations to carry-out the proposed study.

Co-Investigator: Paul Gubanich, MD, MPH, is a sports medicine physician with more than 11 years of experience in treating patients at all levels of competition from the pediatric to the professional athlete. He has had a long standing interest in the evaluation and management of sports concussion in both the clinical and research settings. During his tenure at the Cleveland Clinic, he established a multi-disciplinary clinic to serve the needs of these athletes. As the Director of Primary Care Sports Medicine Research and Director of the Wellness & Safety Committee he worked on several research teams to evaluate risk factors and markers to identify injury and recovery. Serving as Team Physician for The Ohio State University Athletic Department and Director of Concussion Research, he lead both clinical and research endeavors looking at serum biomarkers, social economic status and neurocognitive testing, as well as contributed to stricter state concussion laws and policy. He currently serves as Fellowship Director for the Sports Medicine Program at Cincinnati Children's Medical Center where he works with a multidisciplinary group of providers in the Concussion Clinic which accounts for approximately 50% of his clinical practice. He has organized the divisional concussion outcomes program, has worked on numerous collaborative projects including the validation of new concussion instruments, imaging techniques in concussion, trial of preventive devices, the evaluation of safe return to driving in youth after concussion, rehabilitation post injury, and the longitudinal surveillance of various youth groups after head injury. Dr. Gubanich has the clinical and research experience, collaborations, and interest necessary to support completion of this project.

Co-Investigator: Tara Rhine MD, MS, is an Assistant Professor and attending physician in the Division of Emergency Medicine. She has a MS in Clinical and Translational Research and her primary research goals are to identify tools to accurately

diagnose injury, improve severity stratification, and predict outcomes following TBI in children. She has received multiple successful funding awards for her work in TBI and has collaborated with Dr Quatman-Yates on her work measuring postural stability following mTBI. Dr. Rhine will assist in the study implementation and publication writing.

Co-investigator: Shari Wade, PhD, is an experienced pediatric psychologist who has been investigating predictors of family adaptation to pediatric TBI for more than 20 years and has developed and tested web-based interventions to reduce behavioral morbidity and family consequences for the past fifteen years. Dr. Wade is a leading mentor at the institution for researchers interested in TBI and is currently serving as a mentor for Drs. Quatman-Yates, Kurowski, and Rhine's work in this area. She has authored over 100 peer-reviewed publications regarding TBI, including several focusing on predictors of recovery following mTBI. She will oversee the collection and analysis of the family data and assist in general study oversight including data collection, data analyses, interpretation and preparation of manuscripts.

Biostatistician: Resmi Gupta, MS, is a biostatistician with more than 10 years of experience in designing and analyzing observational and experimental studies. She has specifically worked with PI Dr. Quatman-Yates on numerous projects and is currently funded on Dr. Quatman-Yates Trustees Grant which investigates autonomic dysregulation in children experiencing protracted recoveries from mTBI.

IV. A review of the literature related to the project topic

It is widely acknowledged that the first few days and weeks following an mTBI are a critical period of recovery for children and adolescents. Preliminary studies in this area indicate that a wide variety of factors may contribute to the recover trajectories including personal factors (e.g., age, gender, previous history of concussion, and pre-injury function)^{4,28-30} and injury-related factors (i.e., loss of consciousness at time of injury, post-traumatic amnesia following the injury and severity of injury).^{30,31} Although not extensively studied, at least two other factors are theorized to be associated with post-mTBI recovery trajectories for children: 1) post-injury activity levels^{12,13} and 2) interactions among parental anxiety and family functioning post-injury.^{11,32}

Post-injury Activity Levels: Until recently, the standard of care recommendations for post-mTBI activities were focused on prolonged rest until symptoms resolved. However, newer evidence indicates that strict and prolonged cognitive and physical rest following an

mTBI may result in greater symptom severity and slower symptom resolution.¹² In fact, there is some evidence that suggests that moderate-level physical and cognitive activities in the acute recovery phase may actually expedite rather than hinder recovery.¹³ However, studies examining the relationship between activity levels and recovery trajectories have been retrospective in nature with self-reports and activity diaries as the primary instruments of measurement for activity levels. In addition, these prior studies have only used patient reports of symptoms as an outcome measure. As symptoms can easily be ignored, hidden, or exaggerated as well as similar in presentation with other common co-morbidities (e.g., attention deficit disorder and migraine headaches),^{8,15} future studies would benefit from evaluating parents' perceptions of the child's symptoms as an additional outcome measure.

