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Characterizing Sleep Patterns in Youth with CP and its Impact on Mood

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UNIVERSITY OF CALGARY

Characterizing Sleep Patterns in Youth with CP and its Impact on Mood

by

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A THESIS

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Abstract

Background. Cerebral palsy (CP) is a lifelong neurodevelopmental condition characterized by limitations in movement and posture (Oskoui et al., 2013; Rosenbaum et al., 2007). There is a growing consensus that sleep difficulties are common and life-long in individuals with CP (Lévis et al., 2016; Newman et al., 2006; Simard-Tremblay et al., 2011). These difficulties encompass various aspects such as sleep duration, sleep quality, staying asleep, and experiencing more difficulty getting up in the morning (Lévis et al., 2016; Newman et al., 2006); however, much remains unknown about the specific sleep patterns in CP and whether they are distinct from those observed in other conditions such as autism or fetal alcohol spectrum disorder (FASD). Additionally, the link between sleep and mood in CP is not well understood (Gadie et al., 2017). While in neurotypical youth, better sleep has been linked to improvements in social, emotional, and psychological well-being (e.g., mood), the extent to which sleep may impact mood within the context of CP remains uncertain (Hamilton et al., 2007). This manuscript-based thesis aims to address these significant gaps in knowledge by examining the sleep patterns in youth with CP and investigate the subsequent temporal association between sleep and mood.

Methods. For this exploratory manuscript-based thesis, we analyzed secondary data from baseline questionnaires and weekly data (accelerometers and daily sleep diaries) collected from a larger study that examined the associations between physiological factors and mental health in youth with CP. In the first study, we investigated the sleep patterns of 45 youth with CP using caregiver and youth reports, the Child/Adolescent Sleep-Wake Scale (CSWS/ASWS), Insomnia Severity Index (ISI), and measurements from actigraphs that youth wore for one week. First, the sleep characteristics were described in relation to available demographic variables (e.g., sex, age, Gross Motor Functioning Classification System level [GMFCS]), using descriptive statistics.

Second, to determine the impact of the presence of a mental health diagnosis on sleep patterns and problems, a hierarchical regression analyses was conducted. In the second study, we focused on a subsample of youth ($n = 32$) who had sufficient daily diaries of sleep and mood. In paper 2, the impact of intraindividual variability (IIV) in sleep patterns on mood (i.e., positive and negative affect) was examined using a series of fixed-effects multi-level modelling. Analyses included age, sex, and GMFCS as covariates as these factors contribute to sleep and mood.

Results. In the first study of 45 youth, the average sleep duration was 10 hours per night ($SD = 0:59$), ranging from 7.5 to 12.85 hours. Youth experienced an average of 14 awakenings (>5 min) per night ($SD = 5.3$), which is substantially higher than previous literature in youth without CP. Most youth reported poor sleep quality based on sleep quality scores from the combined CSWS and ASWS ($M = 3.67$, $SD = 1.24$). Hierarchical linear regression analysis revealed a significant positive association between mental health diagnosis and insomnia severity, even after controlling for participant demographics (age, sex, GMFCS) ($p = .010$).

For the second study, fixed-effect models were used to examine the association between IIV sleep duration and quality and next-day negative and positive affect over a 7-day period. While controlling for covariates, higher within-subjects variability of sleep quality was related to lower next-day negative mood ($b = -.03$, $p < .001$) and increased next-day positive mood ($b = .05$, $p = .018$). To determine the directionality of this association, mood variability predicting next day sleep was examined; however, only higher within-subject variability of negative mood was related to next-day sleep quality ($b = -1.12$, $p = .011$).

Conclusions. This thesis is the first of its kind to examine the group and individual characteristics of sleep patterns among youth with CP (Study 1) and the temporal impact of IIV sleep on daily positive and negative affect (Study 2). Sleep is a complex phenomenon, and

further investigation is necessary to understand the influence of various other factors, which were not available for this thesis. Nevertheless, sleep timing and sleep consistency may be important characteristics of sleep health. Overall, more research is needed to help inform prevention of mental health issues in this already vulnerable population and to help inform the development of supports for sleep.

Preface

This thesis is original, unpublished, independent work by the author, H. Sanguino. The data collected and reported in this study were covered by Review Ethics Board (REB) Certificate number REB19-0481, obtained by the University of Calgary Conjoint Health Ethics Board for the project “Anxiety and depression in youth with cerebral palsy: Role of physiological risk factors” on May 21, 2019.

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Epigraph

Sleep is the golden chain that ties health and our bodies together.

- Thomas Dekker, (1572 - 1632)

Chapter 1: Introduction

Overview and Aims of Thesis

Cerebral palsy (CP) is a brain-based neurodevelopmental condition that affects the development of movement and posture and is caused by disturbance to the developing fetal brain (Rosenbaum et al., 2007; Oskoui et al., 2013). Due to the distinctive features in the central and peripheral nervous system associated with CP, youth impacted by CP can be more prone to challenges in areas regulated by the nervous system, particularly sleep (Angriman et al., 2015; Jan et al., 2008). As a result, youth with CP often face difficulties across multiple dimensions of sleep, such as sleep duration, sleep quality, staying asleep, and experiencing increased difficulty waking up in the morning (Horwood et al., 2018; Lélis et al., 2016). However, despite the prevalence of sleep problems in this population, there is still a significant knowledge gap regarding the specific characteristics and understanding of sleep patterns in youth with CP (Hulst et al., 2021; Horwood et al., 2018). Furthermore, less is known about how variability in sleep (intraindividual variability; IIV), which refers to fluctuations in sleep from night to night, may impact daily mood. By comprehensively understanding the sleep patterns of children and youth with CP, as well as disentangling the complex associations between sleep and other areas of functioning (e.g., mood), findings from this manuscript-based thesis will aid in identifying risk factors for the development of lifelong sleep problems.

The overarching objective of this exploratory manuscript-based thesis is to improve our understanding and characterization of sleep, while exploring the repercussions of IIV sleep patterns on mood in children and youth with CP. Knowledge gained from the current study is particularly valuable as sleep is vital to learning and well-being, and plays an essential role in social, physical, psychological, and cognitive health (Crowley et al., 2018; Horwood et al.,

2019). Furthermore, by understanding the relation between IIV sleep and mood, possible prevention and intervention approaches can be developed to improve youth's functioning. Similarly, this can pave the way for more effective strategies to enhance sleep and mood in this population. The current thesis outlines findings from two manuscripts. The first study comprehensively characterized various sleep patterns in youth with CP using multiple methods. The second study examined the impact of IIV sleep patterns on daily mood. Study 1 will be addressed in Chapter 2, and Study 2 will be explored in Chapter 3.

Review of Literature

Cerebral palsy (CP) is a non-progressive brain-based neurodevelopmental condition that results from damage to the developing fetal or infant brain (Rosenbaum et al., 2007). CP is often considered the most common cause of childhood motor disorder impacting approximately three children for every 1000 live births (McIntyre et al., 2022; Oskoui et al., 2013; Van Naarden Braun et al., 2016). Although several studies have examined the trends of CP over time, and although trends are currently similar worldwide, within Canada, the prevalence of CP has slightly declined, from 2.38 in 2008 to 1.89 in 2010 per 1000 live births (Robertson et al., 2017). Clinical and epidemiological perspectives suggest that CP is more commonly diagnosed in males than in females across different age groups; however, some studies report an equal ratio between males and females (Marret et al., 2013; Romeo et al., 2023).

Children with CP are diagnosed through their delay in meeting movement milestones (McIntyre et al., 2011; Novak et al., 2017). This typically occurs between the ages of 12-24 months, although in cases with milder symptoms, diagnosis may be delayed until the child is older to enable healthcare professionals to effectively observe and identify the clinical features related to movement, posture, or balance (Hubermann et al., 2016; McIntyre et al., 2011; Novak

et al., 2017). The prevalence of CP has fluctuated over time because of advancements in care (Robertson et al., 2007; Robertson et al., 2017; Rosenbaum et al., 2007), specifically, advances in prenatal and pediatric care that have led to an increasing number of surviving preterm and low birth-weight infants at high risk for CP (Robertson et al., 2017). Furthermore, existing guidelines have been extended to assist in the early detection and intervention of CP (Novak et al., 2017). These guidelines highlight the need for early diagnosis in CP, as motor and cognitive gains are more significant when early intervention is implemented (Morgan et al., 2021; Novak et al., 2017). Novak and colleagues (2017) included three comprehensive recommendations, including neuroimaging (e.g., neonatal magnetic resonance imaging; MRI), neurological examinations (e.g., Hammersmith Infant Neurological Examination; HINE), and motor assessments for infants. These assessment tools vary drastically based on how they are administered or evaluated. For example, the HINE is a neurological assessment tool that evaluates motor functioning and predicts infant developmental outcomes (Novak et al., 2017; Romeo et al., 2016). Typical neuroimaging, such as MRI, can provide detailed information about the brain and identify any structural abnormalities associated with CP (Bosanquet et al., 2013; Novak et al., 2017), while the Prechtl Qualitative Assessment of General Movements is a method of observing and assessing the quality of movements in infants (Bosanquet et al., 2013; Einspieler et al., 1997; Novak et al., 2017). Despite these advances and early diagnosis, individuals with CP continue to experience significant barriers in everyday life (Zeidan et al., 2021).

Multiple births, infections, premature birth, and low birth weight have been identified as risk factors for CP (Adegbite et al., 2004). Premature birth and low birth weight are among the leading risk factors for CP (Adegbite et al., 2004; Robertson et al., 2017). Based on the functional ability of the youth, the Gross Motor Function Classification System level (GMFCS)

distinguishes between five levels of severity ranging from mild (i.e., walking independently; level I) to severe (i.e., being dependent for all types of mobility; level V) (Robertson et al., 2017; Rosenbaum et al., 2007). The categorization of CP can be described as spastic, dyskinetic, ataxic, and mixed, with hemiplegia (including monoplegia) being the most common clinical phenotype of CP (Smithers-Sheedy et al., 2022). Despite being a non-progressive disability, individuals with CP often experience co-occurring symptoms and conditions that worsen over time, increase with age, and have progressive effects on their overall well-being (Hollung et al., 2020; Honan et al., 2023; McPhee et al., 2020). More specifically, CP is associated with an increased risk of physical and mental health problems among youth (e.g., Novak et al., 2017; Whitney et al., 2019) and adults (e.g., McMorris et al., 2021; Smith et al., 2019). Symptoms such as sleep problems, fatigue, anxiety, and depression are quite common in people with CP, and exacerbate functioning across all domains of life (Smith et al., 2019; Van Der Slot et al., 2012; van Gorp et al., 2021). For example, youth with CP experience higher levels of depressive symptoms and sleep disturbances than those without CP (Horwood et al., 2019; Smith et al., 2019; Van Der Slot et al., 2012; Whitney et al., 2019). Furthermore, Horwood and colleagues (2019) found a strong positive association between sleep problems and emotional functioning, suggesting that sleep problems may drive the emotional and psychological well-being of youth with CP. Similarly, adults with CP have an increased risk of anxiety and depression compared to same-aged neurotypical adults (Smith et al., 2019; McMorris et al., 2021). It is hypothesized that this heightened risk could be attributed to several factors commonly observed in CP, such as co-occurring mental health diagnosis, increased pain, difficulties with social relationships and worse sleep (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019).

Mental Health

Mental health issues are common in individuals with CP (Downs et al., 2018; McMorris et al., 2021; Whitney et al., 2019). In a large nationwide study in the United States (US), Whitney and colleagues (2019) found that adults with CP had a higher prevalence of mental health disorders, such as anxiety and depression, compared to adults without CP. As in the case of Canada, regardless of the presence of intellectual disability, adults with CP in Canada are more likely to have at least one mental health diagnosis compared to the general population (McMorris et al., 2021). Similarly, Bjorgaas and colleagues (2012), reported that approximately 60% of youth between seven and eleven years with CP met criteria for a co-occurring mental health condition. In adults, a retrospective longitudinal study of adults with CP and without CP, Smith and colleagues (2019), found that individuals with CP had an increased risk of being diagnosed with depression or anxiety, compared to age- and sex-matched control group without CP. To date, it is still unclear as to why youth with CP are at heightened risk for experiencing mental health issues; however, there is some evidence to suggest that the presence of physiological health conditions (fatigue, pain, disordered sleep, etc.) that many people with CP experience, are likely contributing factors (Horwood et al., 2019; Jacobson et al., 2020; van Gorp et al., 2019). Mental health symptoms may be further impacted by GMFCS, as Downs and colleagues (2018) found that mental health difficulties are more prevalent in youth with CP with GMFCS levels II to V.

