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Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy

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Abstract

Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy

Background

Fifty-seven percent of children with cerebral palsy (CP) experience mental health symptoms including symptoms of anxiety and depression. Although CP is non progressive, secondary conditions can have progressive effects on an individuals' functional abilities. Particularly, untreated mental health symptoms can negatively affect a child's quality of life. Children with CP also experience fatigue, pain, poor physical activity, and sleep disturbances. The presence of these physiological symptoms, separate and in combination, may impact mental health; however, it has not been systematically examined. Identifying factors that contribute to mental health symptoms may prevent the maintenance of these issues into adulthood.

Objectives

This study aimed to understand the associations between fatigue, pain, sleep, physical activity and mental health symptoms for children with CP. We hypothesized that moderate levels of fatigue, pain and/or sleep difficulties were associated with presence of psychological symptoms. In addition, we hypothesized that lower levels of physical activity were associated with mental health symptoms.

Methods

An observational study was conducted to assess physiological and mental health symptoms and physical activity in children with CP. Twenty-six participants and their caregivers responded to risk factor specific questionnaires before wearing accelerometers for one week, providing non-invasive data on movement patterns and sleep cycles. Using pairwise correlations and backward stepwise linear regressions, we examined the associations between the risk factors and severity of mental health symptoms.

Results

Significant regression models demonstrated associations for behavioural, depressive and anxiety related symptoms in children with CP. Models were able to explain 61%, 18% and 41% of the variance in child report internalizing behaviours, caregiver reported depression and anxiety, respectively.

Conclusion

Fatigue, pain severity, sleep efficiency and physical activity outcomes all contributed in some way to mental health outcomes. Longitudinal research is required to determine causal relationships.

Future Applications

This study will help develop evidence-based interventions to treat these factors and have the potential to inform clinicians on the determinants of mental health outcomes in this population. Individualized, targeted interventions can be developed and implemented to address the modifiable risk factors that threaten the wellbeing of children with CP.

Summary for Lay Audience

Cerebral palsy (CP) is the most prevalent and most impactful long-term motor disability in children. As children with CP grow, they experience new or worsening symptoms, including mental health symptoms, that can have negative effects on their quality of life. Identifying factors that contribute to mental health symptoms can prevent these issues from being maintained into adulthood. The objective in this study was to understand the association between fatigue, pain, sleep, physical activity and mental health symptoms for children and youth with CP. We determined that fatigue, pain, sleep and physical activity were all associated with mental health outcomes. We hypothesized that moderate levels of these physical symptoms would be related to the presence of having mental health symptoms. This study will help inform the development of evidence-based interventions to treat the physical symptoms that contribute to poor mental health.

Co-Authorship Statement

Research questions, specific objectives and individual study design were developed by Daniela Testani and Dr. Laura Brunton with inputs from Dr. Carly McMorris. All written work was primarily completed by Daniela Testani with revisions and suggestions by Dr. Laura Brunton, Dr. Carly McMorris and Dr. Trish Tucker. Larger study design, data collection and contributions were made by the CereBRUM team from the University of Calgary and Western University.

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Chapter 1: Review of the Literature

Cerebral palsy (CP) is the most prevalent childhood physical disability, affecting two children for every 1000 live births.(Oskoui et al., 2013; Van Naarden Braun et al., 2016) The disorder is complex due to the range of clinical signs and symptoms that vary from person to person, however, the primary impairments are in movement and posture.(Colver et al., 2014) In addition, CP is associated with co-occurring impairments that can have progressive effects on a seemingly non-progressive condition. Secondary conditions associated with CP include sleep disorders, cognitive and/or musculoskeletal dysfunction, epilepsy, and behavioural symptoms.(Novak et al., 2012) In particular, children and youth with CP are at higher risk of experiencing mental health symptoms than the general population.(Downs et al., 2018; Goodman, 1998) Untreated mental health symptoms can lead to a higher risk of developing depression and anxiety disorders that persist into adulthood.(Pine et al., 1998) Furthermore, untreated anxiety and depression can lead to significant academic, adaptive, and social difficulties, a decreased quality of life, and can have substantial economic burden on the healthcare system.(Sienko, 2018)

Experiencing fatigue, pain and disruptions in sleep, are related to mental health outcomes for children with CP.(Van Der Slot et al., 2012; Whitney, Warschausky, et al., 2019) These evolving secondary impairments have significant consequences for individuals in this population.(Frisch & Msall, 2013) Conversely, the relation between physical activity (PA) and mental health has been less examined in CP; however, PA may have a positive impact on mental health such as increased cognitive performance, improvements in behaviour disturbances, and promote social behaviour.(Gapin et al., 2011; Menear & Neumeier, 2015) Literature suggests that these factors together may contribute to the experience of mental health symptoms and give clinicians and researchers an avenue by which they may intervene and provide treatment. People with disabilities or chronic health conditions may be as much as three to four times more likely to develop depression and anxiety disorders.(Sienko, 2018; Van Der Slot et al., 2012) This study will seek to examine the relation between mental health symptoms in children and youth with CP and physiological risk factors and PA. It is hypothesized that children with CP who experience fatigue, pain, and disordered sleep will experience increased mental health symptoms of depression and anxiety.(Baxter, 2013; Helseth et al., 2016; Lindsay, 2016) In addition, it is hypothesized that PA will have a negative association between physiological risk factors and

mental health, and could be employed as a protective intervention.(Keawutan et al., 2018) By identifying modifiable physiological factors that may contribute to the development of psychological symptoms in youth with CP, targets become available for intervention to improve the lives of children with CP and their families. CP is a lifelong disability, and thus secondary conditions experienced by individuals without targeted interventions would likely be experienced across the lifespan. Mental health interventions specifically tailored for children with CP are rare, and as such, there may be opportunities to change mental health experiences through addressing the physiological conditions, such as those that are being investigated here.

Mental Health

Like CP, mental health disorders are complex pathophysiological diseases with heterogeneous etiology. Mental health symptoms for children and adolescents include feelings of stress, anxiety and depression in their day to day lives.(Lindsay, 2016) Experiencing mental health symptoms is sometimes a preliminary sign of developing a more serious condition or a mental illness. Mental illness or a mental disorder can be diagnosed when preliminary symptoms become more severe, chronic, or increase in frequency. These psychological disturbances can progress into psychiatric diagnoses if left untreated. Results from the United States of America's National Comorbidity Survey Replication -Adolescent Supplement (NCS-A) in 2010 showed that approximately 25% of all youth met criteria for a mental health disorder, with severe impairment across their lifetime.(Merikangas et al., 2010) Their rates suggested that most mental health disorders emerged before, and persisted into, adulthood where incidence of mental health increases with age.(Lewinsohn et al., 1998) Cross sectional data has shown that rates of mental health symptoms double from 13 to 14 (8.4%) years to 17 to 18 (15.4%) years.(Merikangas et al., 2010) Mood disorders were the most commonly occurring mental disorder, specifically anxiety-related disorders.(Merikangas et al., 2010) While this statement encompasses mental health prevalence at large, children with disabilities, including CP, are at a higher risk of experiencing mental health symptoms compared to their peers.(Whitney, Warschausky, et al., 2019) Children with CP tend to experience more emotional and behavioural symptoms including depression, anxiety and attention problems compared to their siblings without CP.(Levy-Zaks et al., 2014) In a longitudinal retrospective study, Smith et al., (2019), found that individuals with CP had an increased risk of being diagnosed with depression or anxiety, compared to a matched control group without CP.(Smith et al., 2019) In a study by Bjorgaas et al., (2012), researchers

concluded that 57% of their sample of children with CP met criteria for a psychiatric disorder.(Bjorgaas et al., 2012) Youth with CP may be at increased risk in part due to the presence of physiological health conditions (fatigue, pain, disordered sleep, etc.) that can impact mental health more so than their peers.(van Gorp et al., 2019) People with CP experience many physiological, psychological, social and health related risk factors that have been shown to be associated with depression and anxiety such as pain(Jahnsen et al., 2004), functional limitations(Odding et al., 2006), difficulties in social relationships(Cacioppo et al., 2006) and poor sleep.(Tremblay et al., 2011) Mental health and wellness can be affected by chronic pain, social difficulties and loss of independence, all of which are experienced by children with CP.(Krigger, 2006) To further compound the issue, external mental health resources are costly and availability of such resources are scarce. Although individuals with CP experience more anxiety and depression compared to their peers, it is not yet known why, or which combination of factors contribute most to poorer mental health outcomes.

Depression and Anxiety in CP

Major depressive disorder (MDD) is categorized by a combination of symptoms including low mood, loss of affect, and loss of interest. Depressive disorders are commonly found to be linked to fatigue and pain in the general population.(Trivedi, 2004) Whitney et al., (2020) found pain, fatigue, and sleep disorders further increased the likelihood of a mood disorder in a population of young and middle-aged adults with CP.(Whitney et al., 2020) Pediatric MDD is often left untreated and undiagnosed with only 50% of adolescents diagnosed being treated for their psychological symptoms prior to adulthood.(Kessler et al., 2001) In the general population, implications for later in life diagnoses and delay in treatment is associated with poorer health outcomes including worsening of mental health status, development of other mental disorders and an increased risk of suicide.(Kisely et al., 2006) Prolonged and untreated mental illness can have costly effects on healthcare and social service systems. It is estimated that the cumulative cost of providing treatment, care, and support services over the next 30 years in Canada is expected to exceed $2.5 trillion in current dollars.(Smetanin et al., 2011) There is ample and increasing evidence that investing in the right programs can contribute to helping the prevention of mental illnesses, delaying their onset, and reducing associated ill health and disability.(Mental Health Commission of Canada, 2011) It is vital for clinicians to be able to

address mental health-related symptoms as soon as they develop to limit progression to mental illness and maximize overall health and well-being.

Behavioural Disorders in CP

In addition to mental health symptoms that are prevalent in this population, behavioural difficulties can also be present, which can impact children's relationships and interactions. One in four children with CP have behavioural difficulties.(Horwood et al., 2019b) A study by Parkes et al., (2008) determined that 95% of parents reported that their children with CP had behavioural problems that lasted over a year and 37% said that these problems caused their child distress.(Parkes et al., 2008) These children often have difficulties with relationships, attention problems, hyperactive behaviour and exhibit antisocial characteristics including isolation, being disobedient and having troubled relationships with their peers.(McDermott et al., 1996) These behavioural characteristics are more often associated with psychological impairments (Sigurdardottir et al., 2010) and are significant to note as peer interactions and the development of relationships are vital at a young age to develop social skills required in adolescence and adulthood. The same study by Parkes et al., (2008) also determined that a significant proportion of participants that had psychological symptoms that were severe enough to warrant intervention, with over 40% of their sample scoring in the borderline to abnormal range on the Strengths and Difficulties Questionnaire.(Parkes et al., 2008) Further evidence of the impact of behavioural challenges comes from a study by Whitney et al., (2019), where children that had a harder time making friendships were found to have a higher prevalence of psychiatric conditions. In addition, there was an elevated presence of behaviour and conduct problems in children who experienced bullying.(Whitney, Peterson, et al., 2019)

Physiological Risk Factors and CP

Secondary conditions including fatigue, pain, and sleep disturbances, can have worsening effects on the motor disorders of CP which may increase the possibility of experiencing mental health symptoms or disorders. Although physiological risk factors can impact all levels of motor disturbances, physical health status is lower in children and youth that are less ambulatory than their peers.(Jacobson et al., 2020)

Fatigue

Fatigue is a common secondary condition associated with CP. Fatigue may be categorized by tiredness in muscles and reduced endurance for sustained work and can affect

activities of daily living.(Brunton & Bartlett, 2017) Interestingly, in a study conducted by van der Slot et al., (2012), fatigue severity was associated with depressive symptoms in adults with CP. Chronic pain and severe fatigue co-occurred in 34% of participants and further in combination with depressive symptoms in 16% of participants.(Van Der Slot et al., 2012) In a thematic qualitative synthesis by Lindsay et al., (2016), researchers collated themes that were classified according to the International Classification of Functioning, Disability, and Health - Child and Youth Framework and found that many of the studies included in the review suggested youth with CP often experience pain, fatigue and other physical or physiological impairments to body structure and function, which affect the ability to cope and participate in leisure and recreation activities.(Lindsay, 2016) Brunton et al., (2019) described the main contributors to fatigue for youth and young adults with CP including activity-related tasks, general demands of life, sleep, mental health concerns and environmental concerns.(Brunton et al., 2019) The authors suggested that many of these factors are modifiable and may be targeted by an intervention, however, further research is needed to determine if these factors are indeed modifiable in this population. The fatigue presentation appears to be relatively stable within adults with CP over time across all functional ability (Gross Motor Function Classification System (GMFCS)) levels.(Oude Lansink et al., 2018) Fatigue scores in the Oude Lansink et al., (2018) study did not change over a three-year follow up period, indicating that adults who experience fatigue are likely to remain fatigued without intervention.(Oude Lansink et al., 2018) In a study by McPhee et al., (2017), researchers examined the experience of fatigue in adults with CP, inclusive of all five GMFCS levels, and if PA, sedentary time and body mass index levels (BMI) could predict fatigue outcomes in this population. Using the Fatigue Impact and Severity Self-Assessment (FISSA), McPhee et al., (2017) determined a significant and positive association between BMI and fatigue scores indicating that participants with higher BMI levels had increased fatigue. In addition, they found a significant negative relation between MVPA per hour and FISSA scores, suggesting that physical activity intensity may be a potential target for mitigating losses in function in this population.(McPhee et al., 2017) Brunton (2018) determined that the overall effect of fatigue is greater for participants with more functional limitations.(Brunton, 2018; Brunton & Bartlett, 2017) In addition, there were non-significant differences between groups on items related to strategies to mitigate fatigue, indicating that

although fatigue may be overly present in this population, there are few fatigue-focused interventions available for people with CP.(Brunton, 2018)

Chronic Pain

Pain is a common secondary condition associated with CP and is often experienced in childhood and may become a chronic impairment throughout adulthood. Acute pain becomes chronic if it persists after three months or beyond the expected time for healing and is an increasingly common concern for children and adolescents with disabilities.(Massaro et al., 2013) Children with CP are at risk for chronic pain due to a combination of surgical, orthopaedic, gastrointestinal and/or rehabilitative experiences.(McKearnan et al., 2004) The prevalence of pain in children in this population varies with estimates ranging from 20% to 65%.(Houlihan et al., 2008) Common contributors to pain can include hip subluxation, muscle spasms, dystonia and constipation.(Penner et al., 2013) Recurrent musculoskeletal pain is the most prevalent pain experienced by children and adolescents with CP and becomes more prevalent with age.(Ramstad et al., 2011) Specifically in CP, overuse of muscles or strains caused by involuntary movements, atypical joint position and the imbalance of muscle use are all factors related to the experience of pain.(Jahnsen et al., 2004) Chronic pain in children can lead to broader impairments in a child's functioning including to their mobility, interpersonal interactions, physical and psychosocial functioning as well as restrict their school participation.(Palermo, 2000)

In a study by Penner et al., (2013), researchers concluded that 25% of children with CP experienced moderate to severe pain which affected their ability to participate in activities.(Penner et al., 2013) Pain has also been shown to negatively affect mental health and quality of life for children with CP and their families.(Findlay et al., 2016; Ramstad et al., 2012) Pain becomes more prevalent with age, but is not correlated to a specific type, or severity of CP and may contribute to additional functional impairments experienced by the individual.(Baxter, 2013; Houlihan et al., 2008; Mckinnon et al., 2019)

Disordered Sleep

Sleep allows for important biological processes to occur including restoration to memory, cognition and learning.(Verschuren et al., 2016) In a study by Noel et al., (2018), researchers determined that sleep mediated the association between post-traumatic stress symptoms and pain characteristics in a population of children with chronic pain.(Noel et al., 2018) Twenty-three

percent of children with CP were determined to have a significant pathological sleep disorder score compared to only five percent of children in the general population.(Newman et al., 2007) Both biological and environmental factors contribute to the increased frequency of sleep disorders in children with CP.(Mindell et al., 2006) Sleep disturbances often experienced by children with CP include initiating and maintaining sleep, sleep and wake transitions, sleep breathing disorders, nightmares and sleep talking.(Newman et al., 2007) Sleep deficiency is an outcome of disordered sleep and can increase the risk of negative mood, behavioural problems, cognitive impairments, poor school performance and metabolic disturbances.(Dutt et al., 2015) Furthermore, sleep has also been shown to be strongly associated with behavioural difficulties in children with CP.(Horwood et al., 2019b) There is also a strong bidirectional relationship between pain and sleep, which can reduce sleep quality in children and youth with CP. Factors including skin breakdown, pressure ulcers, involuntary movements and abnormal muscle postures can increase the experience of pain during sleep.(Newman et al., 2007) Sleep may be a modifiable and quantifiable risk factor that should be considered when analyzing mental health symptoms or in an interventional study.