Family Functioning and Parental Anxiety: Limited, extant research suggests a complex relationship between pre- and post-injury parental anxiety, family burden, and post-concussive symptomatology.^{11,32} Given that many post-concussive symptoms are common in healthy children (e.g., headache), parental interpretation of and reaction to child symptoms post-mTBI may be an important factor in determining symptom origin, symptom burden, and the timing and intensity of a child's re-integration into activities. Additional research is needed to further elucidate how these factors may specifically contribute to a child's post-mTBI recovery processes.^{11,30,31,33}

V. Historical perspectives on the topic of this report

Mild traumatic brain injuries (mTBIs), commonly known as concussions, can lead to life-altering effects on a person's physical, mental, and emotional health in the short-term^{10,18,34,35} and are associated with complications including depression,²² chronic traumatic encephalopathy,^{23,36,37} and motor control deficits in the long-term.^{24,25} These injuries, which are highlighted as a leading cause of morbidity in youth,^{1,2,38-40} are estimated to affect millions of individuals and cost over \$17 billion in the United States annually.^{1,2,38-40} Because neural development for many advanced cognitive and motor skills continues into early adulthood, head trauma during youth may compromise cognitive and physical development resulting in long-term functional deficits.^{21,41} In addition, although many individuals who suffer mTBIs are symptom-free within a few weeks, up to 1/3 experience protracted recoveries that profoundly affect their daily function.^{6,42,43} Therefore, it is imperative that efficacious treatment protocols be developed to reduce the morbidity associated with recovery after mTBI.

There is controversy around the physiologic and clinical effects of physical activity introduced early after mTBI--particularly for youth.¹⁰ Symptoms and impairments after mTBI have been linked to metabolic, physiologic, and microstructural mechanisms, including altered cerebral blood flow and autonomic dysregulation. Because physical exercise improves these mechanisms in healthy individuals, exercise training is a potential intervention that can directly target the putative causal pathways associated with mTBI dysfunction. However, there is hesitation to recommend exercise soon after injury due to concerns that it could hinder recovery by exacerbating the metabolic and physiologic impairments that occur with mTBI. Alternatively, a rest-focused approach may lead to secondary effects such as physical deconditioning that can confound symptomology and recovery. The current study has the potential to provide new insight into these debates.

Although not extensively studied in mTBI, findings from the literature on more severe pediatric brain injuries indicate that parenting behaviors and home family dynamics can influence a child with TBI's overall outcomes and the everyday functioning of the family post-injury.^{33,44} There is some early evidence to indicate that mTBI induces a greater family burden and more parental distress than other types of pediatric injuries.¹¹ This study further explores this phenomenon with the intent to provide more in-depth understandings of the patient and family experience following pediatric mTBI.

VI. A brief review of the current status of the topic in Ohio, the surrounding states, and nationally

Pediatric TBI is also the leading cause of morbidity and mortality in Ohio, similar to the national trends described previously. Under Ohio law (R.C. 3313.539 and R.C.3707.511), an individual with a suspected head injury is prohibited from returning to interscholastic (school-based) or youth sport organization practice or competition until written clearance is obtained from a physician or approved licensed health care provider. However, the criteria physicians and health care providers use to determine readiness to return-to-play is not currently standardized or legally mandated. This leads to great variance in the decision-making processes used to clear youth to return to their pre-injury activities. The lack of standardization is due, at least in part, to the lack of evidence and understanding regarding the recovery processes children and adolescents experience following mTBI.^{4,21,45}

VII. Future trends, both regionally and nationally

Currently, evidence-based guidelines and treatment recommendations for pediatric mTBI are lacking. Much of the guiding literature that is available has been derived primarily from expert opinion and consensus-generation processes. There is growing recognition that strict rest may not be an ideal option, and that the recovery processes and needs for patients may vary significantly from patient to patient. There is a critical need to develop a robust understanding of recovery patterns and patient and family experiences in order to provide more effective treatment recommendations and protocols. With the growing interest in personalized medicine as a whole, future trends in mTBI management are likely to align with improved protocols that factor in the unique needs and preferences of patients and their families. The data from this study has great potential to help shape the foundations of the evidence in these regards.