In terms of specific types of mental health issues, individuals with CP are more likely to have mood or internalizing disorders, such as depression and anxiety (Bjorgaas et al., 2012; McMorris et al., 2021; Whitney et al., 2019). Sienko (2018) found that approximately 42% of young adults with CP between the ages of 18 and 30 years reported depression, with symptoms ranging from mild (25%) to moderate (13%) and severe (4%). Additionally, Downs and

colleagues (2018) found that children and adolescents with GMFCS levels II to V and those individuals who have less than average cognitive abilities were found to have an increased risk of depression compared to peers without CP (Downs et al., 2018). Anxiety disorders are also quite common among children and youth with CP, with rates ranging between 38% and 46% compared to 8-12% of neurotypical children and youth (Downs et al., 2018; McMahon et al., 2020; Melton et al., 2016; Sienko, 2018). More specifically, utilizing the Screen for Child Anxiety Related Emotional Disorders (SCARED) questionnaire, McMahon et al, (2020) revealed that 35% of children with CP had clinically significant anxiety based on parent reports, while 46% were identified as experiencing clinically significant anxiety based on self-reports. Furthermore, this study found that females had significantly higher rates of anxiety than males, with prevalence of 47% versus 31%, respectively (McMahon et al, 2020). Taken together, the mental health difficulties that individuals with CP commonly experience may be influenced by co-existing physiological health conditions, including sleep.

Sleep

Sleep is a core behaviour of youth, consuming approximately a third or more of each day (Tarokh et al., 2016). Sleep is related to physical, social, emotional, behavioural, and psychological well-being in neurotypical and neurodiverse youth (Esbensen et al., 2016; Horwood et al., 2019a; Horwood et al., 2019b; Ohayon et al., 2000). Only within the last few decades has sleep been increasingly recognized as a factor associated with optimal physical and mental health (Buysse, 2014; Chaput et al., 2018). Recently, Buysse (2014) has also argued that objective and subjective information needs to be incorporated into sleep research to better capture the construct of good sleep. Good sleep does not only entail getting enough sleep each night, but other domains, such as the timing, quality and fluctuations of one's sleep, are even

more important and almost always disregarded (Buysse, 2014; Chaput et al., 2018; Meltzer et al., 2021). For example, sleep health, another term that has been proposed to better understand sleep in a holistic matter, encompasses multiple domains of sleep (Buysse, 2014; Dong et al., 2019; Meltzer et al., 2021). Five key dimensions of sleep that have been consistently associated with health outcomes are Regularity in sleep, Satisfaction with sleep, Alertness during waking hours, Timing of sleep, sleep Efficiency, and sleep Duration (RU SATED; Buysse, 2014; Dong et al., 2019). RU SATED considers specific characteristics and qualities of sleep, which holistically captures the complex nature of sleep (Buysse, 2014).

Importance of sleep

The National Sleep Foundation (NSF) recommends that children 6 to 13 years of age get between 9 and 11 hours of sleep a night, and those youth 14 to 17 years of age get between 8 and 10 hours of sleep a night (Hirshkowitz et al., 2015). Despite this recommendation, extensive literature demonstrates that youth, on average, sleep less than the recommended amount and overall less than they used to (Chaput et al., 2018; Matricciani et al., 2013; Yip et al., 2020). Matricciani and colleagues (2013) identified that youth, on average, have decreased their sleep by 0.75 minutes per year over the past century, with this rate being more prominent among adolescents than younger school-aged children. This trend is alarming as sleep is a vital component of daytime functioning at all stages of development (Buysse, 2014; Dong et al., 2019; Tarokh et al., 2016). Furthermore, youth often attempt to catch up on their sleep debt during the weekend, and so oversleeping up to two hours or more (Owens et al., 2014). The combination of later sleep timing and weekend sleep debt catchup poses challenges for adolescents to obtain sufficient sleep, potentially further disrupting their vulnerable developmental stage (Crowley et al., 2018; Dong et al., 2019; Nicholson et al., 2023).

Sleep is essential not only for regulating physiological functions but also for cognitive processes and intelligence across various domains (Buysse, 2014; Crowley et al., 2018; Dong et al., 2019). Sleep significantly influences children and adolescents' overall health, well-being, and cognitive functioning (Abel et al., 2013; Dewald et al., 2010; Dong et al., 2019; Goldstein & Walker, 2014). For example, the effects of sleep loss are detrimental to executive functioning and problem-solving; as such, these difficulties, in turn, are associated with more significant impairments in adolescents' learning capacity and school achievement (Goldstein & Walker, 2014). Adequate sleep is essential for optimal learning capacity and school achievement. Furthermore, insufficient sleep can worsen symptoms for youth with comorbid mental health concerns (Vanderlind et al., 2014). Given the alarming trend of youth sleeping less than the recommended amount and experiencing poor sleep quality, addressing sleep-related difficulties and promoting healthy sleep habits should be a priority to support their development and overall functioning (Buysse, 2014; Matricciani et al., 2013; Owens et al., 2014).

Sleep Duration

Sleep duration refers to the number of hours a child spends sleeping within a 24-hour period (Hirshkowitz et al., 2015). Although the recommended number is between 9 to 12 hours, sleep duration varies drastically between individuals and is often affected by age, sex, and lifestyle (Hirshkowitz et al., 2015). Sleep duration, in particular, has received increasing attention in research over the years and has been shown to have an important influence on many biological processes, such as inflammation, appetite and energy expenditure (Al Khatib et al., 2017; Matricciani et al., 2017), as well as psychological processes such as memory, attention, and mood (Buysse, 2014; Dong et al., 2019; Goldstein & Walker, 2014; Owens et al., 2014; Tarokh et al., 2016). Sufficient sleep duration is crucial for overall physical, mental, and

emotional well-being (Dewald et al., 2010; Matricciani et al., 2017). Conversely, insufficient sleep duration is linked to heightened negative emotions, such as depression and anxiety (Gadie et al., 2017; Matricciani et al., 2017). Within the literature, sleep duration research has played an important role in informing specific guidelines and recommendations and informing parents about healthy sleep behaviours, as it is an aspect of a child's lifestyle that can be easily modified (Hirshkowitz et al., 2015; Matricciani et al., 2013).

Sleep Quality

Sleep quality refers to how an individual personally experiences and perceives their sleep, including various aspects such as how awake they may feel, how alert they are during the day, and how uninterrupted their sleep was throughout the night (Dewald et al., 2010; Meltzer et al., 2021; Parsons et al., 2022). Understanding sleep quality is crucial, especially for youth, as it directly affects their physical health, cognitive abilities, and emotional well-being (Dewald et al., 2010; Meltzer et al., 2021; Parsons et al., 2022). Several factors can influence sleep quality in youth, and one of them is sleep hygiene. Sleep hygiene refers to the behaviours and practices surrounding sleep routines that promote good sleep quality (LeBourgeois et al., 2005; Meltzer et al., 2021). Good sleep hygiene habits increase the chances of getting enough sleep and feeling alert during the day (Galland et al., 2017; LeBourgeois et al., 2005; Tan et al., 2012). Examples of good sleep hygiene include sleeping alone in a quiet environment and having regular bedtime routines (Tan et al., 2012). Maintaining healthy sleep hygiene is even more critical for children because, during these vulnerable years, their physiological and mental functions experience significant growth and development (LeBourgeois et al., 2005; Tan et al., 2012). Sleep literature has often focused on sleep recommendations that primarily emphasize sleep duration, overlooking the importance of sleep quality (Hirshkowitz et al., 2015); however, children may

still experience poor sleep quality regardless of how much sleep they get or the time they spend in bed (Alonzo et al., 2021; Dewald et al., 2010; Gadie et al., 2017; Liu et al., 2005).

Intraindividual Variability

Intraindividual variability (IIV), commonly observed in child and youth sleep, refers to the night-to-night changes within an individual's sleep patterns rather than variations between individuals (Dillon et al., 2015; Langberg et al., 2019). Sleep IIV is associated with various physical factors and mental health outcomes (Becker et al., 2017; Veeramachaneni et al., 2019; Zhu et al., 2019). For example, greater IIV in sleep onset, duration and sleep quality have all been associated with higher reports of psychological health issues, including anxiety, insomnia, more significant depressive symptoms, and negative mood (Becker et al., 2017; Vanderlind et al., 2014). Furthermore, the concept of sleep IIV recognizes that sleep patterns and their correlates may differ across different stages of development (Becker et al., 2017; Dillon et al., 2015). Specifically, adolescence is when youth may experience variations in their sleep patterns from night to night or over a longer time (Becker et al., 2017; Dillon et al., 2015; Kelly et al., 2022). While some researchers suggest that quantifying sleep variability is challenging, and there has yet to be a consensus on its measurement (Becker et al., 2017; Fischer et al., 2021), one commonly used approach involves calculating the daily variations of sleep patterns around an individual's average value (Bei et al., 2016). As Bei et al. (2016) discussed, this method provides insight into sleep patterns by creating a metric for intra-individual standard deviation (SD). In their systematic review, Bei and her colleagues (2016) summarized the adult literature and reported that sleep IIV was uniquely associated with various mental health outcomes. Depression and stress were the most consistently associated with IIV sleep patterns (Bei et al., 2016). Similarly, Becker and colleagues (2017) outlined existing literature in adolescents and reported

an association between fluctuations in the time it takes for adolescents to fall asleep and internalizing symptoms such as more anxious/depressed behaviours.

Insomnia

Insomnia is a specific sleep disorder during adolescence, characterized by difficulty initiating or maintaining sleep for at least three nights per week for at least three months (de Zambotti et al., 2018). In the general population, about 10% of youth meet criteria for insomnia, and approximately 33% report experiencing some insomnia symptoms (American Psychiatric Association [APA], 2022; Dohnt et al., 2012). Not only is it quite prevalent, but current literature also suggests that youth who struggle with other co-occurring conditions are more susceptible to insomnia in later adulthood (Dohnt et al., 2012; Johnson et al., 2006). For example, Johnson and colleagues (2006) report that approximately 50% of youth with insomnia had pre-existing conditions, with anxiety disorders and depression being the most common. In addition to mental health conditions, physical health problems and pain have been reported to have a bidirectional association with insomnia (Kundermann et al., 2004; Oh et al., 2019; Sutton et al., 2001). Pain may disturb sleep, increasing insomnia symptoms, while insomnia symptoms increase pain sensitivity (Haack et al., 2012; Kundermann et al., 2004). Moreover, a recent systematic review and meta-analysis reported that higher rates of insomnia symptoms were associated with higher pain intensity and vice versa (Bilterys et al., 2021).

The development of insomnia is characterized by the Spielman (i.e., 3P model) model of predisposing, precipitating, and perpetuating (Spielman et al., 1987). Spielman suggested that predisposing factors, such as personality traits, can make some people more vulnerable to insomnia than others (Harvey et al., 2014; Spielman et al., 1987). Common factors that make individuals more vulnerable to develop insomnia include emotional distress and physiological

health factors, for example, low mood and pain (Bastien et al., 2004; Harvey et al., 2014). Typically these predisposing factors are compounded by a precipitating event (e.g., death of a significant caregiver, medication side effects) or ongoing emotional distress (Harvey et al., 2014; Spielman et al., 1987). Over time, these events or experiences exacerbate early insomnia symptoms and inhibit sleep (Harvey et al., 2014; Spielman et al., 1987). Finally, perpetuating factors such as negative associations with bed and keeping an irregular sleep-wake schedule keep the insomnia symptoms persistent over time (i.e., keep the individual over the “insomnia threshold”) (Harvey et al., 2014; Spielman et al., 1987). Thus, this theory suggests that individuals with added stress and mood difficulties are most at risk of experiencing insomnia (Spielman et al., 1987).