The Importance and Impact of Physical Activity

It is recommended that children and adolescents achieve at least 60 minutes of PA every day with diversified activities, including fitness, strength, coordination, and flexibility exercises.(Waltersson & Rodby-Bousquet, 2017) CP is mainly characterized by impairment in motor control, which depending on GMFCS level, can impact habitual physical activity levels. A systematic review by Keawutan et al., (2014) determined that higher habitual physical activity levels were associated with higher motor capacity in children with CP.(Keawutan et al., 2014) Children with CP are not as physically active as their peers and often participate in lower intensity PA.(Maher et al., 2007) This may produce a deconditioning of the muscular, skeletal, and cardiorespiratory systems which can contribute to a cycle that increases the disability level over time.(Maher et al., 2007) Using an accelerometer, a study by Ryan et al., (2015) determined that children with CP spent more time in sedentary behaviour and accumulated less time in total, moderate, vigorous PA and sustained MVPA than their typically developing peers.(Ryan et al., 2015) In addition, low levels of PA have contributed to the development of chronic pain, fatigue and osteoporosis for people with CP.(Fowler et al., 2007) In an integrative review conducted by Koldoff et al., (2015), researchers found that addressing the decline in PA in adolescents may

carry over into adulthood and provide benefits in physiological, emotional, cognitive and social domains, however this needs to be investigated further.(Koldoff & Holtzclaw, 2015; Martin, 2013)

Physical Activity as a Potential Therapeutic Target

Participating in daily PA provides benefits across a number of different health domains. A systematic review by Warburton and Bredin (2017) demonstrated a dose-response relationship between PA and premature mortality, highlighting the power of PA for prevention of many chronic medical conditions. The study depicts a curvilinear relationship whereby health benefits are observed with relatively minor, thus achievable, volumes of PA.(Warburton & Bredin, 2017) Children and youth that experience high PA and low sedentary behaviour also experienced health benefits(Saunders et al., 2016), for example, children with CP that engage in more PA behaviours exhibit lower systolic blood pressure than those that are more sedentary.(Ryan et al., 2014) In addition, PA levels have also been shown to directly impact the secondary impairments associated with CP such as chronic pain(Hirsh et al., 2011) and fatigue(Nieuwenhuijsen et al., 2011) and perhaps PA can be used as a treatment option for this population to reduce the impact of these comorbid impairments.

Physical Activity and Mental Health

Increased PA frequency and intensity is associated with decreased depressive symptoms in children and adolescents generally.(Korczak et al., 2017) Conversely, decreased PA and increased sedentary behaviour can vulnerably dispose children to developing depressive symptoms.(Sund et al., 2011) PA interventions are becoming more widely used in mental health research, specifically for treating affective symptoms including depression and anxiety, as well as and behavioural symptoms including inattention and oppositional defiant behaviours.

Children with CP are more sedentary and engage in less PA related behaviours than their peers due to the motor limitations associated with the disorder.(Lauruschkus et al., 2013) In addition, the energy expenditure that these children experience while standing or moving with or without support is elevated significantly.(Verschuren et al., 2014) Increased energy expenditure can lead to higher physical strain which may contribute to early onset fatigue in children with CP.(Dallmeijer & Brehm, 2011; Maltais et al., 2005) PA interventions have been shown to be successful in reducing fatigue severity and increasing health-related quality of life with respect to bodily pain and mental health.(Slaman et al., 2015) Furthermore, a study conducted by

Lauruschkus et al., (2017) indicated that a PA intervention was feasible and effective for children with CP to promote participation, motivation and engagement in physical activities to limit sedentary behaviours.(Lauruschkus et al., 2017)

Physical Activity in Mental Health Interventions

Evidence based interventions for children and youth with depression include cognitive coping methods, problem solving strategies, activity scheduling, and social skill building.(Wissow et al., 2016) Mental health interventions have not yet been adapted and validated for youth who experience other physiological risk factors including fatigue, pain and sleep disturbances. However, these factors are thought to be modifiable and could be the target of interventions to increase the quality of life and address the mental health symptoms experienced by children with CP. Identifying modifiable physiological risk factors that play a role in mental health is vital for early intervention in childhood and adolescence and to limit the persistence of symptoms into adulthood where they may be confounded by age-related changes to the motor disorder. PA may be an avenue for treatment of these factors and may have the ability to relieve or lessen some of these symptoms. Reducing sedentary activity by integrating PA into the daily routine of people with CP may also contribute to functional independence and enhance the quality of life of these individuals.(Rimmer, 1999)

Purpose

The purpose of this study was to observe physiological factors (including fatigue, pain, disordered sleep), and PA and their combined association with mental health symptoms in children with CP. Many children and youth experience these physiological symptoms in tandem, and they may have a combined effect on mental health symptoms. Mental health symptoms considered for the purpose of this study included internalizing and externalizing behaviours, depression and anxiety. The combined effects of these elements have not been assessed in relation to PA. In addition, this research has yet to be conducted in a pediatric population, as most of the research regarding physiological risk factors and mental health was conducted with adult populations. It is imperative to determine the associations between these factors to better understand the course of mental health in CP. This study aims to examine the associations between PA, symptoms of fatigue, pain, sleep disturbances and determine their impact on mental health outcomes in children with CP.

Chapter 2: Methods

Ethical Approval and COVID-19 Amendments

This study is a part of a larger study examining associations between physiological factors and mental health in children and youth with CP. This study was approved by the Health Sciences Research Ethics Board at Western University and by the Conjoint Health Research Ethics Board at the University of Calgary (Appendix A). All participants and/ or parents provided informed consent to participate in the study (Appendix B). Due to recent events associated with the COVID-19 pandemic, the data collection methods were amended as per Western University regulations. The study was able to be conducted completely remotely, and even allowed for recruitment of some participants and their families that resided in rural communities, which would not have been possible with the planned data collection methods prior to COVID-19.

Design

This cross-sectional observation study examined the contribution of secondary risk and protective factors to mental health outcomes using online surveys and accelerometers. This exploratory research is part of a larger study that examines mental health and collected measures beyond what is included in this analysis. Data was collected from September 2019 to August 2021.

Participants with CP and/or one of their caregivers completed a variety of standardized assessment measures, and caregiver/self-report questionnaires to assess symptoms of anxiety and depression and secondary physiological risk factors. All questionnaire data collection was collected via online survey platforms. Using the platforms REDCap, Q-Global and MHS Measurements, a link was provided via email to parents to fill out the questionnaires. Following the online questionnaires participants wore two accelerometers (ActiGraph GT9X Link; wrist and waist) to document sleep and PA data for 7 days and nights. It has been recognized that attachment sites of the Actigraph can influence counts per minute between wrist and waist bound sites.(Hjorth et al., 2012; Loprinzi & Smith, 2017) Actigraphy sites were thereby distinguished between sleep (wrist) and PA (waist).

Hypothesis

It was hypothesized that all physiological factors (fatigue, pain and sleep disturbances) and PA would contribute to the variance observed in the mental health measures (both child and parent report).

Participants

Inclusion Criteria

Children and youth with CP ages 8 to 18 years, with any level of functional ability (as measured by the GMFCS) were recruited with parental consent and/or assent by convenience sampling from a variety of Calgary, AB and/or London, ON health and community institutions. This age range was chosen for two purposes, 1) based on the validity and availability of the measures for this population and 2) to address the onset and course of mental health symptoms prior to adolescence and through the transition to adulthood. To participate, children had to communicate using verbal language. Children with CP with other medical conditions including medication-controlled epilepsy, an intellectual disability, among others, were able to participate in the current study.

Exclusion Criteria

Children with disorders other than CP were not eligible for the study including those with epilepsy (without a CP diagnosis), traumatic brain injury, neurofibromatosis, or any autoimmune disorders. Children with these disorders were excluded due to the differing etiology of disorders compared to CP. Children/youth that were not able to communicate verbally were also deemed ineligible for the study due to the nature of collecting data.

Measures

Functional Ability Level

Functional ability level was assessed by the GMFCS. Due to the remote data collection methods of the study, GMFCS level was provided by caregiver knowledge. The GMFCS is a reliable and valid five-level scale that classifies a child's gross motor function with an emphasis on movement initiation, sitting control, and walking.(Bodkin et al., 2003; Palisano et al., 1997) Level I represents the highest gross motor function, whereas level V represents the lowest.(Bodkin et al., 2003) CP is a heterogeneous condition with multiple causes, clinical types, neuropathy, and functional abilities.(MacLennan et al., 2015) Homogeneity in a sample would be

preferred, however due to the variability across multiple domains in this population, functional ability level was used to describe the sample.

Mental Health: Anxiety and Depression

To measure symptoms of anxiety and depression, both parent and child completed the Behaviour Assessment System for Children, Third Edition (BASC-3)(Altmann et al., 2017), the Child Depression Inventory (CDI)(Kovacs, 2015), and the Multidimensional Anxiety Scale for Children, Second Edition (MASC-2)(March, 2000). For all mental health measures, T scores were used in the analysis. Raw scores are not comparable between children since they may have a different number of items between scales depending on the type of report (i.e. self-report vs parent-report). To facilitate interpretation of the results, raw scores were converted into T scores, or standardized scores. T scores for these measures use age and sex-based norms to determine how one participant's score compares to others that are the same age and same sex to enhance interpretation.

The BASC-3 assesses emotional disorders, personality constructs, and behavioural problems in children and adolescents and has shown good validity compared to other similar measures.(Burback, 2020; Kamphaus, 2015; Merenda, 1996) Internalizing behaviours are defined as inwardly directed distress which are indicative of a child's emotional state, while externalizing behaviours are those behaviours presented outwardly and are observed by the child's behaviour in their environment.(Liu et al., 2011) Higher scores on the BASC-3 indicates higher incidence of internalizing problems. Average T scores are between 41 and 59 (range within which two thirds of the general population will score), while clinically relevant scores vary between from 0 to 30 and 70 and above.(Altmann et al., 2017) For the purpose of this study, the internalizing behaviour T score from child self-reported scales was used as a dependent mental health symptom variable.

The CDI is a brief self-report test that helps assess cognitive, affective and behavioural signs of depression in children and adolescents. The CDI has been shown to have high internal validity.(Finch et al., 1987; Helsel & Matson, 1984; Smucker et al., 1986) Higher scores on the CDI (both child and parent report) indicate more marked or definite symptoms of depression. T scores that fall below 60 indicate average item endorsements for the child's age and sex. Scores 60 to 64 fall into the high average category while scores greater than 70 would endorse multiple depression symptoms and many areas of functional impairment.(Kovacs, 2015) For the purpose

of this study, the total *T* score for child and parent reports was used as a dependent mental health outcome variable.

Finally, the MASC-2 is a reliable and valid, 39-item assessment that collects anxiety related data across 4 domains (physical symptoms, social anxiety, harm avoidance and separation anxiety).(March et al., 1997) Higher scores on the MASC-2 indicate more marked or definite symptoms of anxiety. *T* scores between 40 and 54 indicate typical level of concern and are deemed within "Average" range. Scores 55-59 indicate a "High Average" range that causes borderline concern. Scores between 60 and 64 indicate slightly elevated and indicate more concerns than are typically reported. Scores greater than 70 are deemed very elevated and a significant cause for concern.(March, 2000) For the purpose of this study, the *T* score will be used as the dependent outcome variable for both child and parent reports. Together these measures will provide good insight to mental health impacts in this population.

Fatigue

Fatigue was measured by the Fatigue Impact and Severity Self-Assessment (FISSA), see Appendix C. The FISSA has been shown to have adequate test-retest reliability and is a valid measure of fatigue for individuals with CP.(Brunton & Bartlett, 2017) The FISSA is a 37-item measure that provides a preliminary description of activities that fatigue interferes with, an overview of the severity of fatigue experienced by the individual and the specific management strategies used by an individual.(Brunton & Bartlett, 2017) Responses to the first 31 items provide a total score (ranging from 31 to 157) and higher scores indicate higher fatigue. The remaining six questions are qualitative in nature and are not included in the total score.(Brunton & Bartlett, 2017) The Total FISSA, Impact and Severity Subscale, and Activity Modification and Management Subscale Scores were considered as physiological predictor variables in the data analyses.

Pain

Self-reported pain was measured by the Youth Pain Questionnaire, see Appendix D. The Youth Pain Questionnaire is a reliable and valid measure designed to assess functional impairment due to chronic pain in school-age children.(Noel et al., 2016) The variables of most interest for the purpose of this study were pain impact, severity and duration.

Objective Movement Data

Using an accelerometer to record movement is both non-invasive and objective.(Ancoli-Israel et al., 2015; Cellini et al., 2013) An accelerometer can capture raw activity volume in structured activities of increasing intensity including sitting, walking and jogging. Although there is no gold standard device for measuring objective movement data, the ActiGraph and ActiLife software have been used extensively for measuring PA and sleep data in populations with CP, which allows for comparability of results. Furthermore, ActiGraph accelerometers have been validated to be feasible and unobtrusive for participants with all GMFCS levels.(Capio et al., 2010; Clanchy et al., 2011; Gorter et al., 2012)

Accelerometer instructions and logs were distributed to each family via Canada Post mailing, see Appendix E. Participants were asked to wear their ActiGraphs for 24 hours for 7 days. However, if participants did not wear the ActiGraphs for 7 days, their data was still used. Participants mailed their accelerometers back to their local PI where a cleaning/disinfecting procedure was implemented. Local PIs wore medical grade gloves and used Lysol disinfectant to wipe down each accelerometer and a solution with Lysol and water was used to clean the fabric straps used to secure the accelerometer prior to uploading the data. Each accelerometer was cleaned a second time, again with the PI wearing gloves, before being sent to the next participant. Each instruction package included a link to an instructional video and daily logs (see Appendix E), to capture sleep and rise times and device removal.

Sleep

Accelerometers worn on the wrist have been previously determined to be both valid and reliable for measuring sleep and wake periods in 60-second epochs in young adults and children.(Cellini et al., 2013; Taylor et al., 2015) To objectively measure movement data, participants were asked to wear one accelerometer (Actigraph GT9X Link) around their wrist to capture sleep data. Scoring of wrist activity provides useful information about sleep and wakefulness that can be applied in clinical and research applications.(Cole et al., 1992) Wrist actigraphy, worn on the non-dominant hand, has been validated and deemed reliable to collect sleep information.(Weiss et al., 2010) In addition, the accelerometer data was used to estimate the prevalence of sleep disturbances including sleep efficiency, wake after sleep onset (WASO) and number of awakenings. WASO is described by the number of minutes children are awake after they have two continuous minutes scored as sleep.(Blackwell et al., 2008) These variables

were determined from the daily average of sleep data collection per participant and were considered physiological predictor variables in the analyses.