VIII. Financial Issues and Considerations

It is estimated that direct medical and indirect costs related to TBI total \$76.5 billion annually in the U.S.^{46,47} Children who experience protracted recoveries often end up getting referred to multiple types of specialists, accruing greater medical costs. There is a great need to optimize care for children who sustain mTBI early in their recovery to help mitigate the chances for prolonged recoveries, reduce family burden, and minimize costs.

IX. Education and training issues and considerations

There is potential for the results of this study to directly inform education and training for clinicians who manage the care for children with mTBI and their families. The robust nature of the data collected is expected to help generate a conceptual model for the patient profile patterns that can be studied at a later date. Such a model could help greatly inform education and training modules for clinicians training to help manage pediatric patients with mTBI.

X. Legislative and regulatory issues and considerations

All 50 states, have passed laws on mTBI and return to sport protocols for youth with concussion. These laws emphasize three primary areas: 1) education for coaches, parents/guardians, and athletes, 2) removal of athlete from play for the same day of injury, and 3) mandatory health care provider evaluation prior to return to play.⁴⁸ This study did not directly address legislative and regulatory concerns. However, findings from this study have the potential to inform future activity recommendations and policies.

XI. Data and information issues and considerations

Symptoms

The Post-Concussion Symptom Inventory (PCSI) was used to assess self- and parent/guardian-reported post-concussion symptoms throughout the study.^{49,50} The PCSI was used to obtain symptom ratings pre-injury, at the enrollment visit, every two days over the first month post-injury, and again at participants' final visit. The adolescent version of the PCSI is a 7-point Likert scale (0-6) with participants rating 21 items related to common concussion symptoms (e.g., headache, sleep, dizziness, nausea). The scores on each item can be summed to compute a total score ranging from 0 to 126. The parent version of the PCSI uses the same 7 point Likert scale to rate 20 items, with total scores ranging from 0-120. Additionally, there is a 5-point Likert scale (0-4) asking adolescents and parents to rate "In general, to what degree do you (your child) feel (act) 'differently' than before the injury (not feeling (acting) like yourself (himself/herself))?", with "0" indicating no difference and 4 indication a major difference. Since the PCSI was collected during interval visits, in addition to pre- and post-intervention, it was used as the primary outcome measure to monitor recovery trajectory.

Self-Reported Activity Levels

The child and parent/guardian were each issued a daily online survey regarding each of the following domains:

1. School attendance, difficulty of school work load, symptom exacerbations with school work
2. Physical activity participation, intensity of activities, symptom exacerbations with physical activities
3. Social interactions with peers, duration of social interactions, symptom exacerbations with social interactions
4. Electronics use, duration of use, symptom exacerbations with use of electronics

Activity Tracker Data

Child participants were instructed to wear a Fitbit HR for as many hours as possible over the course of the study with the exception of showering and charging. Each participants' data was extracted at the final follow-up visit. Data available from the Fitbit extractions include:

1. Steps
2. Distance traveled

3. Minutes sedentary (device generated number)
4. Minutes lightly active (device generated number)
5. Minutes fairly active (device generated number)
6. Minutes very active (device generated number)
7. Activity calories
8. Minutes asleep
9. Minutes awake
10. Number of awakenings

Interview Data Semi-Structured Question Guide

Each child and parent/guardian dyad completed a follow-up interview completed by a study staff member who followed a semi-structured format relative to the following guiding questions:

1. How has the injury affected your family?
2. What aspects have been most stressful?
3. How have job schedules and family activities been affected?
4. How have siblings been affected?
5. How have friends and family reacted and were their responses helpful/unhelpful?
6. How did the school respond? (if appropriate)
7. In retrospect, what was most helpful in getting through the initial days/weeks following the injury?
8. What was least helpful?
9. Is there any activity that you/your child was able to do prior to the injury that you/he/she is unable to do now?

Surveys on Coping, Family Dynamics and Perceived Social Support

Parents and children were asked to complete the following questions via a series of online REDCap surveys after enrolling in the study. These will be used for the modeling analyses proposed in Aim 3.

Brief COPE: The Brief COPE was developed based on the original COPE Inventory and contains 28 items that measure 14 different coping strategies in response to stress⁵¹. Individuals are asked to rate how true each statement is with a rating from 1 (“I haven’t been doing this at all”) to 4 (“I have been doing this a lot”). The Brief COPE

identifies coping strategies that are adaptive versus coping strategies that are problematic.