Assessing Sleep in Children and Youth: Subjective–Objective Measures

Sleep can be measured in various ways, but most commonly, previous research has relied on objective measures (Díaz-Román et al., 2018; Horwood et al., 2018; van Rijssen et al., 2023). However, a strong emphasis has been made on adopting a multi-method sleep assessment approach (Buysse et al., 2006; Short et al., 2020). Subjective methods rely on individuals' perceptions and self-reports, such as sleep quality and feelings of restfulness, to assess their sleep experiences (Horwood et al., 2019; Matricciani et al., 2013). For example, sleep diaries are often used as a simple and efficient way to record sleep information such as sleep/wake patterns and perceived sleep quality over multiple days with minimal cost and inconvenience (Carney et al., 2012; van Rijssen et al., 2023). On the other hand, objective methods typically rely on actigraphy, which uses activity or motion counts as a proxy measure of sleep (Meltzer et al., 2015; Short et al., 2012; van Rijssen et al., 2023). Actigraphy is used frequently in research due to its cost-effectiveness and is considered a valid means of characterizing sleep patterns in

children (van Rijssen et al., 2023). However, actigraphy may overestimate sleep patterns in youth with CP (Horwood et al., 2019; Simard-Tremblay et al., 2011). For example, van Rijssen and colleagues (2023) highlighted that actigraphy measures body movements, not sleep itself, as such, activity during the night (e.g. spasms, restlessness, or other involuntary movements), which may be more pronounced in children with CP, might be considered wakefulness (van Rijssen et al., 2023). On the contrary, periods of long awakenings without movements may not be captured as awakenings (van Rijssen et al., 2023). Therefore, accurately assessing sleep in children and youth with CP is essential for identifying and supporting them with their sleep difficulties (Horwood et al., 2019; van Rijssen et al., 2023).

Sleep in youth with CP

Sleep plays a critical role in the well-being and development of youth with neurodevelopmental disability (NDDs), including CP. Nevertheless, sleep problems are prevalent among youth with CP, with estimates indicating between 23% to 45% of children experience clinically significant sleep problems (Horwood et al., 2019). However, there is notable variability in the prevalence of these sleep problems across different subgroups of children with CP (Horwood et al., 2019; Lélis et al., 2016). In their recent meta-analysis, Horwood and colleagues (2019) found that daytime sleepiness was highly prevalent, with rates of 91.3% in youth with CP without epilepsy and 41.4% in CP with epilepsy (Horwood et al., 2019). Poor sleep can trigger or exacerbate core and associated symptoms for children with co-occurring mental health concerns or co-occurring diagnoses (Horwood et al., 2019; Lélis et al., 2016; Marcus et al., 2008). Furthermore, disrupted sleep (i.e., awakenings that occur following sleep onset) was reported in 18.6% of children aged 8-12 years and 25.0% of adolescents aged 13 to 17 years (Horwood et

al., 2019). These findings emphasize the heterogeneous nature of sleep problems among children with CP and emphasize the importance of tailored supports for addressing their individual needs.

The importance of recognizing and treating sleep problems in children with CP cannot be overemphasized. It is well known that the consequences of sleep problems in children with CP are broad and impact both the child and the family. For example, sleep problems have a negative effect on youth's daytime functioning, cognition and executive functioning in both neurotypical and neurodiverse individuals (Chaput et al., 2018; Duncan & Maitre, 2021). Moreover, family outcomes are also impacted; in particular, child sleep problems are significantly related to both sleep disturbance and depression symptoms in mother caregivers (Wayte et al., 2012).

Sleep problems in youth with CP can also worsen their already compromised physical and cognitive functioning and can impact their quality of life (QoL) (Albayrak et al., 2019; Badaru et al., 2021; Sandella et al., 2011). Specifically, among children with CP, insomnia has been shown to have a detrimental impact on psychological QoL, while excessive daytime sleepiness predicts lower physical QoL (Sandella et al., 2011). Furthermore, insomnia symptoms seem to increase or worsen with lower gross motor function abilities (i.e., higher GMFCS levels) (Löwing et al., 2020). A large-scale study examining the association between sleep and motor abilities in adults with CP found that those with higher GMFCS levels experience more difficulties achieving adequate sleep (i.e., more insomnia symptoms) and have worse next-day functioning than their peers with lower GMFCS levels (Löwing et al., 2020). Although functional ability, as indicated by GMFCS level, has been recognized as a predictor of physical QoL, sleep disorders, such as insomnia, may further exacerbate existing physical impairments while indirectly impacting QoL (Jacobson et al., 2020; Löwing et al., 2020; Sandella et al.,

2011). As such, addressing sleep problems becomes a crucial aspect of comprehensive intervention strategies to improve emotional well-being and overall QoL for individuals with CP.

Risk Factors for Poor Sleep in Children/Youth with CP

Given the impact that poor sleep has on the overall functioning of children and youth with CP and their families, research interest in sleep disorders in children with CP has steadily grown in recent years (Horwood et al., 2019; Löwing et al., 2020). However, little is known about the factors contributing to these sleep disturbances (Horwood et al., 2019; Newman et al., 2006). A biopsychosocial approach is widely recognized as a method for understanding the potential factors associated with sleep problems in individuals with and without CP (Bıyık et al., 2021; McCabe et al., 2022; Richdale et al., 2009). Sleep problems may occur as a result of 1) biological or physiological abnormalities that alter brain function; 2) psychological or behavioural characteristics (e.g., emotion and cognition) associated with CP; or 3) social or contextual factors (e.g., daily activities, environment, family environment) that may not be conducive to good sleep. As such, any one or combination of these three factors may contribute to sleep problems in children and youth with CP. This intricate interplay between biological or physiological, psychological, and environmental factors is an important consideration for investigation and intervention of sleep problems.

Depression and stress have been shown to be significant psychological or behavioural factors that contribute to sleep problems, as they have been found to both precede the development of sleep issues and exacerbate their severity (Horwood et al., 2018; Lélis et al., 2016; Löwing et al., 2020). Löwing and colleagues (2020) discussed their findings in terms of the interplay of brain structure (i.e., seizures), CP-subtype, age, and sex, all which heighten sleep problems among youth. The interaction of these factors tends to magnify and extend sleep

difficulties in this demographic (Löwing et al., 2020). Similarly, Horwood and her colleagues (2018) highlight that certain sleep practices such as bed sharing, when combined with biological factors such as cognitive impairment and active epilepsy, further worsen sleep outcomes. Overall, the interaction of these factors shapes sleep experiences, emphasizing the need for holistic and personalized approaches to interventions (Horwood et al., 2018; Lélis et al., 2016; Löwing et al., 2020). Depressive symptoms, stress, and the interaction of various neurological and contextual factors all contribute to the complexity of sleep difficulties within people with CP (Horwood et al., 2018; Lélis et al., 2016; Löwing et al., 2020).

There is emerging literature suggesting that similar to children and youth without CP, secondary conditions that many youth with CP experience, such as pain, may exacerbate the risk of sleep problems (Jacobson et al., 2020; MacDuffie et al., 2020; McCarthy & Rastogi, 2017). Additionally, factors associated with different types of CP, such as upper airway obstruction, gastrointestinal (GI) problems, and epilepsy, are also significantly associated with sleep difficulties in CP (Lélis et al., 2016). Motor impairment has also been shown to be associated with sleep problems (Lélis et al., 2016; Simard-Tremblay et al., 2011). Although the severity and type of motor impairment impact on sleep is not yet fully understood, it has been hypothesized that greater total body impairment (i.e., quadriplegic) and more significant restricted movement can significantly decrease sleep outcomes (Lélis et al., 2016; Simard-Tremblay et al., 2011). Finally, Santos and her colleagues (2018) reported that individuals with CP lacked day/night rhythm and had less melatonin during the night compared to individuals without CP. Thus, low melatonin and circadian timing may be abnormal in individuals with CP (Santos et al., 2018).

Moreover, there is growing evidence within the neurotypical population to support a bidirectional association between sleep and psychological well-being (Dagys et al., 2012;

Stewart et al., 2011; Tarokh et al., 2016; Vanderlind et al., 2014). That is, sleep can contribute to impairments in an individual's psychological well-being or mood, and these impairments in one area perpetuate impairments in the other (i.e., sleep) (Dagys et al., 2012). Recent research suggests a bidirectional relationship, whereby symptoms of mental health conditions lead to sleep problems, and sleep problems, in particular insomnia symptoms, can heighten the risk of the other condition (Hamilton et al., 2007; Hertenstein et al., 2019; Waxmonsky et al., 2017). The inter-relationship is best exemplified by the link between insomnia and depression (Hertenstein et al., 2019). That is, depression may lead to insomnia and in turn, insomnia may increase the depressive symptoms of the youth and compound the development and severity of insomnia (Hertenstein et al., 2019).

Furthermore, insomnia severity may exacerbate and prolong greater difficulties with negative affect and increased symptoms of anxiety and depression (Hertenstein et al., 2019; Roberts & Duong, 2013; Ohayon et al., 2000). While this statement describes youth at large, youth with NDDs, including CP, are at a higher risk of experiencing emotional dysfunction than their neurotypical peers (Downs et al., 2012; Sandella et al., 2011; Whitney et al., 2019). For example, youth with CP experience significantly higher levels of depression and anxiety than neurotypical youth. A study conducted by Downs and colleagues (2012) found that emotional disorders and anxiety were more prevalent among children with CP. Although youth with CP experience adverse psychological well-being compared to their peers, it is not yet known why, or which combination of factors contributes most to poorer outcomes (Downs et al., 2012; Whitney et al., 2019).

Sleep and Mood

A growing body of literature has emerged, shedding light on the connection between sleep problems and mood (Becker et al., 2017; Brindle et al., 2018; Dewald et al., 2010; Hairston et al., 2022; Ong et al., 2017; Stewart et al., 2011). Sleep plays a role in the development, progression, and persistence of mood symptoms among youth (Brindle et al., 2018; Hairston et al., 2022; Stewart et al., 2011; Waxmonsky et al., 2017). For example, among youth with and without attention-deficit/hyperactivity disorder (ADHD), those with heightened mood symptoms were likely to have significantly higher sleep problems than those without mood symptoms, regardless of their diagnosis (Waxmonsky et al., 2017). Moreover, youth with sleep problems had significantly higher mood symptom scores than those without (Waxmonsky et al., 2017).

In individuals without NDDs, youth who report more significant sleep problems have heightened negative symptoms (e.g., sadness, anger) and dampened positive symptoms (e.g., happiness, joy) compared to good sleepers (Ong et al., 2017; Stewart et al., 2011). For example, among youth ages 6 to 17 years with anxiety, 98% of those diagnosed with anxiety experienced at least one parent-reported sleep problem (e.g., difficulty falling asleep, shorter sleep duration, and poor sleep quality) and greater sleep problems were associated with greater stress and distressed symptoms (Alfano et al., 2007). However, not all studies have found a significant association between mental health and sleep (Becker & Lienesch, 2018; Sadeh et al., 2014). In a community study of children ages 7-12 years, Sadeh and colleagues (2014) found no relation between parent-reported sleep problems and internalizing problems.

Sleep problems also alter how youth react to emotional events or information, increasing an individual's reactivity (Brindle et al., 2018; Hairston et al., 2022; Stewart et al., 2011; Ong et al., 2017). Conversely, an individual's emotional state can affect sleep quality and lead to difficulties falling and staying asleep (Hairston et al., 2022; Stewart et al., 2011; Ong et al.,

2017). Negative mood states, such as stress, anxiety, and sadness, have been associated with difficulties with sleep onset and sleep problems (Hairston et al., 2022; Lopresti, 2020; Stewart et al., 2011; Ong et al., 2017). In turn, sleep problems, can exacerbate difficulties regulating affect and mood, such as anxiety and depression in youth (Alonzo et al., 2021; Dohnt et al., 2012; Hertenstein et al., 2019). Determining the extent to which sleep, and mood interact will provide additional insight into the effectiveness of interventions, prevention, and risk factors.

Summary

The role of sleep is critical for maintaining good health and overall well-being. Youth with CP are at an increased risk for experiencing both sleep and mood-related challenges (i.e., positive and negative affect). The most common sleep problems in youth with CP include poor sleep quality, shorter sleep duration, difficulty falling asleep, and daytime dysfunction (Horwood et al., 2019; Simard-Tremblay et al., 2011). However, the understanding of sleep patterns and their associated factors in this population remains limited. Additionally, to ensure appropriate intervention and prevention strategies for youth with CP, the relation between sleep IIV and mood in CP requires further exploration. This manuscript-based thesis, comprising of two manuscripts, aims to improve our understanding of sleep in youth with CP and investigate the impact of sleep IIV patterns on mood (i.e., positive and negative affect). By studying these associations, supports to enhance sleep health and overall well-being can be developed. The first study aimed to extend and replicate previous research on sleep by characterizing and describing various aspects of sleep in adolescents with CP, while the second study aimed to examine the influence of sleep IIV patterns on mood. The findings from the two manuscripts can lead to more effective strategies to improve sleep and enhance the overall quality of life for individuals with CP.