Physical Activity

To measure PA, participants were asked to wear an accelerometer around their waist and on their hip, for the duration of the 7 days. PA has been validated with monitor placement on the waist to assess whole-body movement.(Hjorth et al., 2012; Knaier et al., 2019) Waist actigraphy during activities of daily living has been validated and has high interrater reliability.(Migueles et al., 2017; Ozemek et al., 2014) Accelerometers were used to explore three variables including step count, % of time spent sedentary and % of time spent in MVPA. The ActiGraphs were initialized with a sample rate of 30 Hz. A 60 second epoch, across three axes, were used for data analysis. Using the Choi (2011) algorithm, wear and non-wear periods were determined and manually cross examined against log data.(Choi et al., 2011) Variables were extracted using the ActiLife software by applying the following algorithms, Freedson VM3 for energy expenditure, Freedson Children (2005) for metabolic equivalent of task and Evenson Children (2008) for cut points and MVPA.(ActiGraph Software Department, 2012) These algorithms were chosen for their sensitivity and validity for this population.(Clanchy et al., 2011; Trost et al., 2011) These variables were collected each day over the 7 day wear period and a daily average was calculated. Standard Canadian PA guidelines indicate that children and youth should participate in a minimum of 60 minutes of moderate to vigorous PA per day and limit sedentary behaviours.(Canadian Society for Exercise Physiology, 2011) In addition, children and adolescents with cerebral palsy are encouraged to engage in the same physical activity behaviours as their typically developing peers.(Verschuren et al., 2016) The Canadian Physical Activity Guidelines for children and youth ages 5 to 17 years were used to calculate a proportion of the sample that were meeting versus not meeting these guidelines.

Statistical Analyses

All statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS, IBM) Version 27. Descriptive statistics including mean, standard deviation, median and range, as appropriate, were used to describe demographic characteristics of the sample. Pearson's correlation coefficients were used to assess which physiological predictor variables were most highly correlated with the dependent mental health outcomes to determine which physiological predictors would be entered into a linear regression to predict each of the mental health

outcomes. A series of separate backwards stepwise multiple linear regressions were used to examine the associations between physiological variables and mental health outcomes of internalizing behaviours, depression and anxiety parent and child reports. A backwards deletion approach for the regression allows for all the independent variables to be entered into the regression and each is deleted if it does not provide unique contribution to the regression equation once the other variables are accounted for. This method reduces the number of predictor variables and reduces the issue of multicollinearity. Due to the small sample size and missing data, a pairwise case deletion method was used to include as much of the data as possible. Linear regressions were performed with each mental health measure, BASC-3 child, CDI child and parent, MASC-2 child and parent as the dependent variable. The assumptions of linear regression were tested using as follows:

- **Variable Types**: All predictor variables were set as quantitative or categorical and specifically the outcome variable was quantitative, continuous and descriptive statistics were used to determine if it was unbounded.
- **Non-zero variance**: Variance of predictor variables was determined through examining standard deviation of scores.
- **No perfect multicollinearity**: Incidence of multicollinearity indicates that there is an occurrence of high correlation between independent variables found in the regression. Multicollinearity was tested during the linear regression using the variance inflation factor (VIF). VIF values that are between 1 and 10 indicate no multicollinearity and values that are <1 or > 10 indicate multicollinearity.(Field, 2009)
- **Homoscedasticity**: Indicates that at each level, the predictor variables should be constant. Homoscedasticity was examined by visually interpreting the scatter plot where the residuals are equal across the regression line. Scatter plots were plotted with the axes ZRESID; the standardized residual (Y-axis) and *ZPRED; the standardized predicted values of the dependent variable based on the regression model (X-axis).
- **Independent Errors:** The Durbin-Watson Test was used to check whether the residuals in the model were independent. The Durbin-Watson test will always have a value between 0 and 4. Values close to 2.0 indicate that there is no autocorrelation detection in

the sample. Values less than 2 indicate positive autocorrelation and values greater than 2 indicate negative autocorrelation.(Field, 2009)

- **Normally Distributed Errors:** It was assumed that the residuals in each model are random and normally distributed, with a mean of 0. This assumption was tested by examining the histogram and normal probability plot with axes, ZRESID; the standardized residuals, or errors (Y-axis) and *ZPRED; the standardized predicted values of the dependent variable based on the regression model (X-axis). Points were assessed based on their location to the definite line.

- **Linearity:** Mean values of the outcome variable for each increment of the predictors lie along a straight line. Scatterplots of the dependent and independent variables were created to examine if the relationships were linear in nature. Non-linear relationships limit the generalizability of the findings.

Chapter 3: Results

Demographics of study participants are presented in Table 1. In this sample, the mean age was 11.8 years (SD=2.9) and 87.5% of children were ambulatory based on GMFCS criteria (levels I-III). Table 2 presents the descriptive information for all physiological risk factor data.

Table 1

Demographic Factors

	n=26	
Age, Mean† (SD)	11.8 years	(2.9)
Sex†, n, (%)		
Male	15	(57.7)
Female	10	(38.5)
Neither	1	(3.8)
Functional Ability Level‡ (GMFCS), n, (%)		
I	11	(45.8)
II	9	(37.5)
III	1	(4.2)
IV	1	(4.2)
V	2	(8.3)
Ethnic Group†, n, (%)		
White	18	(69.2)
East Asian	1	(3.8)
Hispanic	2	(7.7)
Indigenous	2	(7.7)
Black	1	(3.8)
Multiethnic	2	(7.7)
Parent 1 Highest Level of Education, n, (%)		
High School	1	(3.3)
Some Post-Secondary	6	(20.0)
Completed Post-Secondary	13	(43.3)
Masters	3	(10.0)
PhD	1	(3.3)
Technical College, Vocational School	2	(6.7)
Parent 2 Highest Level of Education, n, (%)		
High School	7	(23.3)
Some Post-Secondary	2	(6.7)
Completed Post-Secondary	7	(23.3)
Masters	2	(6.7)
Technical College, Vocational School	5	(16.7)
Average Annual Household Income† n, (%)		
Prefer not to say	3	(11.5)
$35,000 to $49,999	1	(3.8)
$50,000 to $74,999	3	(11.5)
$75,000 to $99,999	4	(15.4)
$100,000 and over	15	(57.7)

†= Missing data for 4 participants
‡= Missing data for 6 participants

Note. GMFCS= Gross Motor Functioning Classification System

Table 2

Physiological Risk Factor Scores

Physiological Risk Factors		
Fatigue ‡, Mean (SD)		
Total Score	75.5	(28.6)
Impact & Severity	38.46	(16.1)
Activity Modification & Management	38.17	(13.9)
Pain Duration, n‡ (Valid %)		
Less than 1 hour	12	(50.0)
A few hours	5	(20.8)
Half of the day	3	(12.5)
All day	4	(16.7)
Pain Impact, n‡ (Valid %)		
Not at all	6	(25.0)
A little	7	(29.2)
Between a little and a lot	8	(33.3)
A lot	1	(4.2)
Very Much	2	(8.3)
Pain Severity‡, Median (Range)	3.5	(8)
Sleep, Mean‡ (SD)		
WASO	37.5	(16.4)
Efficiency (%)	89.5	(5.2)
# of Average Awakenings	14.4	(5.7)
Physical Activity, Daily Mean§ (SD)		
Step Count	4858.1	(3056.7)
Minutes Spent in MVPA	20.7	(24.5)
% in MVPA	1.4	(1.4)
% in Sedentary	79.2	(9.1)
Proportion of participants meeting Canadian Guidelines, n§ (Valid %)	2	(11.8)

‡= Missing data for 6 participants
§= Missing data for 9 participants

Note. WASO= Sleep After Wake Onset, MVPA= Moderate to Vigorous Physical Activity

Mental Health Profiles

    Descriptive information for scores on the mental health measures are presented in Table 3. Cut point information and frequencies for all mental health measures are reported in Tables 4-7. The BASC-3 parent measure was intended to be included in the analysis; however, due to a clerical error, the wrong survey was uploaded to the online survey platform and only nine parents

were able to complete the full measure once the error was corrected. Therefore, the decision was made to exclude the parent report due to significant missing data. The mean internalizing score for the BASC-3 child report was 51.32 (SD=9.20). Based on *T* score information, BASC-3 Child scores for this sample were considered average. Mean child and parent CDI scores were 53.72 (SD=13.06) and 58.81 (SD=11.29) respectively. Based on this criterion, mean CDI scores reported by both parent and child were within the normal range, with the parent's score reaching the "High Average" range. Mean MASC-2 scores were 52.95 (SD=12.35) and 60.93 (SD=13.79) for child and parent report respectively. Based on this sample, MASC-2 *T* scores based on child reports were in typical range (40-54) for their age. However, based on the parent report, *T* scores indicated a mean score that is slightly elevated (60-64) indicating slightly more concerns than would be expected for children this age.

Table 3

Mental Health Measure Scores

Mental Health Measures	Score Type	Mean	(SD)
BASC-3 Child **	Internalizing *T*	51.3	(9.2)
CDI Child ø	Total *T*	53.7	(13.1)
CDI Parent ¥	Total *T*	58.8	(11.3)
MASC-2 Child *	Total *T*	52.9	(12.3)
MASC-2 Parent ¥	Total *T*	60.4	(13.8)

¥= Missing data for 3 participants
ø= Missing data for 5 participants
*= Missing data for 10 participants
**= Missing data for 11 participants

Note. BASC-3= Behavioural Assessment System for Children 3rd Edition, CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for Children 2nd Edition

Table 4

BASC-3 Cut Points and Sample Frequencies

Classification				
Adaptive Scales	Clinical Scales	*T* score	Frequency Child Report (n=19)	Proportion (Valid %)
Very High	Clinically Significant	70 and above	2	10.5%
High	At Risk	60-69	2	10.5%
Average	Average	41-59	15	79%
At Risk	Low	31-40	-	-
Clinically Significant	Very Low	30 and below	-	-

Note. BASC-3= Behavioural Assessment System for Children 3rd Edition

Table 5

CDI Cut Points and Sample Frequencies

Classification	*T* score	Frequency Child Report (n=20)	Proportion (Valid %)	Frequency Parent Report (n=27)	Proportion (Valid %)
Very Elevated	70+	4	16	5	18.5%
Elevated	66-70	1	4	1	3.7%
High Average	60-65	2	8	7	25.9%
Average	<60	18	72	14	51.9%

Note. CDI= Children's Depression Inventory

Table 6

MASC-2 Cut Points and Sample Frequencies

Classification	*T* score	Frequency Child Report (n=20)	Proportion (Valid %)	Frequency Parent Report (n=27)	Proportion (Valid %)
Very Elevated	70+	2	10%	6	22%
Elevated	65-69	3	15%	3	11%
Slightly Elevated	60-64	1	5%	6	22%
High Average	55-59	2	10%	-	-
Average	40-54	9	45%	12	44%
Low	<40	3	15%	-	-

Note. MASC-2= Multidimensional Anxiety Scale for Children 2nd Edition

Correlations

See Tables 7-10 for the Pearson's correlation coefficient data for each predictor/outcome variable pair. All hypothesized predictor variables (fatigue total score, fatigue impact and severity subscale, fatigue activity modification and management subscale, pain severity, pain impact, pain duration, sleep efficiency, WASO score, number of awakenings, % time in MVPA, % in time in sedentary activity and step count) were assessed and those with the most significant correlations across mental health outcomes were chosen for each hypothesized predictor grouping (Fatigue, Pain, Sleep, PA). However, judgments were made regarding sleep and fatigue variables where the sleep efficiency score contains WASO and the total fatigue score contains the subscales. Based on these factors and considering correlations across all mental health measures, the following variables were included:

- Fatigue Total Score
- Pain Severity
- Sleep Efficiency (%)
- % time in MVPA
- % time in Sedentary Activity

Physiological Factor Correlations with Mental Health Outcomes

Table 7

Fatigue Correlations

		CDI Parent	CDI Child	MASC -2 Parent	MASC- 2 Child	BASC- 3 Child
Fatigue Total	Pearson Correlation	.165	.114	.084	-.017	.035
	Sig. (2-tailed)	.442	.596	.697	.943	.892
	N	24	24	24	19	18
Fatigue Impact Severity	Pearson Correlation	.193	.004	.073	-.063	-.121
	Sig. (2-tailed)	.366	.986	.735	.799	.632
	N	24	24	24	19	18
Fatigue Management	Pearson Correlation	.104	.222	.082	.042	.229
	Sig. (2-tailed)	.629	.297	.703	.864	.361
	N	24	24	24	19	18

**. Correlation is significant at the 0.01 level (2 tailed).
*. Correlation is significant at the 0.05 level (2- tailed).

Note. CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for

Children 2nd Edition, BASC-3= Behavioural Assessment System for Children 3rd Edition

Table 8

Pain Correlations

		CDI Parent	CDI Child	MASC-2 Parent	MASC-2 Child	BASC-3 Child
Pain Duration	Pearson Correlation	.226	.033	-.182	-.230	.065
	Sig. (2-tailed)	.288	.878	.396	.344	.799
	N	24	24	24	19	18
Pain Severity	Pearson Correlation	-.030	-.266	-.342	-.426	-.502*
	Sig. (2-tailed)	.888	.208	.102	.069	.034
	N	24	24	24	19	18
Pain Impact	Pearson Correlation	.196	-.173	-.232	-.264	-.296
	Sig. (2-tailed)	.359	.420	.276	.275	.233
	N	24	24	24	19	18

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).
Note. CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for

Children 2nd Edition, BASC-3= Behavioural Assessment System for Children 3rd Edition

Table 9

Sleep Correlations

		CDI Parent	CDI Child	MASC-2 Parent	MASC -2 Child	BASC-3 Child
Sleep Efficiency (%)	Pearson Correlation	-.158	-.195	-.038	-.255	-.243
	Sig. (2-tailed)	.460	.384	.862	.324	.331
	N	24	22	24	17	18
WASO	Pearson Correlation	.129	.433*	.039	.189	.344
	Sig. (2-tailed)	.549	.044	.858	.467	.162
	N	24	22	24	17	18
# of Awakenings	Pearson Correlation	-.077	.255	-.186	-.017	.089
	Sig. (2-tailed)	.721	.253	.385	.947	.725
	N	24	22	24	17	18

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Note. CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for

Children 2nd Edition, BASC-3= Behavioural Assessment System for Children 3rd Edition

Table 10

Physical Activity Correlations

		CDI Parent	CDI Child	MASC- 2 Parent	MASC-2 Child	BASC-3 Child
Step Count	Pearson Correlation	.345	.373	.462*	.328	.493*
	Sig. (2-tailed)	.126	.116	.035	.233	.044
	N	21	19	21	15	17
% in MVPA	Pearson Correlation	.478*	.287	.363	.215	.649**
	Sig. (2-tailed)	.028	.234	.106	.442	.005
	N	21	19	21	15	17
% in Sedentary	Pearson Correlation	-.267	-.081	-.606**	-.190	-.376
	Sig. (2-tailed)	.242	.741	.004	.497	.137
	N	21	19	21	15	17

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Note. CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for Children 2nd Edition, BASC-3= Behavioural Assessment System for Children 3rd Edition, MVPA= Moderate to Vigorous Physical Activity

Assumptions of Linear Regression

Tests for the assumptions of linear regression determined the following:

- **Variable Types**: All predictor variables were demonstrated to be quantitative or categorical and the outcome variables were unbounded.

- **Non-zero variance**: Standard deviation, range and minimum and maximum values demonstrated non-zero variance for all predictor variables.

- **No perfect multicollinearity**: Results from tests of multi-collinearity are indicated in Table 11. VIF values are between 1 and 10 for all predictors, thus, predictors were not highly correlated with each other. The average VIF score is close to 1, confirming that multicollinearity was not an issue within the models.

- **Homoscedasticity**: Based on the scatterplots of the standardized residuals and standardized predicted values, the histogram and normal probability plots there was no evidence of heteroscedasticity in the data.

- **Independent Errors:** The Durbin-Watson Test for all regression models were between 1.5 to 2.5, demonstrating minimal autocorrelation in the sample.

- **Normally Distributed Errors:** The scatter plots produced demonstrated a random array of dots evenly dispersed around zero confirming normally distributed errors.

- **Linearity:** Scatterplots of the data revealed linear relationships between predictor variables and the outcome variables for those predictors that were significant or remained in the regression models.