Centers for Disease Control and Prevention Health Related Quality of Life Index (CDC HRQOL-4): The HRQOL questions developed by the Centers for Disease Control and Prevention consist of 4 questions about perceived physical and mental health and function (http://www.cdc.gov/hrqol/hrqol14_measure.htm). The questions have demonstrated content and construct validity, predictive validity, internal consistency, and test-retest reliability. The index has been rated favorably as a measure of quality of life⁵².

Multidimensional Scale of Perceived Social Support (MSPSS): The MSPSS is a self-report measure of social support. It consists of 12 items that are rated on a 7-item Likert scale ranging from 1) Very Strongly Disagree to 7) Very Strongly Agree. Its subscales identify three forms of social support: family, friends, and significant others. The subscales have been found to have strong factorial validity and the MSPSS has also demonstrated good internal and test-retest reliability⁵³.

Revised Life Orientation Test (LOT-R): The LOT-R is a 10-item questionnaire that assesses individual differences in optimism versus pessimism⁵⁴. Research has used the LOT-R to examine the behavioral, affective, and health consequences of this personality variable. Individuals use a 5-item scale, from A. I agree a lot, to E. I disagree a lot, when responding to each question.

XII. An analysis of the researcher's findings

At the time of submission of this report, data were available for preliminary analyses for 26 participants. One participant had withdrawn, and two participants' data are currently in the process of being finalized and verified in preparation for the final analyses. Preliminary descriptive analyses were performed for symptom trajectories were performed for the purposes of this report. An initial coding of the interview transcripts was performed. The results from these initial analyses are provided in Figures 1, 2, and 3 and Table 1.

Figure 1.