Current Study

Paper 1: Characterizing Sleep Patterns in Youth With Cerebral Palsy

Only a limited number of studies have comprehensively investigated the sleep patterns of youth with CP. To address this gap, the overarching aim of Paper 1 is to extend and replicate previous research by characterizing and describing various aspects of sleep patterns in youth with CP using both objective and subjective measures. This aim was achieved by addressing the following research questions:

Research Question 1a: What are the sleep patterns, including sleep disturbances, sleep fragmentation and sleep quality, experienced by youth with CP?

Hypothesis: Youth with CP will exhibit variable but altered sleep patterns, including higher prevalence of sleep disturbances, increased sleep fragmentation, and reduced sleep quality compared to existing sleep guidelines for neurotypical youth.

Research Question 1b: Does the presence of mental health issues predict the severity of insomnia in youth with CP?

Hypothesis: Based on existing literature in neurotypical youth (Hertenstein et al., 2019; Roberts & Duong, 2013), it is hypothesized that the presence of mental health issues will be associated with higher insomnia severity symptoms.

Paper 2: Sleep and Mood Among Youth with Cerebral Palsy

Both sleep quality and sleep duration are associated with mood and emotional well-being in youth with NDDs. However, less is known about the relation between sleep IIV and mood in youth with CP, nor about the directionality of this association. To address this gap, the aim of this study is to investigate the temporal association between sleep IIV and mood, in particular positive and negative affect. This aim was achieved through the following research questions:

Research Question 1: Is there an association between IIV sleep quality and next day mood, after controlling for potential confounding factors?

Hypothesis: Consistent with previous research (Becker et al., 2017; Langberg et al., 2019), it was hypothesized that better sleep quality would be associated with same-day lower negative affect and higher positive affect.

Research Question 2: Is there an association between IIV sleep duration and next day mood, after controlling for potential confounding factors?

Hypothesis: It was expected that shorter sleep duration would be associated with same-day higher negative affect and lower positive affect.

Research Question 3: To examine the bidirectional association, are there associations between variable mood and next day sleep quality, considering potential confounding factors?

Hypothesis: Consistent with previous research (Becker et al., 2017; Langberg et al., 2019) documenting mood and sleep associations, it was hypothesized that days of higher positive affect and lower negative affect would be associated with higher sleep quality on the following day.

Research Question 4: Similarly, are there associations between day-to-day variability in mood and next day sleep duration, considering potential confounding factors?

Hypothesis: The limited existing research on this topic in neurotypical youth has suggested that both positive and negative affect are important predictors of next day sleep duration. Thus, it was expected that days of higher positive affect and lower negative affect would be associated with longer sleep duration on the following day.

Chapter 2: Overview

As previously discussed, little research has been conducted characterizing the sleep patterns in youth with CP. This chapter aims to address this gap by providing a comprehensive description of sleep characteristics in youth with CP using both an objective method (i.e., actigraphy), and subjective methods, including daily diaries and self-reported questionnaires. The manuscript proposed in this chapter has been prepared for submission to a sleep-focused journal.

Chapter 2: Sleep Patterns in Youth With Cerebral Palsy

Abstract

Cerebral palsy (CP) is a neurodevelopmental disability caused by a range of abnormalities in the developing fetal brain. Youth with CP experience several sleep difficulties, including poor sleep quality, shorter sleep duration, and nighttime awakenings. Many youth with CP experience mental health issues which increase their susceptibility to experience sleep problems. While it is well known that individuals with CP experience sleep difficulties, research to date has primarily involved objective methods alone or relied on proxy reports of sleep problems (e.g., caregiver questionnaires). Thus, the objective of this study was twofold: 1) to provide a detailed characterization of sleep patterns of youth with CP using both objective (i.e., actigraphy) and subjective (i.e., questionnaire and daily diaries) methods and identify differences in age, sex, gross motor functioning (as measured by the Gross Motor Functioning Classification System GMFCS), presence of psychiatric diagnoses, and medication status; and 2) to examine the association between the presence of psychiatric diagnoses and insomnia severity.

Forty-five youth with CP, between 7 and 17 years of age ($M_{\text{age}} = 11.6$ years) along with their caregivers participated in this study. Sleep patterns, including sleep duration, wake after sleep onset and sleep efficiency obtained using actigraphy generally aligned with sleep guidelines; however, number of awakenings was significantly higher in youth in the present sample relative to youth without CP outlined in the NSF guidelines. Youth experienced poor sleep quality and approximately a quarter of youth experienced insomnia symptoms. While sleep quality did not differ by age, females reported better sleep quality compared to males. Lastly, as anticipated, the presence of a mental health diagnosis significantly predicted greater insomnia

symptoms. Further research is needed to explain these findings, explore the influence of other factors, and identify potential supports that can improve sleep outcomes in these youth.

Keywords: Cerebral palsy, CP, children, youth, sleep, sleep patterns, neurodevelopmental disorders

Introduction

Cerebral palsy (CP) is a neurodevelopmental disability (NDD) affecting an estimated one to three children per 1000 live births worldwide (McIntyre et al., 2022). Motor impairment, communication disturbances, and epilepsy often accompany CP (Rosenbaum et al., 2007). Gross Motor Function Classification System (GMFCS) is used to classify gross motor functioning skills with Level I representing the ability to perform gross motor skills, such as walking and jumping. In contrast, individuals categorized in the GMFCS level V are non-ambulatory, meaning they cannot walk and depend on a wheelchair or other assistive devices for mobility (Palisano et al., 1997; Palisano et al., 2000). In addition to gross motor functioning difficulties, youth with CP experience several co-occurring conditions, including pain, fatigue, mental health issues, and sleep difficulties (Albayrak et al., 2019; Horwood et al., 2019; Jacobson et al., 2020; Whitney et al., 2019).

Sleep

Sleep during adolescence is vital for learning and social, physical, psychological, and cognitive health (Horwood et al., 2019a; MacDuffie et al., 2020; Meltzer et al., 2021). Sleep plays a significant role in our restorative functioning; however, because significant changes occur, both quantitatively and qualitatively, as we age, youth are at an increased risk of experiencing insufficient sleep and poor sleep quality (Keyes et al., 2015; Matricciani et al., 2013; Tarokh et al., 2016). Matricciani and colleagues (2013) identified that youth, on average, have decreased their sleep by 0.75 minutes per year over the past century, with this rate being higher among adolescents (13 to 17 years of age) compared to (5 to 12 years of age) younger school-aged children. Several studies have demonstrated that sleep problems may lead to adverse outcomes in an individual's health, cognitive functioning, and reduced well-being, with

adolescence being a critical time to promote and develop healthy sleep patterns (Badaru et al., 2021; Keyes et al., 2015; Tarokh et al., 2016; Wayte et al., 2012).

Sleep problems, such as reduced sleep duration, difficulties in falling asleep or staying asleep throughout the night, are highly prevalent in youth with CP, and contribute to significant difficulties in daytime behaviour, mood, and family functioning (Horwood et al., 2019; Hulst et al., 2021; Simard-Tremblay et al., 2011; Wayte et al., 2012). As many as 45% of youth with CP may have sleep problems (Horwood et al., 2019), which is relatively higher than the prevalence of sleep problems in neurotypical youth, estimated at around 25% (Alfano et al., 2007; Alfano et al., 2010; Tan et al., 2012). Sleep problems tend to be characterized by specific domains such as difficulty falling asleep, difficulty staying asleep, and reduced total sleep duration (Buysse, 2014). Poor sleep quality is also commonly reported in youth and caregivers of youth with CP (Hulst et al., 2021). *Insomnia*, or difficulty initiating or maintaining sleep with adequate opportunity to sleep accompanied by daytime consequences, is one type of sleep problem that is commonly reported in individuals with CP (Horwood et al., 2019; de Zambotti et al., 2018; Roberts & Duong, 2013). Along with reduced sleep quality, a large proportion of children with CP may not be adhering to the recommended 8 to 13 hours of sleep per day (Horwood et al., 2019). Horwood and colleagues (2019) found that only approximately 81% of the preschool age adhered to the sleep recommendations based on the NSF guidelines.

While sleep problems are considered an everyday experience in many individuals with CP, they may be underreported and can go unrecognized (Horwood et al., 2019; Ashworth et al., 2013). In fact, although a large percentage of youth with NDDs report experiencing sleep problems such as poor sleep quality, early morning wakings, and daytime sleepiness, only about 15% of them express their concerns or report complaints about sleep problems (Ashworth et al.,

2013). This underreporting can lead to underdiagnosis and, subsequently, inadequate management of sleep-related difficulties in this population (Horwood et al., 2019; Simard-Tremblay et al., 2011). Moreover, although sleep problems in youth with CP have been observed to be more prevalent and unique to early adolescence, recent research is shedding light on their persistent effects into adulthood (Lévis et al., 2016; Newman et al., 2006; Simard-Tremblay et al., 2011; Whitney et al., 2020).

Associated Factors

The wide range of sleep problems experienced by youth with CP stem from a combination of different factors (Lévis et al., 2016; Simard-Tremblay et al., 2011). High rates of sleep problems in CP may be due to a neurological or biological condition (e.g., epilepsy) and physical discomfort/muscle pain (Lévis et al., 2016), or other medical factors, such as gastrointestinal and respiratory problems commonly experienced by individuals with CP (Lévis et al., 2016; Simard-Tremblay et al., 2011). Sleep problems can also present in various ways depending on their subtype of CP (i.e., spastic) and the specific brain area associated with their CP that is impacted (Horwood et al., 2018; Lévis et al., 2016; Newman et al., 2006; Simard-Tremblay et al., 2011). In many cases, the hypothalamus, responsible for regulating the sleep-wake cycle, may be affected by the brain injury leading to CP, contributing to disturbances in the sleep patterns of the youth affected (Valrie et al., 2013). Additionally, disruptions in the basal forebrain, involved in sleep induction and maintenance, could further exacerbate sleep problems in those with CP (Pace-Schott et al., 2002; Valrie et al., 2013; Xu et al., 2015).

Several demographic factors can also influence sleep in individuals with CP, including age, sex, and gross motor functioning (Horwood et al., 2019; Löwing et al., 2020). For instance, Löwing and colleagues (2020) found that insomnia and difficult morning awakenings were more

common among children with higher Gross Motor Function Classification System (GMFCS) levels (V and IV). Age has also been shown to be associated with sleep duration and quality in both neurotypical and neurodiverse populations (Horwood et al., 2019; Langberg et al., 2019; van Rijssen et al., 2023). For example, in youth with CP, caregivers reported that older children tended to wake less frequently during the night and their parents reported higher satisfaction with their sleep compared to caregivers of younger children (Horwood et al., 2019). However, findings are mixed as another study by Hulst, and colleagues (2021) found no significant differences between age groups regarding average total sleep time (TST) and sleep onset latency (SOL) in children with CP. Gender and sex may also play a role in sleep. Sleep may be affected differentially by sex due to variations in hormones, physical and mental health conditions. For example, Newman and colleagues (2006) observed that females were less affected by sleep–wake transition disorders and disorders of arousal compared to males with CP. Co-occurring psychiatric conditions also play a vital role in sleep difficulties (Adiga et al., 2014; Horwood et al., 2019). In particular, a bidirectional relationship between sleep disturbances and psychiatric disorders is often reported in the literature, such that those with existing medical or psychiatric disorders are at an increased risk of experiencing more significant sleep problems (Hertenstein et al., 2019; Roberts & Duong, 2013).

Sleep plays a crucial role in various aspects of cognitive functioning, such as attention, memory, and executive functioning (Abel et al., 2013; Duncan & Maitre, 2021), and consequently sleep problems often exacerbate learning and behavioural challenges in children with and without NDDs (Díaz-Román et al., 2018; MacDuffie et al., 2020; Sadeh et al., 2014). For instance, studies with other NDDs populations, like autism, have shown that shorter sleep duration significantly impairs cognitive and adaptive functioning in affected youth (Díaz-Román

et al., 2018; Goldman et al., 2017; MacDuffie et al., 2020; Mughal et al., 2020). Similarly, using actigraphy Mughal and her colleagues (2020) found that shorter total sleep duration and more nocturnal wakings were associated with poorer performance in working memory and receptive vocabulary tests in both youth with autism or FASD. School-aged children with NDDs, also often experience increased sleep anxiety, bedtime resistance, and greater sleep needs, reflecting regular developmental changes in sleep-related behaviours (Angriman et al., 2015; Jan et al., 2008; MacDuffie et al., 2020). The impact of sleep problems extends beyond just sleep disruption; it can also lead to decreased cognitive functioning, learning difficulties, and contribute to behavioural or emotional problems (Duncan & Maitre, 2021). For example, in youth with CP, poor sleep quality, or frequent awakenings during the night, was significantly associated with higher levels of hyperactivity and impulsivity during the day (Simard-Tremblay et al., 2011). These sleep-related issues appear to exacerbate the already challenging behavioural symptoms experienced by these individuals and are related to a range of emotional and behavioural problems as hyperactivity/impulsivity, mood, and anxiety (Adiga et al., 2014; Horwood et al., 2019; Robertson et al., 2017).