Table 11

Multicollinearity Statistics

Dependent Variable	Model of Significance	Included Variables Regression Model(s)	Collinearity Statistics	
			Tolerance	VIF
	1	Pain Severity	.791	1.263
		Sleep Efficiency	.765	1.307
		% in MVPA	.584	1.713
		% in Sedentary	.499	2.004
		Fatigue	.821	1.218
BASC-3	2	Pain Severity	.812	1.231
		Sleep Efficiency	.889	1.125
		% in MVPA	.894	1.119
		Fatigue	.821	1.218
	3	Pain Severity	.826	1.211
		% in MVPA	.979	1.022
		Fatigue	.830	1.204
CDI Parent	5	% in MVPA	1.000	1.000
	1	Pain Severity	.791	1.263
		Sleep Efficiency	.765	1.307
		% in MVPA	.584	1.713
		% in Sedentary	.499	2.004
		Fatigue	.821	1.218
MASC-2 Parent	2	Pain Severity	.792	1.263
		Sleep Efficiency	.765	1.307
		% in Sedentary	.764	1.309
		Fatigue	.823	1.214
	3	Pain Severity	.817	1.224
		% in Sedentary	.973	1.028
		Fatigue	.833	1.201
	4	Pain Severity	.973	1.028
		% in Sedentary	.973	1.028
	5	% in Sedentary	1.000	1.000

Note. CDI= Children's Depression Inventory, MASC-2= Multidimensional Anxiety Scale for Children 2nd Edition, BASC-3= Behavioural Assessment System for Children 3rd Edition, MVPA= Moderate to Vigorous Physical Activity, VIF =Variance Inflation Factor

Regression Analyses

Five hierarchical regressions were conducted, one for each mental health outcome (child and/or parent report) the BASC-3 (Child), CDI-2 (Child and Parent), and MASC-2 (Child and Parent).

Regression 1: BASC-3

Using the backward stepwise linear regression approach with the BASC-3 child-report internalizing T score as the dependent variable, three models were found to be significant. Significant regression equations include:

Model 1: ($F_{(5, 11)}= 5.88$, $p<0.007$), with an adjusted R^2 of 0.60. Participants predicted mental health was equal to 58.69 - 2.43 (Pain Severity) - 0.35 (Sleep Efficiency) +4.48 (% time in MVPA) + 0.231 (% time in Sedentary) + 0.10 (FISSA Total Score), where pain severity was coded on a scale from 0 (no pain) to 10 (very much), sleep efficiency was measured as a percent, % time in MVPA and % time in Sedentary were measured as percent of total wear time spent in each activity category and Total Fatigue Score was measured on a scale ranging from 31-157.

Model 2: ($F_{(4, 12)}= 7.06$, $p<0.004$), with an adjusted R^2 of 0.60. Participants mental health was equal to 66.64 -2.31 (Pain Severity) -0.23 (Sleep Efficiency) +3.68 (% in MVPA) +0.1 (FISSA Total Score), where pain severity was coded on a scale from 0 (no pain) to 10 (very much), sleep efficiency was measured by percent, % in MVPA was measured as percent of total wear time in spent in moderate to vigorous activity and Total Fatigue was measured on a scale ranging from 31-157.

Model 3: ($F_{(3, 13)}= 9.50$, $p<0.001$), with an adjusted R^2 of 0.61. Participants mental health was equal to 45.00 -2.24 (Pain Severity) + 3.93 (% in MVPA) +0.11 (FISSA Total Score), where pain severity was coded on a scale from 0 (no pain) to 10 (very much), % in MVPA was measured as a percent of total wear time spent in moderate to vigorous activity and FISSA Total Score was measured on a scale ranging from 31-157.

Models of Significance

Table 12 visually presents the possible models that were found to be significant. All three significant models were similar in their R^2 and adjusted R^2; however, Model 3 was deemed to be the best fit due to the smallest difference between R^2 and adjusted R^2 values as a conservative

measure of variance explained. The R^2 and adjusted R^2 values indicate the proportion of variance in the outcome variable that is explained by the predictor variables, with the adjusted R^2 accounting for the number of predictors in the model. The predictor variables that remained in Model 3 included Total Fatigue, Pain Severity and % time in MVPA and combined explained 61% of the variance in the child-report internalizing behaviour T score.

Table 12

Significant Regression Models and Predictors of Mental Health

Dependent Variable	Model of Significance	R	R^2	Adjusted R^2	Pain Severity	Sleep Efficiency	% time in MVPA	% time in Sedentary	Fatigue Total
BASC-3 Child	1	0.85	0.73	0.60	✔	✔	✔	✔	✔
	2	0.84	0.70	0.60	✔	✔	✔	-	✔
	3	0.83	0.69	0.61*	✔	-	✔	-	✔
CDI Parent	5	0.49	0.23	0.18*	-	-	✔	-	-
MASC-2 Parent	1	0.74	0.54	0.39	✔	✔	✔	✔	✔
	2	0.74	0.54	0.41*	✔	✔	-	✔	✔
	3	0.70	0.49	0.39	✔	-	-	✔	✔
	4	0.65	0.43	0.36	✔	-	-	✔	-
	5	0.61	0.37	0.33	-	-	-	✔	-

*= Most significant regression model for the dependent mental health variable.

Note. MVPA = Moderate to Vigorous Physical Activity, BASC-3 = Behaviour Assessment System for Children, 3rd Edition, CDI = Children's Depression Inventory, MASC-2 = Multidimensional Anxiety Scale for Children, 2nd Editio

Regression 2: CDI Child

For the CDI-Child, six models were tested for the association between CDI as the dependent variable and the predictor variables above; no significant regression models were found. Based on this information, depression outcomes from child reports could not be modelled.

Regression 3: CDI Parent

Using the backward stepwise linear regression to predict depression based on parent reports from the predictor variables, one model was determined to be significant. The only predictor variable that remained in the model was % time in MVPA with an adjusted R^2 value of 0.18. The significant regression equation is as follows:

Model 5: $(F(1, 17)= 5.04, p<0.038)$, with an adjusted R^2 of 0.18. Participants' depression reported by parent report was equal to $53.61 + 3.77$ (% time in MVPA), where % time in MVPA was measured as percent of total wear time spent in moderate to vigorous physical activity. Mental health increased 3.77 points on the Parent CDI for each additional percent of time spent in MVPA.

Regression 4: MASC-2 Child

For the MASC-2 Child report, six models were tested for the relationship between MASC-2 as the dependent variable and the predictor variables, no significant regression models were found. Based on this information, anxiety outcomes from child reports could not be modelled.

Regression 5: MASC-2 Parent

Using a backward stepwise linear regression to predict parent-reported child anxiety related behaviours using the physiological predictor variables produced five significant models. Significant regression equations include:

Model 1: $(F(5, 13)= 3.10, p<0.046)$, with an R^2 of 0.54. Participants anxiety based on parental report was equal to $81.79 -1.94$ (pain severity) -1.08 (% in Sedentary) -0.35 (% time in MVPA) +

0.67 (sleep efficiency) + 0.15 (FISSA Total score), where pain severity was coded on a scale from 0 (no pain) to 10 (very much), % time in Sedentary and % time in MVPA were measured as percent of total wear time spent in each activity category, sleep efficiency was measured as a percent, and FISSA Total Score was measured on a scale ranging from 31-157.

Model 2: $(F(4, 14)= 4.16, p<0.02)$, with an R^2 of 0.54. Participants anxiety based on parental report was equal to 78.43 -1.94 (pain severity) -1.04 (% time in sedentary) +0.67 (sleep efficiency) +0.15 (FISSA Total score), where pain severity was coded on a scale from 0 (no pain) to 10 (very much), % in Sedentary was measured as a percent of total wear time spent in sedentary activity, sleep efficiency was measured by percent, and FISSA Total Score was measured on a scale ranging from 31-157.

Model 3: $(F(3, 15)= 4.90, p<0.01)$, with an R^2 of 0.49. Participants anxiety based on parental report was equal to 126.13 -2.21 (pain severity) - 0.87 (% time in sedentary) + 0.14 (FISSA Total Score), where pain severity was coded on a scale from 0 (no pain) to 10 very much), % in Sedentary was measured as a percent of total wear time spent in sedentary activity and FISSA Total Score was measured on a scale ranging from 31-157.

Model 4: $(F(2, 16)= 5.98, p<0.01)$, with an R^2 of 0.43. Participant's anxiety was based on parental report is equal to 133.86 - 1.51 (pain severity) - 0.86 (% in sedentary), where pain severity was coded on a scale from 0 (no pain) to (10 very much), % in Sedentary was measured by percent of total wear time spent in sedentary activity.

Model 5: $(F(1, 17)= 9.86, p<0.006)$, with an R^2 of 0.37. Participant's mental health was equal to 133.74 - 0.92 (% in Sedentary), where % in Sedentary was measured as a percent of total wear time spent in the sedentary activity.

Models of Significance

Table 12 visually represents the possible models that were found to be significant. All five of the five models proposed demonstrated significance, and had similar proportions of variance explained; however, Model 2 showed the best fit due to the smallest difference between R^2 and adjusted R^2 values as a conservative measure. and the highest adjusted R^2 to account for the number of predictors in the model. The predictor variables that remained in Model 2 included Pain Severity, Sleep Efficiency (%), % time in Sedentary, FISSA Total Score and explained 41% of the variance in MASC-2 scores of parent-reported child anxiety.

Power Analysis

A power analysis was conducted using the sample size of 26 participants and the BASC-3 Child regression model. The power to detect a significant model was 0.29 based on 5 predictors. The study was underpowered to predict significant models based on the sample size of 26 participants. Based on the variance explained in the regression models and the power of 0.80, a sample size of 78 would be required to be fully powered.

Chapter 4: Discussion

The principal finding of this investigation is that physiological risk factors in part, contribute to overall mental health symptoms for children with CP. Based on the significant regression models, various combinations of the physiological variables were able to predict mental health symptoms in the sample. Across all outcomes and models, pain severity was the most common predictor retained in the models, followed by % time spent in sedentary activity, FISSA total score, % time spent in MVPA and sleep efficiency respectively. Evidence from the literature suggests that these physiological risk factors and PA are highly inter-correlated, which could explain the different combinations of statistically significant predictors; however, they were not so highly correlated that they did not offer unique contributions to mental health symptoms.

Physiological Risk Factors and Physical Activity

Results from physiological risk factor data indicate that children and youth with CP experience significant fatigue, pain and sleep disturbances. Furthermore, children and youth with CP experience lower levels of PA compared to the recommended PA levels established in the Canadian Physical Activity Guidelines for Children and Youth.(Canadian Society for Exercise Physiology, 2011) Fatigue scores from this sample indicate that children and youth are experiencing fatigue throughout the day; however, mean FISSA scores were lower in this sample than reports of older youth and adults with CP.(Brunton & Bartlett, 2017; McPhee et al., 2017) The variability in fatigue scores (as assessed by the standard deviation) was significant, indicating that there are some participants experiencing more fatigue than others within the sample. Although there are no clinical cut points for the FISSA, these scores indicate that the current sample experiences mild to moderate levels of fatigue daily, based on maximum and minimum scores for the FISSA. Pain severity, duration and impact were variable within the

current sample, with some participants experiencing little pain and others experiencing moderate to high pain levels. Pain severity was most predictive across all regression models, this may indicate that although the average pain level was not considered severe, the pain experience still contributed to the experience of mental health symptoms. The pain levels reported by Brunton et al., (2016) in their sample of youth and adolescents with CP were similar (3/10 for males, 6/10 for females).(Brunton et al., 2016) Sleep efficiency scores in this sample were similar to typically developing children(Borghese et al., 2018) and contradictory to the literature that indicates that sleep disturbances are common in CP populations.(Romeo et al., 2014; van Gorp et al., 2019) Incidentally, sleep efficiency was the least predictive of all the physiological risk factors, and fell out most often from significant regression models, potentially indicating that the method of determining sleep efficiency is not accurately representing any CP-specific sleep disturbances children may experience. Physical activity in this sample was very low compared to Canadian guidelines which suggest children should limit the time they spend sedentary and engage in at least 60 minutes of MVPA per day. MVPA for this sample was one third of the recommended guidelines. Based on results from this sample, children and youth with CP spent almost 80% of their day sedentary and less than 2% in MVPA. The variability in PA scores were limited, indicating that most children in this sample are getting similar amounts of PA per week. This is in accordance with previous literature where Ryan et al., (2015) determined that children with CP spent more time in sedentary behaviour and accumulated less time spent in MVPA than their typically developing peers (Ryan et al., 2015) and potentially limited the ability to assess PA as a protective factor for experiencing mental health symptoms.

Internalizing Behaviours

Table 4 describes cut points and frequencies for the BASC-3. The mean *T* score for internalizing behaviours in this sample for the child report fell within the average clinical range, yet physiological risk factors were able to predict levels of internalizing behaviours *T* score levels. Average scores on the BASC-3 may indicate that behavioural issues or emotional irregularities may be present to a degree, and associated with physiological risk factors. Interestingly, in accordance with the wide spread of the data, standard deviations indicated that there were scores within the at-risk range for internalizing behaviours, despite the mean *T* score falling in the average range. The BASC-3 is meant to illuminate emotional disorders and

personality constructs in children and adolescents. Based on the results from the significant BASC-3 Child regression model, pain severity, FISSA total score and % time in MVPA best predicted the internalizing scores of children with CP. From the three statistically significant models, Model 3 was most representative of the general population given that its adjusted R^2 value was closest to 1, where 1 indicates that the regression predictions perfectly fit the data. However, Models 1 and 2 both had similar R^2 and adjusted R^2 values. A higher adjusted R^2 value indicates that the new term improves the model more than what would be expected by chance. The R^2 value for Model 1 suggests that 73% of the variance for child behavioural outcomes in this sample, is explained by the physiological risk factors. More interesting still, Model 1 included all of the predictor variables, compared to Model 3 which included only total fatigue, pain severity and % time in MVPA. Since Model 1 and 3 are similar in R^2 and in adjusted R^2, perhaps the predictors that fell out of the model (i.e. sleep efficiency and % time spent in sedentary activity) still contribute to overall mental health outcomes or could contribute more if outcomes were outside the average range, or with different levels of these predictor variables. In addition, there could be many factors driving this fit for the regression model. Due to a small sample size, covariates such as GMFCS level, sex and intelligence were not assessed and could have influenced the results. A study with a larger sample size could verify this association.

These findings are in line with other research where Yamaguchi et al., (2014) determined that pain variables (pain intensity and pain anxiety) made significant contributions to predicting mental health outcomes including behavioural and emotional outcomes in children with CP.(Yamaguchi et al., 2014) Persistence of psychological and emotional problems in CP are associated with attentional difficulties and social interaction problems and often persist into adulthood.(Weber et al., 2016) The chronicity of CP means that these issues will ultimately impact them for the rest of their lives. Identifying associated risk factors can mitigate these problems later in life and can provide consistent support in alleviating these modifiable symptoms.

Mood and Depression Symptoms

Table 5 describes the cut points and frequencies for the CDI for both parent and child reports. *T* scores from the CDI-Child and Parent reports were within typical levels of item endorsement expected for children of this age group. These findings do not support recent adult

literature, where people with CP have a higher risk of developing depression compared to typically developing adults (Smith et al., 2019), and that chronic pain, fatigue, and prevalence of depressive symptoms were higher in adults with CP than healthy controls.(Van Der Slot et al., 2012) However, mean age for this sample was 11.8 years (SD= 2.9), perhaps symptoms of depression become more evident and have greater impact with age, which might also explain the lack of significant regression models for the CDI-Child. In addition, based on the variability observed in individual data, some child reports fell within the "Elevated" range compared to average scores which would trigger cause for concern from the assessor. Furthermore, some individual parental reports indicated that their children were classified in the "Very Elevated" range, meaning multiple depression symptoms and functional impairment were endorsed. Research conducted in populations of adults with CP indicate higher depression levels, but little research has been conducted in the pediatric samples. Additional research around the time of transition from childhood to adulthood needs to be explored to determine when depression symptoms may be most apparent. Finally, evidence suggests that depression outcomes based on child reports could not be modelled with the predictors examined in this study. This is an interesting finding that might indicate there is a disconnect between parent and child reports, given the significant results found for the parent reports.