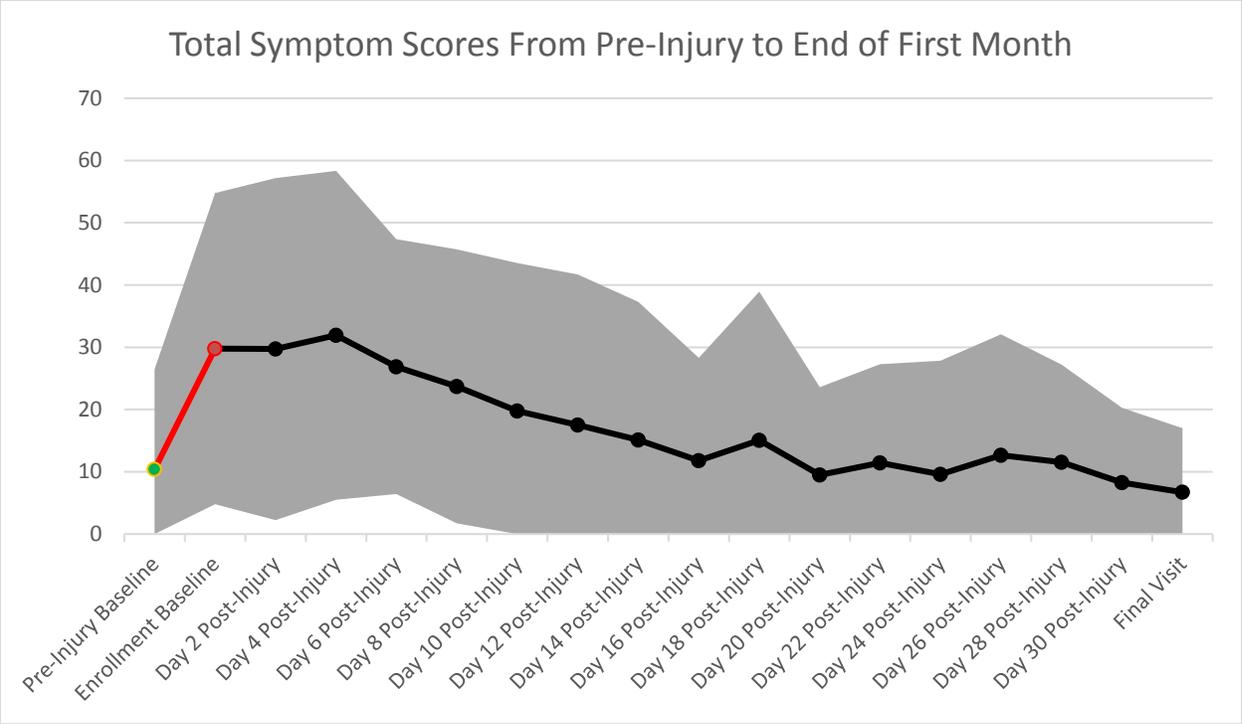


Figure 1 depicts the sample mean (line graph) and upper and lower ranges (shaded area around the mean; based on standard deviation around the mean) for each of the symptom score data collection points. The initial data point represents the participants' retrospective self-rating of pre-injury symptoms. The second data point represents participants' ratings on the date of enrollment in the study. Each subsequent data point represents data collection relative aligned to each participants' post-injury date. Overall, the sample mean indicates a general spike from pre-injury to post-injury ratings (trajectory change from 1st data point to second data point) followed by a gradual symptom score decline over the course of the 30 days after injury.

Figure 2.

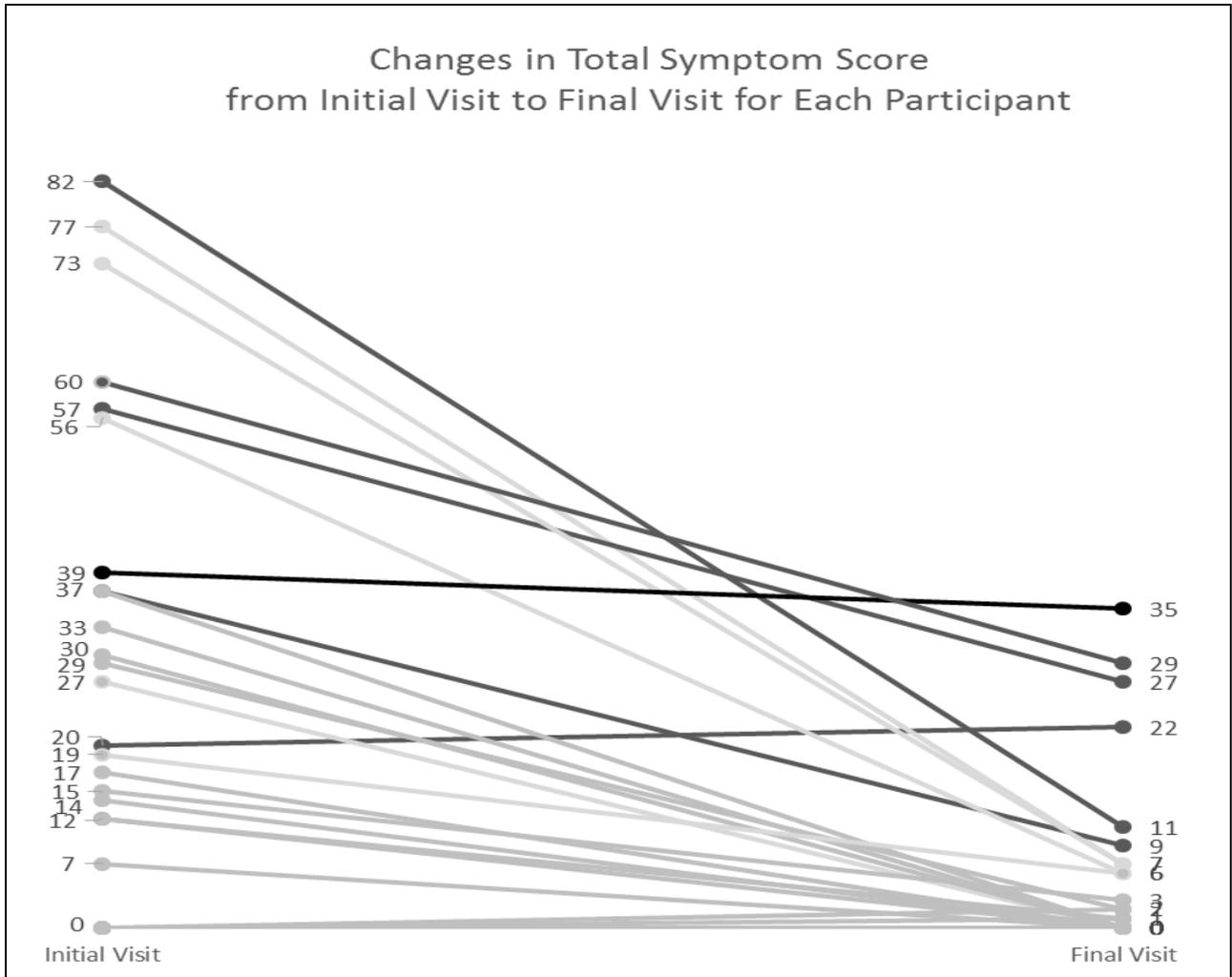


Figure 2 is a slopegraph depicting each participants' change in symptom reports from the time of enrollment to their final visit. The darker lines represent the participants' who were still experiencing symptoms above the estimated population norm of 7 at 30 days post-injury. Most participants demonstrated significant declines in their symptom reports.