Despite evidence highlighting the significance of sleep for the overall well-being of youth, only a few studies have comprehensively examined different sleep characteristics in children and youth with CP. (Horwood et al., 2019; Simard-Tremblay et al., 2011; van Rijssen et al., 2023). To date, existing studies on sleep with CP have only included cross-sectional data, limited to one facet of sleep (e.g., sleep duration), relied on subjective measures of sleep (e.g., questionnaires) and lacked the voice of youth with CP as caregiver's have been the primary respondents. Given the vital importance that sleep has on youth with CP, it is important to consider multiple facets of sleep, such as duration, quality, and associated factors, to gain a more

comprehensive picture of sleep and the impact it may have on in an individual's life (Buysse, 2014; Crowley et al., 2018). Given that historically, sleep research has primarily treated sleep as an outcome rather than a predictor of health (Buysse, 2014; Hale et al., 2020), shifting from this conventional perspective, it is essential to adopt a health promotion approach emphasizing understanding sleep and optimizing it to enhance overall well-being. Characterizing sleep problems in youth with CP and their associated features is crucial, as sleep significantly contributes to social, physical, psychological, and cognitive health (Buysse, 2014; Crowley et al., 2018; Esbensen & Schwichtenberg, 2016; Hale et al., 2020; Horwood et al., 2019).

Research Aims and Hypotheses

The aim of the current study is to fill this significant gap in the existing knowledge and provide an in-depth understanding and characterization of sleep patterns in youth with CP. In particular, (1a) describe multiple dimensions of sleep and provide a detailed description of biological (sex, age) and clinical (severity, medication use) variables and how they are related to sleep; and (2) examine whether the presence of psychiatric diagnoses is associated with insomnia severity above and beyond sex, age, and GMFCS. Insomnia was chosen as a focus for this study as it is the most common sleep problem in children and adolescents with and without CP. Consistent with existing research, it is anticipated that sleep patterns will be variable but altered, including higher prevalence of sleep disturbances, increased sleep fragmentation, and reduced sleep quality and that the presence of a psychiatric diagnosis will be associated with greater insomnia severity after controlling for sex, age, and GMFCS.

Paper 1 Methods

Secondary Data Sources

This cross-sectional study involved the secondary analysis of baseline data collected from a larger study that examined the associations between physiological factors (e.g., sleep, pain, physical activity, mood) and mental health in children and youth with CP. This larger project was funded by the HBI Robertson Fund for Cerebral Palsy Research grant (PI: C. McMorris) and data collection occurred between September 2019 - August 2021. Ethics approval was obtained from the University of Calgary's Conjoint Faculties Research Ethics Board (CFREB, REB19-0481) and the Health Sciences Research Ethics Board (HSREB, 115678) at The University of Western Ontario (Appendix A).

Participants

This study consisted of 45 ($M = 11.66$, $SD = 2.77$) youth with CP ages 8 to 17 years, and one of their caregivers. To participate, youth were required to have a primary diagnosis of CP and had to read and write in English. Youth with varying GMFCS levels (i.e., functioning ability) were eligible to participate. The study included children and youth with CP for participation. Children and youth with CP who had additional medical conditions, such as medication-controlled epilepsy or an intellectual disability, were eligible for inclusion in the study, while those with other neurological conditions like epilepsy (without a CP diagnosis), traumatic brain injury, or autoimmune disorders were not eligible for the study.

Procedure

Participants were recruited from a variety of Calgary, AB and/or London, ON health and community sites including the Pediatrician Neuromotor Clinic, Renfrew Educational Services, and Taking Strides Calgary. Participants were also recruited through advertisements placed in various locations including Alberta Children's Hospital Clinics, Cerebral Palsy Kids and Families, the Cerebral Palsy Association in Alberta (CPAA). Interested families contacted the

research team and were provided with a brief recruitment letter explaining the research study, as well as consent and assent forms. Consent was obtained from youth older than 14 years of age that were cognitively capable of providing their own consent for participation. Capacity for consent was determined by evaluating whether youth could express an understanding of the study aims and what information would be collected from them, as well as understanding the risks and benefits of being involved in the study and the consequences of not participating. Caregivers provided further insight into their child's functioning ability level, and previous psychological reports, when available, were reviewed to understand their capacity to consent. Please refer to Appendix B for parental consent forms and Appendix C for assent forms. Once youth and caregivers provided assent and consent respectively, youth and caregiver questionnaires (described in more detail below) were administered through REDCap (Research Electronic Data Capture) software and sent to participants via email (Harris et al., 2009; Harris, et al., 2019). After completing the questionnaires, youth were asked to wear Actiwatch devices and complete a daily diary for a 1-week (7-day) period (see Appendix D). After completing the daily surveys, caregivers were asked to participate in a diagnostic interview (i.e., The Kiddie Schedule for Affective Disorders and Schizophrenia; K-SADS; Kaufman et al., 1997) conducted over the phone or via Zoom to determine whether their child met the criteria for a mental health concern. Information regarding mental health on the K-SADS was not included in the present study.

Given the stay-at-home order imposed by the COronaVirus Disease of 2019 (COVID-19), most of the study was conducted remotely. As such, two distinct testing protocols were employed to facilitate data collection for the study. Prior to the COVID-19 pandemic, an in-person assessment, which involved masters-level clinically-trained students conducting various

standardized assessment measures, a diagnostic clinical interview (i.e., KSADS), and caregiver/self-report questionnaires ($n = 2$). During the COVID-19 pandemic, all caregiver/self-report testing was administered to participants through remote means (i.e., web-based platforms and REDCap software). Additionally, the mental health diagnostic interview was conducted over the phone ($n = 43$). After completing all aspects of the project, each participant received a \$50 gift card as a reimbursement for their time.

Measures

Demographic information. Caregivers were asked to provide a range of information such as their child's birth date, ethnicity, residence (urban vs. rural), any diagnoses related to mental health or neurodevelopmental conditions, the make-up of the family, current medication usage, service utilization, the presence of family members living in the same household, and the household income. The mental health and psychiatric diagnoses variable was dichotomized into "yes" or "no," with caregivers also providing additional details about the specific type of diagnosis.

Subjective sleep quality. Subjective sleep quality was assessed using the Sleep-Wake Scale (SWS), with the Adolescent's Sleep-Wake Scale (ASWS; LeBourgeois et al., 2001; LeBourgeois & Harsh, 2016; Storfer-Isser et al., 2013) completed by youth aged 13 to 18 years and caregivers completing the Child Sleep Wake Scale (CSWS; LeBourgeois, 2003; LeBourgeois et al., 2005; LeBourgeois & Harsh, 2016) for youth aged 7-12 years. Both scales include five sleep behaviour subscales: Going to Bed, Falling Asleep, Maintaining Sleep, Reinitiating Sleep, and Return to Wakefulness. Each item is rated on a scale from 1 to 6 (e.g., 1 – “Always” to 6 – “Never”) with higher scores indicating better sleep quality. There are no questions related to insomnia on either the ASWS or CSWS. Both scales provide a total sleep

quality score, which is a composite measure that considers all five behaviours of sleep.

(LeBourgeois et al., 2001; LeBourgeois et al., 2005; LeBourgeois & Harsh, 2016; Storfer-Isser et al., 2013). Although the SWS does not employ a specific cut-off score for identifying sleep disorders or poor sleep quality, scores below 4 on the ASWS or CSWS have been shown to be associated with clinically significant sleep problems (Axelsson et al., 2022; Prince et al., 2010).

The SWS has demonstrated good validity and reliability in both neurotypical and neurodiverse youth (LeBourgeois et al., 2005; LeBourgeois & Harsh, 2016; McCarthy & Rastogi, 2017). In our study, the ASWS Cronbach's α were as follows: Going to Bed ($\alpha = .77$), Falling Asleep ($\alpha = .84$), Maintaining Sleep ($\alpha = .85$), Reinitiating Sleep ($\alpha = .86$), and Returning to Wakefulness ($\alpha = .90$). Additionally, for the CSWS, the Cronbach's α in our study were as follows: Going to Bed ($\alpha = .91$), Falling Asleep ($\alpha = .90$), Maintaining Sleep ($\alpha = .90$), Reinitiating Sleep ($\alpha = .75$), and Returning to Wakefulness in the morning ($\alpha = .94$). Regarding the ASWS total score, we observed a high reliability with $\alpha = .94$, while for the CSWS total score, the reliability was also strong with $\alpha = .93$.

The Insomnia Severity Index (ISI; Morin et al., 2011). The ISI consists of seven items assessing the severity of sleep-onset and sleep maintenance difficulties, satisfaction with current sleep, daytime impairments, and degree concern caused by the sleeping problems. Each item is rated on a scale from 0 to 4 ranging from “None” to “Very Severe”, with scores ranging from 0 to 28. Higher scores indicating higher severity of insomnia symptoms, with scores of 8 to 14 suggested to indicate subthreshold insomnia and 15 or above suggested to indicate clinically significant insomnia (Morin et al., 2011). Consistent with prior studies, a cut-off of 10 was also utilized as its valid cut-off to effectively detect insomnia in a community sample (Morin et al., 2011). Morin et al. (2011) suggested that a cut-off score of 10 in the ISI strikes the best balance

between sensitivity and specificity in youth without CP. The ISI has been shown to have good internal consistency with a Cronbach's α of .82 (Manzar et al., 2021; Morin et al., 2011). In our study, the ISI Cronbach's α was .91.

Actigraphy-Determined Sleep. The Actigraph GT9X Link Actiwatch was used to assess objective sleep of youth over seven consecutive days. Actigraphy data has been shown to be valid and reliable for measuring sleep in young adults and children (Carney et al., 2012; Lichstein et al., 2006). Studies have identified that the location of the Actigraph attachment can affect the count of movements per minute, depending on whether it is bound to the wrist or waist (Hjorth et al., 2012; Loprinzi & Smith, 2017). Therefore, youth were asked to wear the actigraph on their non-dominant wrist for seven consecutive days except when bathing or swimming. Wake periods in 60-second epochs are coded by the software (Actigraph GT9X Link). Cole-Kripke sleep algorithm was applied to analyze the data with the Tudor-Locke “default” for sleep period detection. These algorithms have been utilized in youth with CP and were chosen for their sensitivity and validity (Clanchy et al., 2016; Gerritsen et al., 2023). Four main sleep variables were measured: sleep duration, wake after sleep onset (WASO) (i.e., how many times they woke up during the night after initiating sleep), number of awakenings (NOA) (i.e., the number of times an individual wakes up during the night), and sleep efficiency (SE) (i.e., the proportion of time spent asleep over the total time spent in bed). Sleep efficiency is calculated by dividing the amount of time spent asleep by the total amount of time in bed multiplied by 100. These variables provide insights into sleep quantity, continuity, and overall sleep quality. WASO, SE and NOA data was not obtained or available from nine youth participants.

Sleep Diary. Youth also completed sleep-diaries daily for seven consecutive days, in conjunction with wearing the actigraph (see Appendix G). Every evening (approximately 5:00

PM), caregiver and youth received a secure email containing links to REDCap surveys. This is the preferred way to gather self-reported data on sleep (Arora et al., 2013; Carney et al., 2012; Buysse et al., 2006). The daily dairies consisted of questions about their sleep the night before, including bedtime (i.e., “*What time did you go to sleep last night*”), final awakening time (i.e., “*What time did you wake up this morning*”), and sleep quality (i.e., “*How would you rate your sleep last night*”). Sleep duration in hours, sleep quality, as well as wake-up time and bedtime were derived from sleep diaries. Sleep parameters addressed in this manuscript are based off recommendations from National Sleep Foundation (NSF) for school-aged children (i.e., 6-13 years) and teens (i.e., 14-17) years (Hirshkowitz et al., 2015; Ohayon et al., 2017). Table 1 presents the sleep parameters addressed in this manuscript.