Parental reports of child depression were predicted by a single significant model with a single predictor, % time in MVPA accounting for only 18% of the variance. This suggests that greater than 80% of the variance associated with mood related mental health for this population is related to unknown predictors. The small amount of variance explained combined with the inability to use physiological factors to predict CDI-child T scores implies that there may be other physiological factors or predictors that are better suited at predicting CDI T scores in this population that need to be explored. In a study by Asano et al., (2020) severity of self-reported depressive symptoms were higher in children with CP compared to their typically developing peers. These symptoms were mediated by hyperactivity and peer problems.(Asano et al., 2020) Therefore, other predictors to explore in future studies may include social aspects such as peer relationships, coping strategies, meaningful participation or more positive physiological factors such as assistive technology use given that the mood-based scores fell within the typical range for this sample. Additionally, this the conflicting evidence may be due to the small sample size reported on in the current study, potentially reflecting that it was underpowered to fully represent

the contributions of the variables assessed. Based on these models and findings from other significant mental health predictor models in the current study, the most unknowns related to mental health outcomes for this sample rest within the mood/depression outcomes. Given that CDI *T* scores for both child and parental reports were within the normal range, symptoms of depression may not be evident in this sample, perhaps alluding to why physiological risk factors did not significantly contribute to the models beyond % time spent in MVPA in the parent reports. This may indicate that PA could play a small protective role, when depression-related health symptoms are not evident or not clinically significant. In children with CP, happiness and quality of life are associated with higher levels of PA.(Kwon et al., 2020) A study by Maher et al., (2016) determined that PA significantly predicted physical and social quality of life and happiness.(Maher et al., 2016) Exercise training programs have also been found to have significant positive impacts on quality of life in motor, autonomy, and cognitive domains.(Verschuren et al., 2007) Since the majority of our sample (87.5%) is ambulatory (GMFCS levels I-III), findings of protective effects of PA could be made apparent. In addition, being physically active in adolescence doubled the probability of maintaining PA in adulthood in people with CP.(Waltersson & Rodby-Bousquet, 2017) Clinicians are increasingly aware of the physical and health benefits of PA and findings from recent literature and the current study may have positive implications on well-being in children with CP. Interventions that are aimed at increasing PA from youth to adulthood are likely to see lasting positive effects, however, future research should continue to assess mood-related outcomes and account for covariates including GMFCS, intellectual capability, age and sex.

Anxiety Symptoms

Table 7 describes the cut points and frequencies for the parent and child reported MASC-2 *T* scores. The *T* scores for the MASC-2 child report were within the average range based on the MASC-2 manual criteria. Variability within the child reports do indicate that some *T* scores fell within the "Elevated" range, indicating more concerns than are typically reported. However, the mean *T* score from parental reports fell within two criteria above the average level into the slightly elevated category, and some participants fell within the "Very Elevated" range, the highest in the MASC-2 criteria, indicating many more concerns than are typically reported. There is a clear disconnect between child and parent reports for this specific measure. Baldwin et al., (2007) reported low parent-child agreement on the first edition of the MASC in their

Australian sample (Baldwin & Dadds, 2007) and similar findings were found by Wei et al., (2014), where despite good internal reliability across subscales, the MASC displayed low agreement between child and parent reports.(Wei et al., 2014) This information creates uncertainty in terms of which report is more accurate to describe the mental health of the child. It is possible that the parent report is a more accurate representation as a result of the ability to predict five significant models for the outcome, while the MASC-2 child reports were inconclusive. There could also be child-specific factors that were not measured in the current study that should be considered in future research to determine accuracy of reporting from both groups.

Based on regression results for the MASC-2 parent reports, five significant models accounted for at least 30% of the variation in scores. Model 2 had the highest adjusted R^2 value where 41% of the variance was accounted for by pain severity, sleep efficiency, % time in sedentary and total FISSA score. Model 1 had the second highest adjusted R^2 value at 0.39, where all of the physiological risk factors predicted parental reports of anxiety in children with CP. Similar to the predictive outcomes from the BASC-3, the adjusted R^2 values were similar across the models and there was not a clear model that predicts significantly more of the variance for that mental health outcome. This is important to note when examining anxiety outcomes in this population, all physiological risk factors played a significant role and may warrant intervention or monitoring in clinical practice.

Literature suggests that sleep efficiency was correlated with mental health outcomes in children with CP. A study by Romeo et al., (2014) indicates that a moderate correlation was found between the sleep total score and Child Behaviour Checklist scores.(Romeo et al., 2014) This finding aligns with this study since MASC-2 T scores from parent reports indicate slightly elevated anxiety levels. Anxiety is highly prevalent in CP and should be addressed accordingly in childhood. MASC-2 parental reports predicted five significant models for outcomes in anxiety in children with CP. It is important to keep these other models in mind when interpreting the results.

For child measures of both depression (CDI) and anxiety (MASC-2) there is a gap in the understanding of these complex outcomes. Certainly, there are other factors that can predict mental health that have not been included in this model. Perhaps, to a child, there are more important factors that may also be contributing to mental health outcomes, for example social

and emotional networks.(Majnemer et al., 2010; Shikako-Thomas et al., 2013) It is clear that factors including social participation, independence, bullying, acceptance are all important factors that can have a meaningful impact on a child's life. Whitney et al., (2019) determined that social factors including difficulty with friendships, bully victimization, and lower participation were all associated with a higher prevalence of mental health disorders in children with CP.(Whitney, Peterson, et al., 2019) Children may perceive their mental health differently than their parents, and thus the role that these other factors play may be more influential in predicting child reported mental health outcomes. This may help explain the discrepancy between the parental and child reports on the CDI and MASC-2 in this study.

Synthesis

Evidence from the literature suggests that these predictors of mental health are associated with each other. Interestingly, no multicollinearity was found. Incidence of fatigue and pain are closely related, as are sleep and fatigue, and physical activity and pain. In children with physical disabilities, high levels of fatigue are associated with inactivity.(Maher et al., 2015) Fatigue and pain are known to be strongly associated and have significant impacts in this population.(van Gorp et al., 2019) Sleep, GMFCS classification, presence of comorbidity, pain and behavioural difficulties have been shown to be inter-correlated for children with CP.(Horwood et al., 2019a, 2019b) These results mirror findings from this study where different physiological risk factors can have significant impact on children's mental health outcomes. Given that the multicollinearity assessment was within acceptable range for each of the independent variables, this infers an association between mental health and each risk factor. Furthermore, as a result of these complex relationships between physiological factors, it is difficult to determine a single physiological risk factor that significantly contributes the most to modeling mental health. Therefore, all factors may warrant continued assessment, monitoring and clinical intervention as they may be contributing, in different amounts or at different times, to the overall quality of life in children with CP. Sienko et al., (2014) reported that many of the young adults participating in their study reported depression with some attempting suicide, only a small percentage indicated they were receiving appropriate treatment.(Sienko, 2014) Assessment and treatment of these symptoms before they escalate an important clinical finding may have protective mental health benefits for children and adolescents with CP transitioning into adulthood.

Strengths and Limitations

This is the first study to systematically examine the associations between fatigue, pain, sleep disturbances, PA and mental health symptoms in children with CP. Previous literature has documented associations between risk factors, or contributions of sole risk factors on mental health outcomes, however, the results documented here are imperative to the field as they begin to unravel the complex nature of associations between risk factors as predictors of mental health outcomes. Statistical modeling determined that all physiological factors examined in the current investigation play some role in the mental health of persons with CP and that it is vital for clinicians and families to understand these factors to better understand their lives. However, there are limitations to this study that affect the implementation of the findings. Firstly, because of the cross-sectional research design, causality or directionality in association between exposures and outcomes was unable to be determined. Causation can be determined through covariation, temporal precedence and controlling for other variables and should be explored in future work. Additionally, the correlations documented in this study demonstrate value in conducting future longitudinal studies. Secondly, due to the COVID-19 pandemic, the sample size for this study was smaller than expected due to delayed recruitment and challenges associated with data collection and the study was underpowered. With a larger sample size, it is expected that more variability in the mental health outcomes and the predictor variables would contribute to increased power to model the associations presented here. Also, in part due to the remote nature of the study and other external factors, there were several missing data points across participants that resulted in an overall smaller sample size that could be used for analysis at this time point. As a result of the small sample size, the decision was made not adjust for covariates including intelligence, GMFCS level, age and sex. However, the *T* scores that were collected for the mental health measures determine how one score may compare to others of the same age and sex. In this case, we were not able to control for these covariates but by comparing to a normative sample, we were able to consider the findings at the individual level. Future research should consider these and other covariates explicitly in models of mental health outcomes. In addition, there are certainly other factors that contribute to the overall state of mental health in children with CP. Social risk factors, parental stress and burden have also been shown to be associated with adverse child mental health outcomes but were beyond the scope of this study. Not all mental health measures that were used in this study have not been validated

for use with children with CP. Only the CDI has been validated and deemed reliable for children with physical disabilities including those with CP.(de la Vega et al., 2016) However, the BASC-3 and MASC-2 have been demonstrated to be reliable and valid for children and adolescents including with disabilities including adolescents with Down Syndrome for the BASC-3 (Jacola et al., 2014) and youth with learning disabilities for the MASC-2.(Thaler et al., 2010) Additionally, recruitment and data collection for this study took place during the COVID-19 pandemic, and it should be recognized that mental health data may be elevated during this time therefore results should be interpreted with caution and confirmatory studies should be conducted in the future to validate these findings. Furthermore, the COVID-19 pandemic could have influenced PA levels due to restrictions and the inability to participate in PA at school and in the community. Finally, the majority of the data was collected the winter months in Canada which could have impacted PA rates as children are less likely to be active during these times.

Clinical Implications and Future Directions

It is anticipated that this research will aid clinicians and scientists in better understanding the course of CP and assist with educating patients, families and other healthcare providers about the potential impacts physiological factors can have on a child's mental health status. Clinicians should recognize the importance and screen for these physiological risk factors if their clients are demonstrating concerning symptoms of poor mental health. Conversely, clinicians should consider monitoring mental health or referring to a mental health specialist when presence or impact of physiological symptoms are high. Results from the current study contributes to increased transparency about the natural course of CP and highlight the need for early identification of these risk factors. Early identification can be beneficial for this population later in life by introducing helpful interventions that can mitigate morbidity long-term and particularly around the time of transition from adolescence to adulthood where self-advocacy, identification of challenges and self-management become much more important. Determining the modifiable physiological risk factors that can impact mental health and wellbeing for children with CP is the first step in optimizing their quality of life through clinical monitoring, and the development of interventions and/or preventative measures to reduce the burden associated with CP for these children and their families. Examples of modifiable risk factor interventions can include self-management programs for fatigue, pain education and education related to sleep hygiene.

Future research in this area is required to accurately distinguish causality between physiological risk factors, PA and mental health symptoms in this population. Mental health interventions are not readily accessible for children and youth with CP and have not been tailored to their specific needs. Results from this study present the opportunity and knowledge needed to design and test novel interventions specifically intended for this population to address the complex associations between known predictive physiological factors and mental health outcomes. Combining effective treatments for single physiological factors into a multi-modal intervention may be beneficial for clinicians and their families. Multi-modal interventions can be time and economically efficient while still addressing mental health concerns by reducing the contribution associated with these predictors.

Conclusion

Fatigue, pain, sleep disturbances and PA all significantly affect mental health symptoms in children with CP even if the specific outcomes are not clinically concerning. Pain severity, sleep efficiency, percentage of spent in MVPA and in sedentary activity, and fatigue were all represented in the significant regression models. This research highlights the importance of creating and evaluating mental health and physiological risk factor interventions that can optimize quality of life for children with CP. Further longitudinal research is encouraged to determine directionality between these risk factors and mental health symptoms. Finally, targeted research should be conducted at or around the transition stages of adolescence to early adulthood to monitor the time course and development of clinically significant mental health outcomes.

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Appendices

Appendix A

Ethics Approval

Western Research

Date: 30 September 2020

To: Dr. Laura Brunton

Project ID: 115678

Study Title: Anxiety and depression in youth with cerebral palsy: Role of physiological risk factors

Study Sponsor: University of Calgary

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 20/Oct/2020

Date Approval Issued: 30/Sep/2020

REB Approval Expiry Date: 30/Sep/2021

Dear Dr. Laura Brunton

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
CP Parental (Surrogate) Consent v1_COVID UWO	Written Consent/Assent	Received September 25, 2020	
DemographicQuestionnaire_CPV1	Online Survey	30/Jun/2020	
ParentSurvey_CPAndMentalHealth	Online Survey	30/Jun/2020	
DailySurvey_CPAndMentalHealth	Online Survey	30/Jun/2020	
ChildAdolescentSurvey_CPAndMen	Online Survey	30/Jun/2020	
MH in CP Research Proposal Version 1 June 23 2020	Protocol	23/Jun/2020	1.0
Actigraph instructions and logs	Online Survey	25/Feb/2020	
FamiliesFacingCOVID19_CereBRUM	Online Survey	23/Jul/2020	
Functional Mobility Scale RedCap	Online Survey	Received September 25, 2020	
GMFCS RedCap	Online Survey	Received September 25, 2020	
Cerebral Palsy Advertisement v_2	Recruitment Materials	Received September 25, 2020	
Cerebral Palsy V_3 Social Media Recruitment	Recruitment Materials	14/Sep/2020	3
CP Recruitment V_2	Recruitment Materials	Received September 25, 2020	
Assent Form v2_ COVID UWO_3-6	Assent Form	08/Sep/2020	2
Adult Participant Consent v2_COVID UWO_4	Written Consent/Assent	08/Sep/2020	2
Caregiver Consent v2_ COVID UWO_3	Written Consent/Assent	08/Sep/2020	2
CP Parental (Surrogate) Consent v2_COVID_UWO	Written Consent/Assent	08/Sep/2020	2

CP Social Media Caption	Recruitment Materials	21/Sep/2020	1.0
Email Script CP UWO_V2_	Email Script	08/Sep/2020	2
Telephone Script CP UWO_V2_	Telephone Script	08/Sep/2020	2

Documents Acknowledged:

Document Name	Document Type	Document Date
C McMorris budget-summary-chreb (4)	Study budget	01/Oct/2016

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

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

Karen Gopaul, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

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

Appendix B

Informed Consent Forms

Assent Form

<u>**TITLE:**</u>   Anxiety and Depression in Youth with Cerebral Palsy:
                         Role of Physiological Risk Factors

<u>**SPONSOR:**</u>   Hotchkiss Brain Institute (HBI)
                         3330 Hospital Dr NW
                         Calgary, AB T2N 4N1

<u>**INVESTIGATORS:**</u>   **Carly McMorris, PhD[1], Laura Brunton, PhD[2]**, Melanie Noel, PhD[1], Daniel
                         Kopola Sibley, PhD[1], Elizabeth Condliffe, PhD[1], Benjamin Fong, MSW[2],
                         Stephanie Howe[1], Mica Pabia[1], Kate Hall[1]
                         [1]University of Calgary, Werklund School of Education
                         [2] Alberta Health Services (AHS)

                    Local PI: Dr. Laura Brunton

You are being invited to be in a research study help us learn from you and your experience with cerebral palsy related to mental health, fatigue, pain and physical activity.

<u>Why are we doing this study?</u>
We would like to figure out whether the things that you feel in your body, such as how much sleep you are getting, how tired you feel during the day, and whether you feel any pain in your body, affects the way that you feel in your brain (for example your emotions and the way you think about things).

<u>What will happen during the study?</u>
If you are o.k. with participating in this study, we will mail you what you will need to do. The first things are two Actigraphs. Actigraphs are small devices that will give us information about your physical activity during the day and about how much sleep you are getting every night. You will get one to wear around your waist and one to wear around your wrist. You will wear both for 7 days and 7 nights

The second thing will be some questions that you will answer every day about how you are feeling in your body. These will ask how tired you felt, how well you slept, and how much pain you felt that day. Once you receive your Actigraph in the mail we will send you the daily surveys to fill out. These will be sent to you through email and you will be able to complete them online.