Figure 3

Individual Participant Symptom Trajectories

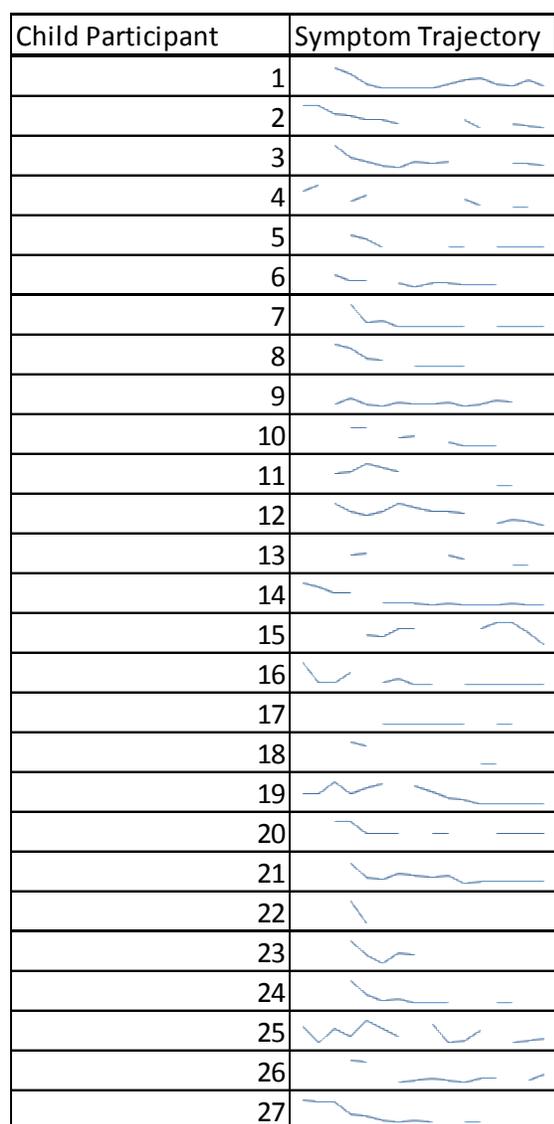


Figure 3 provides sparklines for each symptom checkpoint for each participant. The gaps in the lines represent days where participants missed the open window for survey completion. Participant 22 withdrew from the study. As the sparklines indicate, many participants experienced non-linear recovery trajectories, characterized by varying spikes in their symptom reports over the month.

Table 1. Qualitative Interview Themes: Family Burden of Pediatric mTBI

Theme	Example Quotes
Time Burden	Parent: “a lot of running around for appointments”
Cost Burden	Parent: “Expense...that’s been the frustrating process”
Emotional/Cognitive Distress	Parent: “I think the most frustrating process is balancing doctors’ appointments and work and the concern as to when he’s going to get better”