Table 1

Sleep parameters recommended by the National Sleep Foundation

Sleep Indicators	Definition	Norms for school-aged children	Norms for teens
Sleep duration ^a	Number of hours of sleep while in bed	9 to 11 hours recommended; not recommended, less than 7 more than 12	8 to 10 hours recommended; not recommended, less than 7 more than 11
Sleep efficiency	Ratio of total sleep time to time in bed	Sleep efficiency $\leq 74\%$ does not indicate good sleep quality.	
Awakenings	Number of episodes, per night, in which an individual is awake for greater than 5 min	Four or more awakenings per night are not an appropriate indicator for good sleep quality	

Wake after sleep onset	Amount of time, in minutes, spent awake after sleep has been initiated and before final awakening	a WASO of ≥ 41 minutes does not indicate good sleep quality	a WASO of ≥ 51 minutes does not indicate good sleep quality.
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Definitions adapted from Ohayon and colleagues (2017).

^aSleep duration definitions adapted from Hirshkowitz and colleagues (2015).

Statistical Analyses

Statistical analyses were performed using SPSS statistical software package (IBM SPSS Statistics, Version 26.0). Missing data was examined using Little's missing completely at random test (Little & Rubin, 1987). Descriptive statistics including mean, standard deviations, median and range, as appropriate, were used to describe demographic characteristics of the sample. A quantitative descriptive approach was used to characterize the sleep patterns among the 45 youth participants with CP. For these analyses, subjective sleep characteristics were averaged across the seven days. Descriptive statistics were used to summarize each of the self-report and objective variables. Characteristics were described including sleep duration, wake-up time, bedtime, sleep-wake, and insomnia characteristics. To examine the variables of interest, a series of bivariate correlations and an independent t-tests were used for normally distributed variables (Aim 1). In line with the guidelines provided by the NSF, age was recoded into a dichotomous variable to distinguish between two age groups: school-aged children (6-13 years, $n = 35$) and teenagers (14-17 years, $n = 14$) (Hirshkowitz et al., 2015).

To address aim two, a two-step hierarchical linear regression was conducted in the sample ($n = 45$) to determine the association between presence of psychiatric diagnosis and heightened insomnia severity symptoms (Aim 2). In step one, youth age, sex, GMFCS level were entered as covariates given their association with insomnia in both typically developing and

neurodiverse populations. The associations between independent predictor variables (i.e., GMFCS, age, gender) and dependent variables are shown in Table 5.

Results

Sample Characteristics

Demographic characteristics are presented in Table 2. On average, participants were 11 years old ($SD = 2.67$, range, 8-17 years). Among the 45 youth participants, there were 18 females (40%), 26 males (57.8%) and one youth (2.2%) who did not identify as female or male. In terms of ethnicity, 77.8% of the youth identified as White, 17.8% as biracial or belonging to other racial backgrounds, and 4.4% as First Nations. A small portion of youth (6.7%) were born outside of Canada. The level of severity of CP among youth, according to the Gross Motor Function Classification System (GMFCS), was 42.9% Level I, 38.1 as Level II, 8.9% as Level III, 6.7% as Level IV, and 2.2% as Level V. GMFCS levels were also collapsed into two groups, GMFCS levels I-II (independently ambulant; 81%) and GMFCS levels III-V (not independently ambulant; 20%) (Horwood et al., 2019). GMFCS level data was not obtained or available from 3 participants.

In terms of psychiatric health issues, approximately 24.4% ($n = 11$) of the youth had received a mental health or psychiatric diagnosis from a registered health professional prior to participation. Specifically, three youths had an anxiety disorder, three had attention-deficit/hyperactivity disorder (ADHD), one had depression, and five had multiple co-occurring diagnoses, with Specific Learning Disorders (SLD), anxiety, and depression being the most common. Additionally, 35.6% ($n = 16$) of our sample were on medication at the time of enrollment. Specifically, nine participants were on psychotropic medication, four were on non-psychotropic medication (e.g., Baclofen to treat muscle spasticity, or Sulthiame to prevent seizures), and three did not provide any information regarding the type of medication they were taking. Youth with psychiatric health diagnosis were significantly older ($M = 13.91$, $SD = 2.43$)

than those without ($M = 10.66$, $SD = 2.25$, $t_{(43)} = 4.07$, $p < .001$, Cohen's $d = 1.41$). No sex differences were observed when examining youth with and without psychiatric health diagnoses or medication use at the time of enrollment (p 's $> .05$).

Table 2

Youth Demographic Information (N = 45)

	<i>M (SD)</i>	n	%
Age	11.5 (2.68)		
Sex			
Female		18	40
Male		26	57.8
Other		1	2.2
GMFCS^a			
Level I		18	42.9
Level II		16	38.1
Level III		4	8.9
Level IV		3	6.7
Level V		1	2.2
Psychiatric diagnosis			
Yes		11	24.4
No		34	75.5

Note GMFCS = Gross Motor Function Classification System.

^aGMFCS was missing or not available for 3 participants.

Missing Data

In the current study, each study variable was analyzed separately for missing data by initially using frequency distribution. According to Tabachnick and colleagues (2012), 5 to 10% of missing cases are reasonable. There was minimal missing data, with less than 10% missing for all sleep variables apart from WASO, NOA and SE, which had missing data for 9 participants. Sleep diary data was missing from 1 to 4 days with the highest missing days on 1 and 7. Little's Missing Completely at Random (MCAR) test resulted in a non-significant p-value ($\chi^2 = 107.906$, $df = 115$, $p = .66$), which demonstrated that data were missing in a random fashion and analysis

was conducted using all available data (Little & Rubin, 1989). GMFCS data, with 6.7% missing data, was unavailable for three participants due to caregivers omitting this item. Additionally, two participants did not complete all items on the ISI or CSWS, preventing the computation of a total composite score for each of these measures. To assess the pattern of missing data, the MCAR test was conducted. The results indicated a non-significant p -value for both the ISE and CSWS ($\chi^2 = 0.039$, $df = 3$, $p = .99$, and $\chi^2 = 11.34$, $df = 6$, $p = .07$, respectively), suggesting that the data was missing completely at random

Caregiver Characteristics

Most parents were married/common-law (91.1%), with 82.2% having college/university education or higher and were aged between 29 and 59 years ($M = 43.7$, $SD = 5.69$). Regarding household income, approximately half of the participants (53.3%, $n = 24$) reported an income above \$100,000. Approximately 22.4% ($n=10$) of participants chose not to share their income information. Among the caregivers in the study, 41 (91.1%) were biological parents, three (6.7%) were adoptive parents, and one (2.2%) were foster parents or grandparents. Family structure was reported as follows: living in a two-parent household (all family members biologically related, 73.3%), two-parent household stepfamily (6.7%), single-parent household (6.7%), two-parent adoptive family (6.7%), and other (6.7%).

Objective Measures of Sleep Characteristics

The sleep characteristics of youth were determined using actigraphy, and the patterns were described in relation to what is known about sleep in youth without CP utilizing the National Sleep Foundation (NSF) guidelines (Hirshkowitz et al., 2015). A description of youth's sleep characteristics as recorded by the actigraph are presented in Table 3.

Bedtime and wake-up time

On average, youth reported a bedtime of 9:35 PM ($SD = 1:18$) and a wake-up time of 7:21 AM ($SD = 1:04$). Youth's bedtime ranged from 6:42 PM to 1:44 AM whereas wake-up time ranged from 5:00 AM to 10:30 AM. While most youth had early bedtimes (i.e., before 10:30 PM), there were five youth in our sample that had average bedtimes past 10:30 PM. Significant differences were not observed in bedtime and wake-up time patterns based on sex, age, psychiatric diagnosis, and medication status, all p -values $>.05$. With a larger sample size, it is likely we would see differences in bedtime and wake-up time. However, we found significant differences among youth with different levels of gross motor functioning (I-II vs. III-V). Youth with gross motor functioning levels I-II had significantly later bedtimes ($M = 21:48$ PM, $SD = 1:18$) and wake-up times ($M = 7:35$ AM, $SD = 1:00$) compared to youth with levels III-V ($M = 20:27$ PM, $SD = 0:58$ and $M = 6:34$ AM, $SD = 0:47$, respectively) ($t_{(36)} = 2.56, p = .015$, Cohen's $d = 1.07$ and $t_{(36)} = 2.50, p = .017$, Cohen's $d = 1.04$, respectively).

Sleep duration

The average sleep duration of youth was 10:01 hours per night ($SD = 0:59$), ranging from 7.5 hours to 12.85 hours. Two youth slept more than the recommended amount for their age based on the National Sleep Foundation's (NSF) recommendations ($n = 2, \geq 11$ hours, teenagers 14 - 17 years; Hirshkowitz et al., 2015). This recoding allowed us to analyze and compare sleep characteristics within these distinct developmental stages, aligning with the NSF's age-based sleep guidelines. An independent samples t -test revealed no significant differences between age group (based on the NSF's sleep guidelines) on sleep duration ($t_{(39)} = -.557, p = .43$). No other differences were observed based on sex, psychiatric diagnosis, or medication status.

Awakenings

Youth experienced a mean number of 14 awakenings (>5 min) per night ($SD = 5.3$), with the number of awakenings ranging from 1 to 29 awakenings. Nighttime awakenings exceeded the four awakenings that are typical for youth as indicative of good sleep quality, according to the NSF (Hirshkowitz et al., 2015). There were no differences in number of awakenings by age, sex, psychiatric diagnosis, GMFCS or medication status (all p 's < .005).

Wake after sleep onset (WASO)

In regard to wake after sleep onset (WASO), or the average duration of time that the youth was awake after initially falling asleep, youth displayed different levels of WASO. The mean WASO was 36 minutes ($SD = 15$ min), ranging from 8 minutes to 76 minutes. Eight youth in our sample experienced WASO durations that exceeded the recommended amount for their age groups by the NSF (Hirshkowitz et al., 2015). Specifically, among school-aged children (6 to 13 years of age), six participants ($n = 6$) had WASO greater than 41 minutes ($M = 52.17$, range, 46.89 – 65.44) (Hirshkowitz et al., 2015). Additionally, two teenagers (14 to 17 years of age) had WASO durations exceeding 51 minutes ($M = 68.59$ min, range, 60.50 – 76.67, $n = 2$) indicating a potential concern for disrupted sleep (Hirshkowitz et al., 2015). Youth who were taking medication had significantly lower WASO ($M = 28.7$ min, $SD = 8.93$) compared to youth not taking medication ($M = 40.5$, $SD = 16.12$; $t_{(32)} = -2.73$, $p = .019$, Cohen's $d = 0.86$). There were no differences in number of awakenings by age, sex, psychiatric diagnosis, or GMFCS (all p 's < .005).

Sleep efficiency

On average, sleep efficiency (the length of time spent asleep, as a percentage of the total length of time spent in bed) was within the guidelines of the NSF, which recommends SE above 85% (Hirshkowitz et al., 2015). In our sample, mean sleep efficiency was 89.9% ($SD = 4.7\%$),

ranging from 79.9% to 97.3%, indicating that most youth did not have poor objective sleep quality (Hirshkowitz et al., 2015). However, six youth's sleep efficiency (13.3%) fell below the range for "good sleep quality" ($\geq 85\%$) but remained above the range for "poor sleep quality" ($\leq 74\%$), ranging from 79.9% to 82.0% sleep efficiency (Hirshkowitz et al., 2015). There were no differences in sleep efficiency by age, sex, psychiatric diagnosis, GMFCS or medication status (all p 's $> .005$).

Table 3

Distribution of youth sleep patterns based on sex differences

	Full sample	Females	Males
	(N = 42)	(N = 13)	(N = 28)
Sleep Data^a	M + SD	M + SD	M + SD
Sleep duration (h)	10:01 \pm 0:59	9:49 \pm 1:17	10:09 \pm 0:44
Bedtime (h)	21:35 \pm 1:18	21:54 \pm 1:30	21:22 \pm 1:10
Wake-up time (h)	7:21 \pm 1:04	7:35 \pm 1:13	7:13 \pm 0:59
Wake after sleep onset (min)	35.68 \pm 14.70	32.90 \pm 12.53	35.43 \pm 13.50
Number of awakenings	13.94 \pm 5.30	12.53 \pm 4.98	14.07 \pm 4.30
Sleep efficiency (%)	89.90 \pm 4.78	90.04 \pm 4.97	90.08 \pm 4.75

Note. The discrepancy sample sizes reported in the table is due to missing or incomplete data.

^aDerived from actigraphy.

Subjective ratings of sleep quality

Subjective measures of sleep quality were measured using the total score of the Sleep-Wake Scale (SWS)–self-report (i.e., ASWS) for youth 13 years or older and SWS–parent report (i.e., CSWS) for youth aged 7 to 12 years old. Given the range of ages of the current study participants and consistent with existing literature, total scores from the CSWS and ASWS were analyzed together as an overall representation of sleep quality in the current sample

(Hockenberry et al., 2021; Hooke et al., 2018; LeBourgeois et al., 2001; LeBourgeois & Harsh, 2016; Lewandowski et al., 2011; Storfer-Isser et al., 2013).