We will also email you some things to do online. Online questionnaires will ask you questions about your mood, things that you do, how well you sleep, and whether you feel any pain in your body. Your parent will be asked the same types of questions about you. We will also call you to ask you some more questions about how you feel, think, and behave. We will talk to you either on the phone or over video chat. All of this will take about 3 hours of your time.

Are there good things about the study?
Most kids like doing the activities that we will ask you to do. The things that we learn from doing this study will be used to help other kids with cerebral palsy.

Are there bad things about the study?
Sometimes kids may get bored or tired when they are doing the activities. You may ask to take a break whenever you need to. Most kids are ok with wearing the Actigraphs and it does not bother them at all but some kids may find it uncomfortable to wear the Actigraph for a long time. We will make sure that the things we mail to you are extra clean so that you don't get sick. If you really don't want to wear the Actigraph, you don't have to do that part of the study.

Who will know about what I say or do in the study?
If you are part of this study, we won't tell people outside of the research team about what you said or did or how you answered your questionnaires. We may want to write papers about what we learned from doing this study, but these papers won't include your name or information that could let people know that you were a part of this study. If we are worried about your safety, or if we think that you could use help with something that we are not able to help you with, we may ask your mom or dad if we can contact your doctor or psychologist and let them know. We will destroy any papers that we used in this study or any of your information once the study is done. We will be sending your parents a summary of how you did on the different tasks.

Can I decide if I want to be in the study?
You can decide if you want to be in the study. It is O.K. if you do not want to be part of the study. It is O.K. if you say yes now and change your mind later. Your parents know about the study and have said that you can be in it. You can ask questions any time that you want. If you decide you do not want to be in the study we will not keep any of your information.

Assent:
The study has been explained to me. I know that I can ask questions about the study at any time. I know that I can stop at any time. I have been told that all of the information collected will not be given to anyone. Your parents and the research team will only see the information collected.

If you have any questions about the information here, you can ask your mom or dad for help, or you can contact the researchers and we can help explain it to you.

If you understand everything that was explained to you here, and are ok with participating in the study, please click on the button that says, "I am ok with participating in this study"

☐ I am ok with participating in this study
☐ I do not want to participate in this study

Parental Surrogate Consent

TITLE: Anxiety and Depression in Youth with Cerebral Palsy:
Role of Physiological Risk Factors

SPONSOR: Hotchkiss Brain Institute (HBI)

INVESTIGATORS: **Carly McMorris, PhD[1], Laura Brunton, PhD[2],** Melanie Noel, PhD[1], Daniel Kopola-Sibley, PhD[1], Elizabeth Condliffe, PhD[1], Benjamin Fong, MSW[2], Stephanie Howe[1], Mica Pabia[1], Kate Hall[1]
[1]University of Calgary, Werklund School of Education
[2] Alberta Health Services (AHS)

CONSENT FORM: **Caregiver Consent for Child to Participate**

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something, please ask. Take the time to read this carefully to understand the information. You will receive a copy of this form.

BACKGROUND
Anxiety and depression are very common in kids and teens with cerebral palsy (CP), affecting about 57%. It is unknown why anxiety and depression develop and continue in this population. Importantly, existing mental health treatments haven't been adapted for kids with CP and mental health concerns. Untreated anxiety and depression in these kids and teens can lead to difficulties in many areas of life at home and at school.

WHAT IS THE PURPOSE OF THE STUDY?
The purpose of this study is to identify physical risk factors that may lead to the development of anxiety and depression in kids with CP. This will be the first study to look at the relationship between physical symptoms (pain, low energy levels, and trouble sleeping) and anxiety and depression in kids with CP. Findings from this study will help identify risk factors that we can treat, and improve the lives of this vulnerable population.

WHAT WOULD MY CHILD HAVE TO DO?
Participation involves three parts: 1) a mental health interview, 2) online questionnaires, and 3) a 7-day assessment of your child's physical health symptoms.

1. <u>Mental Health Interview:</u> we will arrange a time with you and your child where we will call you either on the phone or on video chat. We will ask your child questions about their mental health symptoms, emotions, and behaviours. We will record the interview so that we can remember your child's information correctly.

2. <u>Questionnaires:</u> We will send questionnaires to your child's (and/or your) email address for your child to complete. These questionnaires will ask about your child's mental health, physical health, pain, energy levels, and sleep.

3. Seven (7)-day assessment of physical health symptoms: Your child will receive a package with the materials they will need in the mail. We will ask your child to wear two Actigraphs at all times for 7 days and 7 nights: one on their waist, and one on their wrist. These Actigraphs are small devices that will record your child's activity. The Actigraph will give us information about your child's physical activity and how well they are sleeping. We will also ask your child to answer a few questions each day about their mood, sleep, pain, and energy levels for the 7 days, through a short (5 minute) survey that we will send to them over email at the same time each day.

WHAT ARE THE RISKS?
All the parts of this study have been reviewed and there are minimal risks involved.

- The only risk of your child completing the questionnaires is that they may become tired. For this reason, they may take breaks or stop at any time. They will be working on the questionnaires in their own time at home and will have up to two weeks to complete them. The questionnaires and the interview will take a total of about 3 hours.
- Some children (especially children with sensory sensitivities) may find wearing the Actigraphs uncomfortable. The Actigraphs should not cause any more discomfort than a regular belt or wristwatch. However, if your child finds wearing the Actigraph particularly uncomfortable, they may decline to participate in that portion of the study.
- Some questions that we ask, your child may not feel comfortable answering. That is ok, and they may skip questions that they do not want to answer.
- As we are currently experiencing a global pandemic, we have made adaptations to the study that allow us to collect information from you without any face-to-face contact. However, we will be sending a package to your home containing the Actigraph and we cannot guarantee that it is free from contamination. Our team will take extra care to sanitize these materials. If you and your child are interested in

taking part in the study, but would rather wait until risks associated with the coronavirus have lowered, please let us know. We would be happy to save your contact information and contact you at a later date. You and your child may also choose to do every part of the study, except for wearing the Actigraph if you would like.

ARE THERE ANY BENEFITS?
This study will be filling a gap in the current research by helping us find health behaviours that can be targeted with treatments that already exist. You will receive a report with information about your child's performance on the measures we collect. You may choose to share this report with support services and schools.

DOES MY CHILD HAVE TO PARTICIPATE?
Whether you would like your child to participate in this study is your decision. You can withdraw your child at any time without it affecting your relationship with your healthcare providers. If any new information comes up that might affect your choice for your child to participate in the study, we will let you know as soon as possible.

WILL MY CHILD BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?
Your family will receive a $50 gift card to compensate you for your time. You will not have to pay for anything; postage will be pre-paid.

WILL MY CHILD'S RECORDS BE KEPT PRIVATE?
We will keep any information about your child that we collect as confidential (private) as possible. We will store all information that we collect about your child in a locked filing cabinet. We will encrypt data and keep it in secured computer databases. We will use a number to identify your records rather than your name.

We will keep a master list connecting your child's name to your study ID number in a separate, secure location. We will keep your research records for at least seven years after the study has ended. We will limit access to your personal information to the researchers listed on the first page of this form. If we let other researchers use the information we have collected from this study, it will not contain your child's personal information. We will not use your child's name in any publication of the research results.

If necessary, we may give reports related to this research to the University of Calgary Conjoint Health Research Ethics Board or the Western University Health Sciences Research Ethics Board. These organizations will treat such information with strict confidentially.

If you decide to revoke this consent at any time and withdraw your child's data from the study, we will destroy your child's research data whenever possible. To revoke your consent, please speak to a member of the research team.

☐ I agree to be contacted about my child's future participation in other research studies with the understanding that I can decline at any time.

QUESTIONS/CONCERNS

If you have any further questions or want clarification regarding this research and/or your child's participation, please contact the Local Investigator, Dr. Laura Brunton.

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics.

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

CONSENT

Selecting the "I consent…" option below indicates that 1) you understand to your satisfaction the information provided to you about your child's participation in this research project, and 2) you agree for your child to participate in the research project.
In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw your child from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

☐ I consent for my child participate in this research study
☐ I do not wish for my child to participate in this research study

Adult Participant Consent

TITLE: Anxiety and Depression in Youth with Cerebral Palsy:
Role of Physiological Risk Factors

SPONSOR: Hotchkiss Brain Institute (HBI)
3330 Hospital Dr NW
Calgary, AB T2N 4N1

INVESTIGATORS: **Carly McMorris, PhD[1], Laura Brunton, PhD[2]**, Melanie Noel, PhD[1], Daniel Kopola Sibley, PhD[1], Elizabeth Condliffe, PhD[1], Benjamin Fong, MSW[2], Stephanie Howe[1], Mica Pabia[1], Kate Hall [1]
[1]University of Calgary, Werklund School of Education
[2] Alberta Health Services (AHS)

Local PI: Dr. Laura Brunton

<u>CONSENT FORM:</u>   <u>**Adult Participant** Consent to Participate</u>

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something, please ask. Take the time to read this carefully to understand the information. You will receive a copy of this form.

<u>BACKGROUND</u>

Anxiety and depression are very common in kids and teens with cerebral palsy (CP), affecting about 57%. It is unknown why anxiety and depression develop and continue in this population. Importantly, existing mental health treatments haven't been adapted for kids with CP and mental health concerns. Untreated anxiety and depression in these kids and teens can lead to difficulties in many areas of life at home and at school.

<u>WHAT IS THE PURPOSE OF THE STUDY?</u>

The purpose of this study is to identify physical risk factors that may lead to the development of anxiety and depression in kids with CP. This will be the first study to look at the relationship between physical symptoms (pain, low energy levels, and trouble sleeping) and anxiety and depression in kids with CP. Findings from this study will help identify risk factors that we can treat, and improve the lives of this vulnerable population.

<u>WHAT WOULD I HAVE TO DO?</u>

Participation involves three parts: 1) a mental health interview, 2) online questionnaires, and 3) a 7-day assessment of your physical health symptoms.

1.   <u>Mental Health Interview:</u> we will arrange a time with you where we will call you either on the phone or on video chat. We will be using the Zoom platform to complete the video chat calls. We will ask you questions about your mental health symptoms, emotions, and behaviours. We will record the interview so that we can remember your information correctly. Your parent will also be asked to answer the same questions about you separately. These video calls will be recorded for our research purposes for up to 7 years after your assessment.

2.   <u>Questionnaires:</u> We will send questionnaires to your (or your parent's) email address. These questionnaires will ask about your mental health, physical health, pain, energy levels, and sleep. We will also ask your parent to fill out some questionnaires about you.

3.   Seven (7)-day assessment of physical health symptoms: You will receive a package with the materials you will need in the mail. We will ask you to **wear two Actigraphs** at all times for 7 days and 7 nights: one on your waist, and one on your wrist. These Actigraphs are small devices that record your activity. The Actigraph will give us information about your physical

activity and how well you are sleeping. We will also ask you to answer a few questions each day about your mood, sleep, pain, and energy levels for the 7 days, through a short (5 minute) survey that we will send to your email at the same time each day.

WHAT ARE THE RISKS?

All the parts of this study have been reviewed and there are minimal risks involved.

- The only risk of you completing the questionnaires is that you may become tired. For this reason, you may stop or take breaks at any time. You will be working on the questionnaires in your own time at home and will have up to two weeks to complete them. The questionnaires and the interview will take a total of about 3 hours.
- Some participants (especially those with sensory sensitivities) may find wearing the Actigraphs uncomfortable. The Actigraphs should not cause any more discomfort than a regular belt or wristwatch. However, if you find wearing the Actigraph particularly uncomfortable, you may decline to participate in that portion of the study.
- Some questions we ask, you may not feel comfortable answering. That is ok and you may skip questions if you would like.
- As we are currently experiencing a global pandemic, we have made adaptations to the study that allow us to collect information from you without any face-to-face contact. However, we will be sending a package to your home containing the Actigraph and we cannot guarantee that it is free from contamination. Our team will take extra care to sanitize these materials. If you are interested in taking part in the study, but would rather wait until risks associated with the coronavirus have lowered, please let us know. We would be happy to save your contact information and contact you at a later date. You may also choose to do every part of the study, except for wearing the Actigraph if you would like.
- There is always the possibility of a privacy breach with online data collection; however, we will use best practices including passwords, firewalls and limiting access to your data to only essential personnel to reduce this risk.

ARE THERE ANY BENEFITS?

This study will be filling a gap in the current research by helping us find health behaviours that can be targeted with treatments that already exist**.** You will receive a report with information about your performance on the measures we collect.

DO I HAVE TO PARTICIPATE?

Whether you would like to participate in this study is your decision. You can withdraw at any time without it affecting your relationship with your healthcare providers. If any new information comes up that might affect your choice to participate, we will let you know as soon as possible.

WILL I BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Following completion of the in-person assessment, your family will receive a $50 gift card to compensate you for your time. You will not have to pay for anything; postage will be pre-paid.

WILL MY RECORDS BE KEPT PRIVATE?
We will keep any information about you that we collect as confidential (private) as possible. We will store all information that we collect about you in a locked filing cabinet. We will encrypt data and keep it in secured computer databases. We will use a number to identify your records rather than your name. The platform we use to record your questionnaires called RedCap will keep your information confidential (private).

We will keep a master list connecting your name to your study ID number in a separate, secure location. We will keep your research records for at least seven years after the study has ended. We will limit access to your personal information to the researchers listed on the first page of this form. If we let other researchers use the information we have collected from this study for related research, it will not contain your personal information. We will not use your name in any publication of the research results.

If necessary, we may give reports related to this research to the University of Calgary Conjoint Health Research Ethics Board or the Western University Health Sciences Review Ethics Board. These organizations will treat such information with strict confidentially.

We will also ask for your doctor's name which we will keep along with your file. This is in case of any mental health concerns we might have later into the study.

If you decide to revoke this consent at any time and withdraw your data from the study, we will destroy your research data whenever possible. To revoke your consent, please speak to a member of the research team.

QUESTIONS/CONCERNS

If you have any further questions or want clarification regarding this research and/or your participation, please contact the Local Investigator, Dr. Laura Brunton.

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics.

CONSENT

Selecting the "I consent…" option below indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

☐   I consent to participate in this research study
☐   I do not wish to participate in this research study

Caregiver Consent

TITLE: Anxiety and Depression in Youth with Cerebral Palsy:
                Role of Physiological Risk Factors

SPONSOR: Hotchkiss Brain Institute (HBI)
                3330 Hospital Dr NW
                Calgary, AB T2N 4N1

INVESTIGATORS: **Carly McMorris, PhD[1], Laura Brunton, PhD[2]**, Melanie Noel, PhD[1], Daniel Kopola-Sibley, PhD[1], Elizabeth Condliffe, PhD[1], Benjamin Fong, MSW[2], Stephanie Howe[1], Mica Pabia[1], Kate Hall[1]
                [1]University of Calgary, Werklund School of Education
                [2] Alberta Health Services (AHS)

                Local PI: Dr. Laura Brunton

CONSENT FORM: **Caregiver Consent to Participate**

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something, please ask. Take the time to read this carefully to understand the information. You will receive a copy of this form.

BACKGROUND
Anxiety and depression are very common in kids and teens with cerebral palsy (CP), affecting about 57%. It is unknown why anxiety and depression develop and continue in this population. Importantly, existing mental health treatments haven't been adapted for kids with CP and mental health concerns. Untreated anxiety and depression in these kids and teens can lead to difficulties in many areas of life at home and at school.

WHAT IS THE PURPOSE OF THE STUDY?
The purpose of this study is to identify physical risk factors that may lead to the development of anxiety and depression in kids with CP. This will be the first study to look at the relationship between physical symptoms (pain, low energy levels, and trouble sleeping) and anxiety and

depression in kids with CP. Findings from this study will help identify risk factors that we can treat, and improve the lives of this vulnerable population.

WHAT WOULD I HAVE TO DO?
Participation involves two parts: three parts: 1) a mental health interview, 2) online questionnaires, and 3) a 7-day assessment of your child's physical health symptoms.