	<p>Parent: “Worry about like when is his memory going to come back? When is he not going to be confused anymore if we give him directions? His school work... how is this going to affect him for the rest of his life?”</p> <p>Parent: “It’s not like him to not want to go to youth group. I could tell that something wasn’t right when he didn’t want to go...It can be a bit concerning because it’s how many weeks and he’s still having these symptoms.”</p> <p>Parent: “I was just really upset and concerned about him because it had been weeks thinking that he would recover faster and he hadn’t. Then it was concerning seeing him at physical therapy when he was getting confused when they would ask him a question. There’s still some frustration when we would go to a doctor- like we went to cognitive therapy. And he’s always saying “I’m ok” I’m ok, but yeah I see the difference. And I’m thinking like – I guess I don’t understand where he is coming from. If he’s so ok, why are headaches still here? Why are you getting confused? Why is there an issue? And I know there’s missing assignments because he’s missed school, but his grades have suffered because of it”</p> <p>Parent: “Looking back, maybe I didn’t do all of what I needed to as a parent to help him get caught up and keeping the lines of communication open with the teachers. But then there was also the responsibility of communicating with the staff to get all of the doctor’s notes to document all of the absences because the state requires them to send something out after he has missed so many days.”</p> <p>Parent: “I can’t keep him in a bubble. It makes you think twice and there’s a little bit of a fear when they want to try something new.”</p> <p>Parent: “The being bored is the absolute hardest thing. He saw 6 different doctors in the first couple of days and I asked all of them what could he do? And everyone kept saying sleep and rest. HE’s not a sleeper. He gets his 8 hours and he’s done. He doesn’t take naps. He did take more naps than normal, he did sleep more than normal. He is a really active kid, so to tell him to rest was really hard. I really tried to find things that he could do, or that he would be interested in doing. That worked a little bit.”</p> <p>Child: “School...just catching up on everything there. And I still want to get back to sports and stuff...”</p> <p>Child: “I wasn’t able to do anything like go hang out with my friends. I just had to sit at home. I couldn’t even play video games. I was so bored.”</p>
<p>Care Coordination Burden</p>	<p>Parent: “I think the combination of keeping appointments straight and letting my boss know when I need time off...arranging a ride for him back and forth...It’s been frustrating.”</p> <p>Parent: “It’s hard to balance. When I go to lunch I have to book all these doctors’ appointments, there’s some reading I have to get done, and I have to make up this time, I need to come in early. Things were slipping through the cracks.”</p>

<p>Parent-Child Communication</p>	<p>Parent: "I know me hounding him and fussing at him has not been helpful because that would trigger the headaches because he would get stressed. Sometimes it's hard not to do that. Sometimes I feel like there are times he's not helping me help him or he's not doing enough. Sometimes it's Hard to remember he is a fifteen year old and I can't expect a fifteen year old to always do what they're needed to do. Because Adults we forget too. I guess being stressed and frustrated has been least helpful. I know, Not getting enough sleep those are some of the things that haven't helped the situation. I feel like him not resting enough could be part of the issue. Having to force him to take a nap."</p> <p>"His relationship with the family changed because he was a snarky teenager, not wanting any attention from the family. You don't like when we level over you or when we give you too much attention like that. But – you were willing and letting us do more things for you. Which has been nice. It's like getting to know you a little bit, because you let us in a little more. But now – we can tell that he's back to normal because he's not letting us in again."</p>
<p>Social Support</p>	<p>Parent: "I would say faith, family, and friends have helped"</p> <p>Parent: "I have a knitting group I knit with, and when I had a major meltdown they all sent words of encouragement and said that they would pray for him."</p> <p>Parent: "People at work...someone I didn't really know, here daughter had multiple concussions and it was nice to hear from other parents who have been supportive at my job...they are lifting me up."</p> <p>Parent: "Kids showed the tape the recording of what happened to some of the teachers. When the teacher she saw what happened, it wasn't just a student to her, it was someone. She treated him like family. She said, I cut the information down and accommodated him so that he could understand basic concept or what's going on. And that's he needs to be tested over and she kept him away from computer. And that was – I was very thankful for that. To have a teacher to take the time to be understanding and show concern for your kid. Not just treat him as any student but like their own son that's been a blessing for me."</p> <p>Parent:" He is a varsity wrestler, and it was the end of the season – well middle to end of the season. Then he couldn't hang out with them or see them. Well, you did a little bit. They came and visited you. That was hard because you wanted to go be with them. You went to a couple tournaments and meets, but even that was too much for you. You had headaches and other problems with that...And they couldn't really come over because he's not supposed to do anything... Luckily he had a girlfriend – and she's been coming over a lot to talk and watch movies and do things. And that, I think, has really, really helped."</p>

XIII. Conclusions

Recovery trajectories can be highly variable and non-linear in response to activity levels. In cases where recovery processes are linear and relatively quick, the burden on the family is minimal and the family dynamics can remain relatively unaffected. In cases where the recovery processes are slower or exacerbations in symptoms are experienced, the family burden can be more significant.

XIV. Recommendations

Optimal management strategies remain unclear for youth who sustain mTBI. Clinician considerations of child's self-identity relative to activity levels and family dynamics may be important factors to consider when making decisions regarding activity restrictions and progressions. A robust understanding of common patient and family profiles and how they affect and are affected by mTBI could greatly enhance clinicians' ability to optimize recovery processes and the patient and family experience.

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