The mean score for CSWS was 4.03 (SD = 1.07, range 1.72 – 5.80), and for the ASWS, it was 3.12 (SD = 1.31, range 1.04 – 5.20). The overall total sleep quality score for all youth was 3.68 (SD = 1.2; range = 1.04 – 5.80), indicating that most youth experienced low sleep quality (Axelsson et al., 2022; Prince et al., 2010). Lastly, we found significant differences between males and females in terms of sleep quality (see Table 4). Females had a better overall sleep quality ($M = 4.15$, $SD = 1.09$) compared to males ($M = 3.37$, $SD = 1.26$, $t_{(40)} = -2.11$, $p = .041$, Cohen's $d = 0.66$). No other differences in subjective sleep quality by age, psychiatric diagnosis, GMFCS or medication status were observed (all p 's > .005).

Table 4

Distribution of youth subjective sleep quality based on sex differences

Sex Differences				
	Full sample	Females	Males	
	(N = 42)	(N = 18)	(N = 24)	
	M + SD	M + SD	M + SD	t
Total sleep quality score ^a	3.68 (1.24)	4.15 (1.09)	3.37 (1.26)	-2.11*
Going to bed ^a	3.19 (1.33)	3.27 (1.37)	3.13 (1.36)	-0.358
Falling asleep ^a	3.93 (1.35)	4.28 (1.08)	3.75 (1.48)	-1.28
Maintaining sleep ^a	3.48 (1.48)	3.74 (1.48)	3.40 (1.44)	-0.737
Reinitiating sleep ^a	3.44 (1.60)	3.48 (1.60)	3.47 (1.60)	-0.005
Returning to wakefulness ^a	3.69 (1.55)	3.86 (1.30)	3.58 (1.30)	-0.571

Note. ^aRatings are calculated as a mean score for each subscale, ranging from 1 to 6, with higher scores indicating better sleep quality. Scores include both the CSWS and the ASWS.

CSWS = Children's Sleep Wake Scale.

ASWS = Adolescent Sleep Wake Scale.

The discrepancy in numbers reported in the table is due to missing or incomplete data.

(*) denotes a significant group difference ($p < .05$)

Sleep problems – insomnia

The ISI score among all youth participants was 6.76 (SD = 6.59; range, 1 – 27), indicating that most youth were not presenting with clinical insomnia; however, approximately 11% had moderate-to-severe insomnia symptoms ($n = 5$, 10.9%) (Bastien et al., 2001; Morin et al., 2011). Nine youth reported subthreshold insomnia (ISI total score 8 – 14), two had scores indicating clinically moderate severity insomnia (ISI total score range = 15 – 21), and three had scores indicating clinically severe insomnia (ISI total score range = 22 – 28). Most of the youth did not experience clinical insomnia (i.e., above subthreshold, 71.1%). Furthermore, among the youth, the most identified sleep complaints, in descending order, were sleep initiation (38.1%), early morning awakenings (30.9%), sleep maintenance (i.e., difficulty staying asleep; 28.6%), and daytime impairment (28.6%). There were no differences in ISI total scores by age, sex, psychiatric diagnosis, GMFCS or medication status (all p 's $> .005$)

Regression analyses predicting severity of insomnia

The number of variables included in the regression analyses were based on the rule of thumb that estimate the minimum sample size for a regression analysis based on a constant (e.g., > 50), the ratio of observations to predictor variables, or a combination of these factors. The most common rule of thumb is reported to be the “rule of 10” which is widely acknowledged and applied in research and are important for power, and effect size implications (Green, 1991; Westland, 2010). As such, only sex, GMFCS, and age were included in the regression analysis given their association with insomnia in both typically developing and neurodiverse populations. Above and beyond youth demographics (i.e., sex, GMFCS, and age), psychiatric diagnosis was

significantly negatively associated with insomnia severity, indicated by ISI total score. Block one only explained 9.7% of the variance in the model ($p = .305$). Block two of the hierarchical linear regression, which included psychiatric diagnosis, while controlling for participant demographics, did account for a significant amount of unique variance in insomnia severity, $R^2 = .26$, $\Delta R^2_{(1, 34)} = .16$, $p = .010$. Overall, the presence of psychiatric diagnosis was significantly associated with greater insomnia severity scores, above and beyond other relevant youth demographic variables. See Table 5 for a full summary of the results of the hierarchical linear regression.

Table 5

Regression Predicting Insomnia Severity from Psychiatric Diagnosis

Regression Step	R^2	B	SE	β
Step 1	.09			
Age		-0.51	0.41	-0.21
Sex		-2.25	1.95	-0.19
GMFCS		1.21	1.20	0.16
Step 2	.26 ^{*,+}			
Age		-1.25*	0.47	-0.48
Sex		-0.96	1.86	-0.09
GMFCS		0.02	1.19	0.01
Psychiatric diagnosis		-8.35*	3.06	-0.53

Note. For sex, 1 = male, 2 = female. For psychiatric diagnosis, 1 = yes diagnosis, 2 = no

diagnosis. GMFCS = Gross Motor Function Classification System.

(*) = $p < 0.05$.

⁺Denotes significant R^2 change.

Discussion

This exploratory study aimed to characterize and describe the sleep patterns of youth with CP and determine how youth demographics (age, sex, GMFCS, psychiatric diagnosis, and medication status) may impact sleep. Sleep is a dynamic process that changes throughout childhood and adolescence, playing a crucial role in promoting both physical and mental health. (Brindle et al., 2018; Chaput et al., 2018; Crowley et al., 2018; Dagys et al., 2012; Dewald et al., 2010). At the same time, sleep is a complex and multifaceted phenomenon that varies and is unique to each person, especially neurodivergent individuals (Brindle et al., 2018; Chaput et al., 2018; Crowley et al., 2018; Dagys et al., 2012). Thus, understanding the multiple domains of sleep in youth with CP is essential, as it provides important insight that can help inform the development of more tailored interventions (Brindle et al., 2018; Chaput et al., 2018; Crowley et al., 2018; Dagys et al., 2012).

In the current study, youth with CP displayed unique sleep patterns and difficulties. Compared with existing literature in neurotypical youth, the CP group exhibited significantly greater disrupted sleep as measured by the actigraphs. Specifically, youth showed varying levels of WASO, with approximately a quarter (23.5%, $n = 8$) experiencing WASO durations exceeding the recommended amount (i.e., ≥ 41 minutes), which could be a distinct characteristic of sleep in this group. While over 75% of youth had WASO durations that were, on average, within what would be expected relative to age-based norms, they experienced a significantly greater number of awakenings per night (i.e., an average of 14 awakenings), surpassing the NSF's recommendation of fewer than four awakenings per night, which is considered indicative of good sleep quality (Hirshkowitz et al., 2015). While sleep efficiency (SE) based on the actigraphs was within the normal range, most participants reported poor subjective sleep quality

(Hirshkowitz et al., 2015). Additionally, females had better overall sleep quality compared to males. Other actigraphic sleep parameters, including sleep duration, bedtime, and wake-up time, were similar to what we expect of same-age peers (Hirshkowitz et al., 2015; Honaker et al., 2014). Lastly, most youth did not meet the subthreshold for clinical insomnia; however, approximately 11% had moderate-to-severe insomnia symptoms (Manzar et al., 2021; Morin et al., 2011). Psychiatric health issues were associated with higher insomnia severity, over and above the impact of GMFCS level, age, and sex.

Regarding sleep duration, we found that most youth (92%) met the age-appropriate sleep duration recommendations according to actigraphy, which adds to already mixed literature. Consistent with the present findings, Horwood and colleagues (2019) also found that approximately 90% of school-aged children with CP met sleep recommendations. However, Hulst et al. (2021) found that only 35.5% of their sample of youth with CP meet age-appropriate recommendations. In other recent studies, the proportion of youth without CP that adhere to sleep recommendations ranged from 50% to 60%, demonstrating that most youth in the current sample were unique in meeting sleep duration recommendations (Hansen et al., 2022; Schmied et al., 2022). An explanation for this inconsistency in these results relative to previous literature could be the potential impact of the COVID-19 pandemic, as most data for this study was collected during the early phases of the pandemic. We now know that the COVID-19 pandemic led to substantial lifestyle changes due to stay-at-home orders implemented globally to prevent the spread of the virus (Bigalke et al., 2020; Breda et al., 2023; Łuszczki et al., 2021; Kiss et al., 2023). There is emerging evidence highlighting that these changes and social restrictions significantly impacted sleep timing behaviours, resulting in individuals either sleeping less or exceeding the NSF's guidelines for sleep duration (Łuszczki et al., 2021; Kiss et al., 2023).

Given that there is no study that has examined how the sleep patterns of people with CP were impacted by the pandemic, it is unclear if the current findings are representative of our sample's 'normal' sleep durations or were extended due to such lifestyle changes. Further longitudinal research is needed to determine typical fluctuations and patterns of sleep duration and quality, as well as recommendations for sleep in particular for children and youth with CP.

Similarly, the role of race/ethnicity and socioeconomic indicators (e.g., income, parental education) may also explain the inconsistency between our findings and previous literature. For instance, in the context of neurotypical youth, females tend to sleep longer compared to males, and ethnic minority youth tend to experience less sleep in comparison to their White counterparts. Importantly, most of the youth in our study were male and White, which may contribute to the differences observed in our results when compared to previous literature (Duncan et al., 2023).

Our findings show similar patterns in bedtimes and wake-up times. Although most youth in our sample had early bedtimes, five youth had average bedtimes past 10:30 PM. Although there are no particular bedtime guidelines in the general population, the limited amount of literature suggests that bedtimes beyond 10:30 PM may be associated with higher odds of experiencing mental health outcomes such as greater anxiety, lower alertness, and increased negative thoughts (Honaker & Meltzer, 2014; Merikanto et al., 2013; Reid et al., 2023). It is unknown whether youth with CP prefer later bedtimes, and more research is needed to determine if a later circadian profile is the norm for this population. Sleep is typically driven by two overlapping processes: the homeostatic process (Process S) and the circadian drive process (Process C) (Borbély et al., 2016). The circadian drive provides alertness, or wakefulness during the day and sleepiness later in the evening (Borbély et al., 2016). In people with

neurodevelopmental disabilities (NDDs), particularly ADHD, it has been suggested that a shift in the profile exists. For example, a recent systematic review suggests that a delayed or later circadian phase (evening preference) is common in youth and adults with ADHD (Coogan & McGowan, 2017). In particular, this review included 25 studies in adults with ADHD and 37 studies involving children or adolescents with ADHD (Coogan & McGowan, 2017).

Although most youth in our sample had average WASO durations based on age-appropriate recommendations, about one-third experienced WASO durations exceeding those recommendations (Ohayon et al., 2017). This is interesting given that WASO is generally shorter in the general youth population, with approximately 50 minutes based on the NSF guidelines being generous (Ohayon et al., 2017; Sivertsen et al., 2017). In the existing literature, WASO durations in youth with CP range substantially from around 41 minutes (Angriman et al., 2015) and others reporting approximately 181 minutes of WASO (Xue et al., 2022). In particular, Xue and colleagues (2022) found that children with CP had longer WASO compared with children without (181 vs 113 min). However, it is important to note that Xue and colleagues (2022) employed different actigraphy placements (i.e., forehead and wrist) and a specific algorithm to estimate sleep or wake intervals. They used polysomnography (PSG), a gold standard sleep monitoring method, to align the first night of actigraphy to sleep–wake stages of PSG (Xue et al., 2022). Second, they divided participants ($n = 26$) into two groups (CP and control group), and then examined differences based on where they wore the actigraphy devices, forehead or wrist to find the most consistent placement. Finally, they used weighted logistic regression to accurately predict whether a given 1-minute time interval was sleep or wake, considering the differences in movement patterns and group characteristics (Xue et al., 2022). Overall, they found their method to be valid and reliable. These results suggest that this specific algorithm enhances the

actigraphy's ability to measure sleep accurately. These findings demonstrate that further research is needed to explore existing algorithms for capturing sleep in youth CP, especially considering their motor challenges.