1.   Mental Health Interview: We will arrange a time with you where we will call you either on the phone or on video chat. Our video chat calls will be held over Zoom. We will ask you questions about your child's mental health symptoms, emotions, and behaviours. We will record the interview so that we can remember the information correctly.P

2.   Questionnaires: We will send questionnaires to your email address. These questionnaires will ask about your child's mental health symptoms and what kinds of services they have received. Additionally, we will ask you to complete several questionnaires about yourself. This will include questions about your family's income, how many people are in your family, your education and employment, your own mental health and your parenting style.

3.   Seven (7)-day assessment of physical health symptoms: Your family will receive a package with the materials they will need in the mail. We will ask your child to wear two Actigraphs at all times for 7 days and 7 nights: one on their waist, and one on their wrist. These Actigraphs are small devices that will record your child's activity. The Actigraph will give us information about your child's physical activity and how well they are sleeping. We will also ask your child to answer a few questions each day about their mood, sleep, pain, and energy levels for the 7 days, through a short (5 minute) survey that we will send to them over email at the same time each day.

WHAT ARE THE RISKS?
All the parts of this study have been reviewed and there are minimal risks involved.
- The only risk of completing the questionnaire assessments is that you may become tired. For this or any other reason, you may stop at any time. You will be working on the questionnaires in your own time at home and will have up to two weeks to complete them. The questionnaires and the interview will take a total of about 3 hours.
- Some of the questionnaires may reveal issues about your child that you were not worried about before. If that is the case, the records will be reviewed by Dr. McMorris, who will discuss with you about how to follow-up.
- As we are currently facing a global pandemic, we have made adaptations to the study that allow us to collect information from you without any face-to-face contact. However, we will be sending a package to your home containing the Actigraph and we cannot guarantee that it is free from contamination. Our team will take extra care to sanitize these materials. If you and your child are interested in taking part in the study, but would rather wait until risks associated with the coronavirus have lowered, please let us know. We would be happy to save your contact information and contact you at a

later date. You and your child may also choose to do every part of the study, except for wearing the Actigraph if you would like.

• There is always the possibility of a privacy breach with online data collection; however, we will use best practices including passwords, firewalls and limiting access to your data to only essential personnel to reduce this risk. In addition, the platform used to collect the questionnaire data, RedCap, ensures confidentiality and privacy of your and your child's results.

ARE THERE ANY BENEFITS?

This study will be filling a gap in the current research by helping us find health behaviours that can be targeted with treatments that already exist. You will receive a report with information about your child's performance on the measures we collect. You may choose to share this report with support services and schools.

DO I HAVE TO PARTICIPATE?

Whether you would like to participate in this study is your decision. You can withdraw at any time without it affecting your relationship with your healthcare providers. If any new information comes up that might affect your choice to participate, we will let you know as soon as possible.

WILL I BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

Your family will receive a $50 gift card to compensate you for your time. You will not have to pay for anything; postage will be pre-paid.

WILL MY RECORDS BE KEPT PRIVATE?

We will keep any information about you that we collect as confidential (private) as possible. We will store all information that we collect about you in a locked filing cabinet. This cabinet will be in the CHEaR Lab at Western University. We will encrypt data and keep it in secured computer databases. We will use a number to identify your records rather than your name.

We will keep a master list connecting your name to your study ID number in a separate, secure location. We will keep your research records for at least five years after the study has ended. We will limit access to your personal information to the researchers listed on the first page of this form. If we let other researchers use the information we have collected from this study for related research, it will not contain your personal information. We will not use your name in any publication of the research results.

If necessary, we may give reports related to this research to the University of Calgary Conjoint Health Research Ethics Board or the Western University Health Sciences Research Ethics Board. These organizations will treat such information with strict confidentially.

We will also ask for the contact information of your child's physician. This is in case of any concerns our team may come across during your child's assessment. You will be notified if we choose to contact them.

If you decide to revoke this consent at any time and withdraw your data from the study, we will destroy your research data whenever possible. To revoke your consent, please speak to a member of the research team.

QUESTIONS/CONCERNS

If you have any further questions or want clarification regarding this research and/or your participation, please contact the Local Investigator, Dr. Laura Brunton.

If you have any questions about your rights as a research participant or the conduct of the study, you may contact The Office of Research Ethics.

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

CONSENT

Selecting the "I consent…" option below indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.
In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

☐   I consent to participate in this research study
☐   I do not wish to participate in this research study

Appendix C

Fatigue Impact and Severity Self- Assessment (FISSA)

Fatigue Impact and Severity Self-Assessment (FISSA)

Please answer the following questions about your experience with fatigue. For the purposes of this questionnaire we would like you to think about fatigue in terms of:
- · physical tiredness
- · muscle soreness
- · exhaustion of your muscles and body
- · or any related feeling

When answering the questions, please try to focus on fatigue as it is defined above and not pain you may experience that is different from muscle soreness.

Impact Scale

Completely Disagree 1	Somewhat Disagree 2	Neither Agree nor Disagree 3	Somewhat Agree 4	Completely Agree 5

Using the scale above and thinking about **a <u>typical</u> week** (7 days), to what extent do you agree with the following statements?

Fatigue interferes with …

1. my general everyday activities	1	2	3	4	5
2. my ability to move around indoors	1	2	3	4	5
3. my ability to do things on my own	1	2	3	4	5
4. my ability to move around in my community	1	2	3	4	5
5. my ability to get outside of my house	1	2	3	4	5
6. my ability to finish things	1	2	3	4	5
7. my participation in social activities	1	2	3	4	5
8. my ability to start things	1	2	3	4	5
9. my ability to take care of myself (examples: dressing, eating, bathing, brushing my teeth/hair, toileting etc.)	1	2	3	4	5

In addition,

10. I use adaptive equipment to manage my fatigue (examples: a walker, manual wheelchair, power wheelchair etc.)	1	2	3	4	5
11. I have had to reduce my work responsibilities outside of my home because of fatigue (examples: school work, job-related work, volunteering etc.)	1	2	3	4	5
12. I have had to reduce my responsibilities at home because of fatigue	1	2	3	4	5

!

Using the scale given with each question, please think about the <u>last</u> **seven (7) days** and answer the following statements or questions.

13. Rate your level of fatigue on the day within the last week that you felt the **<u>most</u>** fatigued:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

14. Rate your level of fatigue on the day within the last week that you felt the **<u>least</u>** fatigued:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

15. Rate your **average** level of fatigue for the past week:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5

16. On average, how much of the day do you feel fatigued?

None	A Quarter of the Day	Half the Day	Three Quarters of the Day	All Day
1	2	3	4	5

17. For how many days <u>last week</u> did you feel fatigued at least part of the day?

1	2	3	4	5	6	7

!

Management and Activity Modification Scale
Using the scale below and thinking about a **typical** **week** (7 days), to what extent do you agree with the following statements?

Completely Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Completely Agree
1	2	3	4	5

!

Fatigue interferes with …

18. my enjoyment of life	1	2	3	4	5
19. my leisure and recreational activities	1	2	3	4	5
20. the length of time I can be physically active	1	2	3	4	5
21. my balance and coordination	1	2	3	4	5
22. my motivation to do physical activities	1	2	3	4	5
23. my motivation to participate in social activities	1	2	3	4	5

!

In addition,
!

24. my muscles ache when I am fatigued	1	2	3	4	5
25. long periods of inactivity increase my fatigue	1	2	3	4	5
26. stress increases my fatigue	1	2	3	4	5
27. fatigue increases my stress	1	2	3	4	5
28. I pace my physical activities to manage my fatigue	1	2	3	4	5
29. I think about fatigue when I plan my day	1	2	3	4	5
30. I limit my physical activity to manage my fatigue	1	2	3	4	5
31. I stop and rest during activity to manage my fatigue	1	2	3	4	5

!

Additional Questions:

32. Does your level of fatigue change depending on the time of day?

        Yes   (If yes, please answer question 32b)   No

32b. What time of day is your fatigue the worst?

Early Morning	Mid-morning	Noon	Late afternoon	Evening
1	2	3	4	5

33. Does your level of fatigue change depending on the day of the week?

        Yes   (If yes, please answer question 33b)   No

33b. On which day of the week are you most fatigued?

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1	2	3	4	5	6	7

34. What factors are responsible for or contribute to your fatigue?

35. What do you do to reduce or manage your fatigue?

36. What else could you do to reduce or manage your fatigue?

37. What could other people do to help reduce your fatigue?
!

Appendix D

Youth Pain Questionnaire CALI-9

Daily Survey

Please complete the survey below.

Thank you!

1) Email _____

2) How much pain did you experience today?

Worst Possible
No Pain   Pain

(Place a mark on the scale above)

3) How much did pain interfere with your day?

Pain interfered
with all
Not at all   activities

(Place a mark on the scale above)

4) How much fatigue did you experience today?

Worst Possible
No Fatigue   Fatigue

(Place a mark on the scale above)

5) How much did fatigue interfere with your day today?

Fatigue
interfered with
Not at all   all activities

(Place a mark on the scale above)

6) How would you rate your sleep last night?

Best Sleep   Worst Sleep
Possible   Possible

(Place a mark on the scale above)

7) What time did you go to sleep last night? _____

8) What time did you wake up this morning? _____

Appendix E

Actigraphy Instructions and Logs

Thank you for participating in this research study!

Your participation will help us understand how pain and sleep impact the mental health of kids with cerebral palsy.

The first thing that you will need to do as part of this study is put on your Actigraphs. When you receive your Actigraphs, they will already be charged, turned on, and ready to go.

There will be two Actigraphs in your package.

One of the Actigraphs will be in a pouch on a belt. This Actigraph will go **around your waist**. It will also already be placed in a pouch the right side up. Please do not remove the Actigraph from its pouch. This Actigraph should be worn close to the hip of your dominant leg.

The other Actigraph will be on a wristband and will look kind of like a wristwatch. This Actigraph is also already on and there is nothing you need to do other than to put it **on your wrist**. It should be worn on the wrist of your dominant hand (your dominant hand is the hand that you would write with).

You will be wearing your Actigraphs for 7 days and 7 nights, only removing them to bathe/shower or go swimming. Please take care not to get the Actigraphs wet. Take care not to damage or lose your Actigraphs.

For more instructions about how to wear the Actigraphs, **please watch this video created by our research team:**

https://www.dropbox.com/s/nm9lx6yyuwk0cie/ActigraphVideo.mp4?dl=0

You can choose to wear your Actigraphs under your clothes or over your clothes but it's important that you wear your Actigraphs close to your body. Please don't wear them over top of bulky clothing like large jackets or sweaters. If you are lying down and your Actigraph becomes uncomfortable, you may move it temporarily to the other side or the centre of your stomach.

Every day you will receive an email that will remind you to answer some questions for us about the amount of sleep you had and the amount of pain you had that day**. Every day, you will also need to fill out 2 different log sheets**. One sheet is to tell us what time you woke up and what time you went to sleep each day. The other sheet is to tell us about any times that you removed your Actigraphs over the 7 days. It is very important that you remember to fill out these sheets, otherwise we won't be able to use your data.

When the 7 days are over, **take off the Actigraphs** and place them in the **return postage paid envelope** we have sent along with your **log sheets**, seal it and mail it back to the study team.

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Alberta Health Services

MONITOR LOG

Wear the Actigraphs for seven (7) days in a row. In the table below, write down the date and the times, including "a.m." or "p.m.", that you put it on and take it off during the day. Also note the reason you took it off. The Actigraph should only be removed for bathing/showering or swimming. Below is a sample entry:

Date	Day	Actigraph (wrist, waist, or both)	Time Off	Time On	Reason
July 15, 2015	Wednesday	Both	7:30 a.m.	8:30 a.m.	swimming
Monitor Off (complete):					
Date	Day	Time Off			

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Alberta Health Services

SLEEP LOG

Wear the Actigraph when you sleep. Please indicate in the columns below what time you woke up in the morning and what time you went to bed including "a.m." or "p.m.". If you did not take a nap, you can put "0" for how many times did you nap today". Below is a sample entry:

Day:	*Example:* Monday	Day 1:	Day 2:	Day 3:	Day 4:	Day 5:	Day 6:	Day 7:
Date:	May 27/19							
Wake time:	6:30 a.m.							
How many times did you nap today?	2							
Bed time:	8:30 p.m.							
How many times did you wake during the night?	0							

OFFICE USE ONLY	
Start Date and Time: _____	Participant ID: _____
Actigraph ID: _____	Valid days: _____
Monitor Off (complete):	
Finish Date: _____	Time Off: _____

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Standard Operating Procedure (SOP) for Actigraph GT3X+ Accelerometer

All ActiGraph activity monitors are designed to monitor human activity and record energy expenditure (calories spent during normal activity, METs, everyday activity, and exercise). Additionally, these devices can also function as a very accurate sleep assessment tool. While collecting day-to-day energy expenditure data, the device should be affixed securely to the body's center-of-mass to ensure the most accurate caloric measurements.

The GT3X+ based activity monitors provide objective measurements of human activity and are used in many research and clinical applications. They include both a micro-electro-mechanical system (MEMS) based accelerometer and an ambient light sensor.

Contents:

- *Initializing a monitor*
- *Downloading data*
- *Wear Time Validation*
- *Scoring and Exporting*
- *Graphing*

Review Update: September 2015
Author: Clodagh Toomey
Version: 1.0
Logistics/Instructions for participants
This section contains the information you need to give to the participant and tips to improve compliance.

i. Tracking Actigraphs

- A sticker should be placed on the back of each monitor to identify the monitor code e.g. AG01 in addition to lab contact details in the case where the monitor has been lost.
- A second small sticker should be place on top of the actigraph beside the USB cap to highlight how the monitor should be worn
- Monitors should be logged in and out via an excel database with the following variables:
    - Monitor Code
    - Serial number

- o Participant ID
- o Date initialized/activated
- o Stop time
- o Researcher
- o Monitor returned
- o Monitor log complete
- o Date/time removed (self-report)
- o Battery life
- o Notes

ii. *Pre-data collection*

- To achieve a minimum of 5 valid days of data collection, the participant is asked to wear the monitor for 7 full consecutive days if possible (a valid day is defined as 10 valid hours)
- The participant will complete a monitor log to fill in a start and end wear time and any period of time where the device is removed for more than 5 minutes (see **Appendix A**). This will be an important cross check for validating wear time.
- Participants are instructed on how to wear the monitor while shown the instructions for wear sheet (see **Appendix B**)
  - o The ActiGraph will be given to the participant already threaded onto the elastic belt. Participants should be instructed to wear the ActiGraph with the blue sticker facing up, the elastic belt fastened around the waist and the monitor positioned over the right hip bone.
  - o The ActiGraph can be worn either over or under clothing, whichever is most comfortable to the participant. The meter does not need to be in direct contact with the body. However, it is essential that the ActiGraph be positioned snugly enough against the body that it cannot flop around.
  - o Participants will be instructed to wear the unit all day and night. Some slight re-positioning of the device is allowable if the participant has trouble sleeping e.g. if they sleep on their right side, they may slightly reposition to the front
  - o The only times they should remove the monitor are if the monitor would become completely wet (e.g. swimming, showering). These times should be logged.
  - o Show participants an example report of the output
  - o Organize a pick-up time and location for returning the device. If collection or drop-off is not possible, give a stamped, addressed and padded envelope for return mail.

- Some useful examples of what to tell the participant:
  - *"We would like you to wear a movement monitor for 7 days. It is similar to a pedometer, except it measures general movement."*
  - *"To the best of your ability, go about your usual days -- don't do anything different."*
  - *"Leave next to your clothes to remind you to put it back on after showering"*
  - *"It runs on a watch battery and isn't a tracking device. It can't tell what type of activity you are doing or where you are."*
  - *"It's really small, I've worn it myself and after a little while I forgot I was even wearing it."*

iii.   *Post-data collection*

- Thank the participant for completing the research and let them know they will receive their physical activity report via email
- Log the return date into the master database
- Wash the waist band after each use by hand (warm soapy water) or cold cycle. Drip dry
- Download the data and charge for next use. Ensure stickers are intact.

Using Actilife Software

i.   *Initializing a monitor*

This section contains information on how to set up the monitor to begin recording data. For an online tutorial, click [here](#)

1. Open Actilife software. Download the latest version of software if you are prompted to do so. Always work under the latest version to ensure compatibility between computers when using the datavault.
2. Open the actigraph USB cap using the key provided and plug in using USB cable. The monitor should appear under devices. Ensure the battery level is at least 3.85V (>80%) or initialization will not be allowed.
3. Select the check box for the device and click on "Initialize – Regular Initialization" in the toolbar.
4. Select your initialization parameters. First input the recording time by selecting a start time and date and a stop time and date. For a 7 day data collection period, it is recommended to set the device to record 8 or 9 days to allow time to make up for periods of non-wear.
5. Set Sample Rate to 30Hz. Under LED options and wireless options, nothing is selected. Idle sleep mode is set to disabled.

6. Enter subject info including participant ID, sex, height weight, DOB and race. 'Limb' is set to waist and 'Side' is set to right.
7. Select 'Initialize 1 device'
8. Check that initialization is complete under 'status' and check recording parameters again under devices before plugging out. You can hover over icons under "mode" to determine if the features you need are activated.
9. Safely remove device, plug out and close cap firmly

ii. *Downloading data*

This section contains information on how to download the data to your computer after the participant has worn the actigraph. See online tutorial here
1. Open Actilife software
2. Open the actigraph and plug in using the USB cable. The monitor should be recognized and appear under devices. Confirm that the device contains data for this wear period
3. Click the download option in the toolbar and a new window will open
4. Download naming convention should be set to <Subject Name><Start Date>
5. For Download Options, ensure 'Create AGD File' is checked Epoch length should be set to 10 seconds and # of Axis should be set to 3. Ensure boxes for 'Steps', 'Lux', 'Inclinometer' and 'Low Frequency Extension' are also checked. You can also edit any participant information here under 'Add biometric and user information' here.
6. Select 'Download All Devices'
7. The progress bar in the main window will show you when the download is complete. Under 'Status' should read 'finished downloading'
8. Click the 'finished downloading' hyperlink and select 'Export GT3X file'. A new window will open. Ensure 'Create AGD', 'Create CSV', 'Create DAT' and 'Low Frequency Extension' are selected. Then click in 'Export RAW Files'
9. These files will save to Actigraph>Actilife>Downloads in your Documents folder

iii. *Wear Time Validation*

The next step in the analysis process is to set the appropriate wear time for the downloaded data. This is done using a combination of wear period algorithms and using the monitor log provided by the participant.
1. Click on the Wear Time Validation tab
2. 'Define a Non-Wear Period' should be set to Choi (2011). Minimum Length (90 minutes), Small Window Length (30 minutes) and Spike Tolerance (2 minutes). Select 'Use Vector Magnitude'
3. For 'Optimal Screen Parameters', nothing is selected

4. Uncheck all Data Sets and check the one(s) you wish to analyze. If it is not there, click on 'Add Dataset' and find the AGD file in the downloads folder

5. Hit Calculate and a new window will open

6. At the end of the window, under 'All Periods' contains a list of Wear and Non-Wear periods as calculated using the Choi algorithm. You will need to cross-check these periods with the monitor log provided by the participant. Normally, shower periods are not recognized if the monitor is off for periods shorter than 90 minutes. Also, a very inactive period (often evening time or during sleep) can be detected in error as a Non-Wear period.

7. Go to the first Non-Wear period. If the participant has not recorded this date and time as a Non-Wear period, click on 'Set As Wear' if appropriate. Scroll down and continue this process for all Wear and Non-Wear periods. Use best judgement call to change between 'Wear' and 'Non-Wear' as appropriate. Also note beginning and end of wear period provided by the participant as the device may continue recording past this time depending on set-up.

8. Click on 'Save' and select the next dataset or click on 'Save and Close'

iv. *Scoring and Exporting*

We now wish to analyze the selected data period and select appropriate algorithms to apply cut-offs for calculation of energy expenditure, METs and exercise intensity. Recommendations are provided below but can be altered depending on the population in question. See https://help.theactigraph.com/entries/21452826 for more details.

1. Click on the 'Scoring' tab

2. On the left, under Algorithms, ensure the following boxes are checked:
   - Energy Expenditure
   - METs
   - Cut Points and MVPA
   - Bouts
   - Sedentary Analysis

3. The following algorithms are recommended for use for an adult population:
   - Energy Expenditure – Freedson VM3 (2011)
   - METs – Freedson Adult (1998)
   - Cut Points and MVPA – Troiano Adult (2008)

4. The following algorithms are recommended for use for a pediatric population:
   - Energy Expenditure – Freedson VM3 (2011)
   - METs – Freedson (2005)
   - Cut Points and MVPA – Evenson Children (2008)

5. Under Filters, check 'Exclude Non-Wear Times from Analysis'

6. Select your required dataset from list or go to 'Add Dataset'
7. Click on 'Calculate'
8. Click on 'Export' in right bottom corner
9. Select required excel files for analysis and hit export. Name your file. It is better to do an export in bulk, selecting numerous datasets so they will all be contained in one excel file
10. One Summary file and one data file with numerous tabs will be saved under CSVFiles in your Actilife folder

Creating a report
1. The type of report you want to create will be based on the research study in question. An example report form is in **Appendix C**.
2. To create the graph, a screen grab is taken from the 'Graphing' tab in Actilife software for the relevant days. Use the clipping tool in Windows software. Ensure the checked box for 'Equal Activity Scales' is selected and set in the region 1500-3000 counts, dependent on the activity level for the individual.
3. Create a table in excel to include date, day, wear time (hrs), activity kcals, average kcals/hr, steps and sedentary, light, moderate and vigorous time presents as mins and %. Calculate total and average values. You can also choose to graph these values in a pie chart a % of total time
4. To allow the participant to interpret these values, show how they compare to Canadian physical activity guidelines and refer to the Canadian Society for Exercise Physiology website

Additional Information
This section contains additional useful information on specification and functionality of the Actigraph device. This information and more is available by accessing the Actigraph GT3X manual.
Steps: Step counts are accumulated on a per-epoch basis and are based on accelerometer data collected on the vertical axis. An algorithm present in the device firmware filters out the accelerometer's baseline noise level to help accurately accumulate the steps-per-epoch.
Inclinometer : The post-processed inclinometer feature helps users identify the orientation of the device and, more importantly, when the device itself was taken off. Each epoch is flagged with a number (1 through 4) to indicate the orientation of the device during that epoch. Important: The inclinometer feature is only valid if the device is worn on the hip with Axis 1 upward facing.

Interpretation of Inclinometer Code (Stored with each Epoch)
0 Device Off (Not Being Worn)
1 Subject Standing
2 Subject Lying Horizontal

3 Subject Sitting

Low Frequency Extension: The Low Frequency Extension (LFE) option, though not a mode or channel, is another data collection option during post-processing for the GT3X+ and wGT3X+. The standard proprietary filter algorithm used in ActiGraph products is used to eliminate any acceleration noise outside of the normal human activity frequency bandwidth. This filter is customized to work with ActiGraph's Energy Expenditure Algorithms. The LFE option, when enabled, increases sensitivity to very low amplitude activities allowing for the study of population groups who move slowly or take very light steps (for example, the elderly). For more details, contact ActiGraph at support@theactigraph.com.

Data Collection: Initialize time options/selections have been reduced significantly due to the new data collection method used by the GT3X+ and beyond devices. During initialization, the user is now only required to select the desired raw data sample frequency (30Hz up to 100Hz in 10Hz increments). Data is automatically collected from all on-board sensors in raw data format. The data recorded includes:

Vertical Axis Activity Acceleration Data (Axis 1)
Horizontal Axis Activity Acceleration Data (Axis 2)
Perpendicular Axis Activity Acceleration Data (Axis 3)
Ambient Light (Lux)

Unlike previous ActiGraph products, the wGT3X+ and wActiSleep+ do not filter or accumulate data into epochs. Raw data is collected at the selected sample rate and is post-processed in the ActiLife. Because these devices collect data from all sensors at all times, users can generate native ActiLife *.agd files containing any desired combination of parametric data at a later time. This helps facilitate backward compatibility and enhances the flexibility of the data by allowing users to compare data to studies which use different filter techniques or accumulation sizes (e.g., 1 second epochs versus 60 second epochs).

Water Resistance: The wGT3X+ and wActiSleep+ are water resistant in accordance with IEC 60529 IPX7, or immersion in one (1) meter of water for up to 30 minutes

Battery: All ActiGraph devices use a lithium ion rechargeable battery that has a maximum voltage of approximately 4.20 volts. At 3.1 volts the devices enter a low voltage mode state (HALT mode).

Low Voltage Mode (HALT): ActiGraph devices enter a "Low Voltage Mode" (or HALT) state when the battery discharges beyond a point of being able to power the device. In this mode, all important variables and data are stored in flash memory to secure the device download. Because the device's internal clock stops in HALT mode, the device cannot be recharged and redeployed; the device must be downloaded and reinitialized to continue use.

Recharging and LED Decoding: Recharging is automatic and is accomplished by connecting the device to a standard USB port. Charging time will depend on the battery life, but typically will not exceed four hours for a fully depleted battery to become fully charged. Once the battery is

completely charged, the green LED will remain illuminated. If the battery voltage drops below 3.1 volts while in use, the device will not have sufficient power to collect data and will warn the user through a series of coded flashes. The battery level, reported in volts, can be viewed at any time by starting the ActiLife software and plugging in the device.

Appendix F

Curriculum Vitae

Daniela Testani

EDUCATION

MSc. Health and Rehabilitation Sciences   2019-Present
Western University
London, Ontario

Thesis: *Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy*
Supervisor: *Dr. Laura Brunton*
-Expected Graduation- August 2021

HBSc. Human Biology and Italian Studies   2015-2019
University of Toronto
Toronto, Ontario

RESEARCH EXPERIENCE

Graduate Student
Health and Rehabilitation Sciences, CHEaR Lab
Western University
2019-2021

> **Responsibilities:**
> Conducting research for thesis project. Using software's including SPSS and ActiLife to complete thesis. Assisting in recruitment methods for the purpose of thesis. Assisting Dr. Laura Brunton in other projects within the CHEaR Research Lab and inter-lab research. Roles included conducting literature searches used for scoping and systematic reviews, extracting data from review papers.

Undergraduate Research Summer Student
Mood Disorders Pharmacology Unit, Toronto Western Hospital
University of Toronto
2018

> **Responsibilities:**
> Conducting searches of the literature and writing a narrative literature review for the purpose of publication. Assisting students in writing and literature searches. Providing customer service to incoming patients.

PROFESSIONAL EXPERIENCE

Graduate Teaching Assistant
Interprofessional Education and Practice (IPE 9802)
Health and Rehabilitation Sciences, Occupational Therapy
Western University
2020-2021

Responsibilities:
Facilitating discussions for interdisciplinary journal clubs and laboratory meetings. Preparing and contributing to laboratory lesson plans and aiding in instructing course material. Grading and providing substantial feedback for minor and major assignments. Providing support for students regarding course material.

Graduate Teaching Assistant
Introduction to Health Ethics (HS2610G)
School of Health Studies, Faculty of Health Sciences, University of Western Ontario
2019-2020

Responsibilities:
Proctoring examinations and final evaluations. Grading and providing substantial feedback on major assignments and essays. Providing support for students regarding course material.

WORK EXPERIENCE

Location Coordinator
City of Toronto
2018-2019

Facility in Charge
City of Toronto
2016-2019

Speciality Sports and Arts Camp Counsellor
City of Toronto
2013-2018

Publications and Papers in Progress

Published

Furtado, R., Marmura,H., Joshi,I.,Nugent,K.,Straatman,L., Schroeder., Testani,D., Rosa,A, Jin,J., Klubowicz, D. and Jovanovic,N. (2021). Health and Rehabilitation Sciences Graduate Student Society Operations Manual. Online Resource

Hamer, J. A., Testani, D., Mansur, R. B., Lee, Y., Subramaniapillai, M., & McIntyre, R. S. (2019). Brain insulin resistance: A treatment target for cognitive impairment and anhedonia in depression. Experimental Neurology. https://doi.org/10.1016/j.expneurol.2019.01.016

CONFERENCES AND PRESENTATIONS

Oral Presentations

Testani, D., Brunton L (May, 2021). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Oral presentation presented at the Arthur Labatt Family School of Nursing Legacy Research Conference, London, Canada.

Testani, D., Brunton L (May, 2021).). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Oral presentation accepted at the Child Health Symposium, London, Canada.

Testani, D., Brunton L (February, 2021). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Oral presentation presented at the Health and Rehabilitation Sciences Graduate Research Conference, London, Canada.

Testani, D., Brunton L (May, 2020). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Oral presentation accepted at the Arthur Labatt Family School of Nursing Legacy Research Conference, London, Canada.

Testani, D., Brunton, L (February 2020) Investigating Physiological Determinants of Mental Health in children with Cerebral Palsy. Competitive oral presentation presented at the 3 Minute Thesis Competition, London, Canada

Testani, D., Brunton L (February, 2020). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Oral presentation presented at the Health and Rehabilitation Sciences Graduate Research Conference, London, Canada

Poster Presentations

Testani, D., Brunton, L (May, 2021). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Poster presented at the London Health Research Day, Schulich School of Medicine, London, Canada

Testani, D., Brunton, L (April, 2021). Investigating Physiological Determinants of Mental Health in Children with Cerebral Palsy. Poster presented at the 5th Annual Parkwood Research Institute Research Day, London, Canada

Conference Positions

Co-Chair
Health and Rehabilitation Sciences Graduate Research Conference
Western University
2020-2021

Responsibilities:
Responsible for facilitating and organizing the annual Health and Rehabilitation Sciences Graduate Research Conference. Acted in the primary leadership role in executing the first virtual conference for Health and Rehabilitation Science Students. Lead in conceptualizing virtual conference, contacting and interacting with speakers, faculty, presenters, collecting abstract submission and providing feedback, organizing sponsorship, delegating roles to committee members.

Abstract Reviewer
Health and Rehabilitation Sciences Graduate Research Conference
Western University
2020-2021

Responsibilities:
Grading and providing constructive feedback for presenter abstracts. Delegating abstract reviewer teams and ensuring feedback was well received and integrated for re-submission.

EXTRACURRICULAR AND COMMUNITY SERVICES

Internal Extracurricular Services

Academic Vice President
Health and Rehabilitation Sciences Graduate Student Society
University of Western Ontario
2020-2021

Responsibilities:
Responsible for facilitating and organizing major, academically oriented events and initiatives, including research days, conferences, forums, and symposia. Provide a leadership role with each of these major initiatives and act as a primary liaison to faculty members that are involved in said initiatives. Responsible for creating and executing for the annual Health and Rehabilitation Sciences Graduate Research Conference.

Canadian Child Health Clinician Scientist Program Student (CCHCSP)
Western University
2019-2021

Responsibilities:
The CCHCSP provides support for these highly qualified child health clinician candidates to develop their requisite knowledge and skills for a career as an independent

scientist in child health research. Trainees engage in research training and a core curriculum that delivers a common multidisciplinary language of research, while imparting professional skills and values. Attended monthly meetings and participated in discussion

External Extracurricular Services

President
Italian Undergraduate Student Cultural Association
University of St. Michael's College, University of Toronto
2018-2019

BIRT/SODR Therapeutic Recreation Volunteer
Holland Bloorview Kids Rehabilitation Hospital
2018-2019

Undergraduate Representative
Italian Studies Department
University of St. Michael's College, University of Toronto
2018-2019

Commuter Don Executive
University of St. Michael's College, University of Toronto
2017-2019

CERTIFICATIONS

- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE)
- Patient-Oriented Research Curriculum In Child Health (PORCCH) Completion of Modules, University of Western Ontario
- Workplace Hazardous Materials Information System (WHIMIS)
- Standard First Aid: CPR-C + AED, Canadian Red Cross
- High Five Principles of Health Child Development
- Coach for the Coaching Association of Canada (NCCP)