Moreover, in a study of youth with ADHD, youth averaged 44.5 min WASO during a 5-day experimental period, which is far less than our CP sample (Owens et al., 2009). Furthermore, both in the general population and neurodiverse population, wrist actigraphy, the current method used in this study, has been observed to underestimate the duration of WASO in youth, particularly those with CP who tend to remain quietly awake (Meltzer et al., 2012; Hulst et al., 2023; van Rijssen et al., 2023; Short et al., 2012; Short et al., 2020; Weiss et al., 2019). For instance, in a study involving neurotypical youth, Short and colleagues (2012) found that actigraphy significantly underestimated their total sleep time (thus overestimating their WASO) by an average of 47 minutes per night. Moreover, this underestimation was more pronounced in boys compared to girls and exhibited greater overall variability (Short et al., 2012). This presents a significant concern in terms of both the accuracy and practicality of using actigraphy for adolescents, especially considering that the majority of the youth in our study were males (Short et al., 2012). As such, the duration of WASO recorded through actigraphy may not fully represent the true WASO experienced by the youth in our sample.

Awakenings are the number of times an individual wakes up during the night, regardless of how long they stay awake during each awakening (Ohayon et al., 2017). Here we found that almost all, but one participant had 4 or more awakenings per night which is an appropriate indicator of poor sleep quality (Ohayon et al., 2017). Given that many youth with CP experience pain, such as spasticity and muscle tension, this may cause them to wake up briefly multiple times during the night (i.e., number of awakenings) (Horwood et al., 2019; van Gorp et al., 2021)

Additionally, it has been reported that youth with CP may have greater abnormalities in sleep spindles and an absence of non-rapid eye movement (NREM) (Newman et al., 2006). For example, Shibagaki and colleagues (1986) found that participants with CP experienced atypical or missing spindle components. More recently, it was found that autistic youth also exhibit alterations in rapid eye movement (REM) density and atypical activity in spindles during sleep (Miano et al., 2007; Richdale et al., 2009). Sleep spindles are brief bursts of brainwave activity during NREM sleep and are associated with memory consolidation, information processing and sleep quality (Miano et al., 2007; Richdale et al., 2009). Sleep literature supports that a reduction in sleep spindles may result in more frequent awakenings during the night, leading to disrupted sleep and poorer overall sleep quality (Miano et al., 2007; Richdale et al., 2009; Steriade, 2006). Although no study has investigated how these atypical or missing spindle components may impact sleep in people with CP, Dang-Vu and colleagues (2015) reported that neurotypical youth were found to experience worse sleep quality with lower spindle activity. Specifically, Dang-Vu and colleagues (2015) found that lower spindle activity at the beginning of the night predicted increases in insomnia symptoms in youth without CP. Lastly, medical comorbidities that many people with CP experience may also interfere with sleep, such as gastroesophageal reflux, upper airway obstruction, spasticity, and vision (Lélis et al., 2016; Simard-Tremblay et al., 2011). The higher fragmentation of sleep, indicated by increased awakenings, can be attributed to these disruptions, which often occur during the night for these individuals (Lélis et al., 2016; Simard-Tremblay et al., 2011). Further research is needed to determine what underlying mechanisms may be contributing to these increased awakenings and identify the best wake-detection method to understand sleep in this population.

With respect to sleep quality, most youth exhibited sleep efficiency (SE), or objective sleep quality, within the normal range, according to the actigraph data (Ohayon et al., 2017). These findings are concordant with previous research, such that Hulst and colleagues (2023) found that the SE of the total study sample was 82.4%. They found that approximately half of the children had an average sleep efficiency above 85%, like most youth in our sample (64.4%) (Hulst et al., 2023). This finding might be due to their lower than expected WASO, indicating that youth may have been able to transition back to sleep efficiently despite the frequent awakenings. The lower WASO data demonstrates that disruptions during the night were minimal, allowing them to experience smoother sleep continuity or re-initiating sleep. This finding further supports the notion that youth with CP demonstrate adequate objectively measured sleep efficiency.

Objective sleep quality was inconsistent with youth, and caregiver reported sleep efficiency or subjective sleep quality. The average sleep quality was reported as $M = 3.67$ which is lower than what has been reported in the literature for both neurodiverse and neurotypical youth (Loram et al., 2021; Essner, et al., 2015). Furthermore, even when compared to studies involving youth experiencing pain, our findings reveal significantly lower subjective sleep quality scores, suggesting potentially unique sleep experiences within youth with CP (Zafar et al., 2012). Zafar and colleagues (2012) investigated self-reported sleep patterns and daytime sleepiness in youth with multiple sclerosis (MS) using the ASWS. Overall, the youth with MS reported much better sleep quality scores (ASWS total score = 4.11) compared to our sample (CSWS/ASWS total score = 3.67). Similarly, in Loram and colleagues' (2021) study, sleep quality scores were significantly higher, as reported by youth with ADHD compared to youth with CP youth in our study. Although only a limited number of studies have utilized a combined

CSWS and ASWS score, it has been shown to be a valid tool to assess sleep (Hockenberry et al., 2021; Hooke et al., 2018; Lewandowski et al., 2011). For example, in a recent study by Hockenberry and her colleagues (2021), assessing the feasibility of Parent Education Discharge Support Strategies (PEDSS) for children with cancer, significant improvements (no mean was reported) in subjective sleep quality were observed using combined CSWS and ASWS.

In addition to sleep patterns, we also found varying insomnia symptoms in our sample, which is a novel finding in youth with CP as existing literature is limited (Löwing et al., 2020). Most youth were not presenting with clinical insomnia, with only 11.1% experiencing moderate-to-severe insomnia as indicated by their Insomnia Severity Index (ISI) scores. Only one study has reported insomnia symptoms in a large cohort (n=95) youth with CP; however, due to the non-normal distribution in their data, results were presented with median and interquartile ranges (Löwing et al., 2022). Löwing and her colleagues (2022) found that youth reported a median ISI value of 3, suggesting that most youth in their study had lower insomnia symptom levels. Moreover, Löwing and colleagues (2022) reported significant differences in median ISI total scores based on GMFCS levels, indicating greater insomnia severity with higher motor difficulties (i.e., GMFCS Level V). The present study contradicts this finding as no differences in insomnia severity total symptoms were found between ambulatory and non-ambulatory GMFCS levels. However, this may be partially explained by our limited ability to analyze data for higher GMFCS levels due to the small number of youth (GMFCS Level V, n = 1). Although no differences were found based on age, sex, psychiatric diagnosis, GMFCS or medication status, a significant percentage of youth experience moderate-to-severe insomnia, which warrants further investigation.

Poor sleep quality, both objective and subjective, is a characteristic feature of insomnia (Bastien et al., 2001; Roberts et al., 2013; Spielman et al., 1987). Although the present study identified poor subjective sleep quality, and not objective sleep quality, it is essential to note that the frequent use of medications may mask sleep disorders such as insomnia (Blake et al., 2017; Dutt et al., 2015; Duncan & Maitre 2021). For example, while poor sleep quality may not always be flagged by objective measures, sleep disturbances, such as insomnia symptoms, can still significantly impact an individual's subjective sleep such that they feel unsatisfied regardless, which may explain why most youth in our study reported 'good' objective sleep quality (i.e., sleep efficiency) but lower subjectively measured sleep quality (CSWS/ASWS total scores) (Dutt et al., 2015; Duncan & Maitre 2021; Wickwire Jr et al., 2008). Moreover, youth with CP often take various medications, such as antihistamines, hypnotics, antispasmodics, antipsychotics, anticonvulsants, and antidepressants, which may influence the overall reporting of insomnia severity (Lélis et al., 2016; Newman et al., 2006; Wright et al., 2006). Notably, just over a third of the youth in our sample were taking medications, with most on psychotropic medication, which could explain the 'good' objective sleep quality but lower subjectively measured sleep quality findings. Although we found no significant difference in ISI, subjective sleep quality or sleep efficiency, between youth using prescription medication and those not using any prescription medications, with a larger sample size, it is likely that we see significant differences between these important sleep variables. This finding is consistent with the study by Hulst and colleagues (2021), who also reported no differences in subjective sleep patterns based on medication status in a sample of youth with CP. The only difference observed was WASO which could be explained by the use of medication (Hulst et al., 2021). It is possible that

medication helps these individuals fall back asleep more quickly compared to those who are not on medication.

Disentangling whether medication improves or worsens sleep is challenging, as both effects have been reported in the existing literature (Lunsford-Avery et al., 2016; Meltzer, & Mindell, 2006). Furthermore, we found a significant association between the presence of a psychiatric diagnosis and the severity of insomnia symptoms. This finding aligns with existing literature in neurotypical populations, where psychiatric diagnoses are linked to increased insomnia severity, even after controlling for chronic medical conditions, age, and sex (Alfano et al., 2007; Becker et al., 2017; Langberg et al., 2019). In a recent large epidemiological study involving a sample of 2086 adult participants, Sarsour and colleagues (2010) also reported that the presence of one or more comorbid illnesses was associated with a rise in insomnia severity. Given the interplay between insomnia and other mental health conditions, future studies need to explore the contributions of mental health conditions, such as depression and anxiety, to insomnia severity in individuals with CP (Alfano et al., 2007; Becker et al., 2017; Blank et al., 2015; Langberg et al., 2019).

Regarding our significant findings for sex differences in subjective sleep quality, historically, literature has described that sex and gender are sociodemographic factors associated with sleep quality, usually females reporting worse sleep quality than males (Forest et al., 2022; Galland et al., 2017). However, our findings differ from the literature on neurotypical youth, such that females in our sample experienced better sleep quality than males (Forest et al., 2022; Galland et al., 2017). An explanation for the gender difference is unclear; however, it is possible that COVID-19 restrictions could have exacerbated sleep problems more in males than females. For example, Fowler and Kumte (2022), found that females reported significantly lower sleep

quality before the stay-at-home order than males. However, after the stay-at-home order, males reported significantly worse sleep quality than females (Fowler & Kumte, 2022). Moreover, some literature highlights that sleep is more impacted in youth with GMFCS levels IV-V (Horwood et al., 2019; Löwing et al., 2020; Simard-Tremblay et al., 2011). In the current study, most of our sample had GMFCS levels I and II, and the sleep problems present in the current literature may be more prominent in higher GMFCS levels. More research with children and youth with varying gross motor impairments is needed as they are likely to have more severe comorbidities, like pain and muscle stiffness, which might have a profound impact on their sleep duration (Hulst et al., 2021; Löwing et al., 2020; Whitney et al., 2020).

While many factors related to CP may further exacerbate poor sleep, pain is a common comorbidity that has been shown to affect sleep experiences in youth with CP (Horwood et al., 2019; Hulst et al., 2021; Löwing et al., 2020; Whitney et al., 2020; van Gorp et al., 2021). For example, in a study involving adults with CP, those with higher proportion self-reported pain experienced significantly more sleep problems (Rodby-Bousquet et al., 2021). Findings from a small sample of children with CP between the ages of 6 and 17 years found that most children reported that pain interfered with their sleep (Engel et al., 2006). Future research may aim to determine whether pain in CP may promote sleep health may be reported by reducing pain and related sleep interference in children and youth's sleep.

Youth with CP may report poor subjective sleep quality due to various factors. First, undiagnosed sleep disorders that affect sleep quality are common in the neurodivergent individuals, even when objective sleep measures, such as sleep efficiency and WASO, appear relatively normal (Ipsiroglu et al., 2022; Jan et al., 2008). Literature highlights that many children and youth with underlying sleep problems go undiagnosed and untreated for conditions

like insomnia, sleep apnea, or restless leg syndrome (Valrie et al., 2013; Youssef et al., 2013). Second, fragmented sleep, characterized by brief awakenings, is common in our sample and among youth with pain, which can significantly impact overall sleep quality over and above objective measures (Allen et al., 2017; Youssef et al., 2013). Lastly, researcher suggests that mood factors, such as anxiety and depression, and low physical activity in the general population are perceived by individuals as directly impacting their subjective sleep quality (Hayley et al., 2013; Hulst et al., 2021; McMorris et al., 2021; Whitney et al., 2020). As such, these daily factors, which are common in youth and adults with CP, may have also contributed to the subjective sleep quality experiences within our study. As such, it would seem, for children and youth with CP at least, that subjective sleep quality appears to be distinct from objective sleep quality.

The results of the current study have several practical and theoretical implications. First and foremost, understanding the sleep patterns of youth with CP contributes to the limited literature on this population. While previous research has primarily focused on sleep duration, other aspects of sleep have been largely overlooked, such as the number of awakenings, WASO, subjective sleep quality, and sleep efficiency (Albayrak et al., 2019; Badaru et al., 2021; Sandella et al., 2011). Furthermore, sleep disturbances have been consistently identified as significant risk factors for later worse quality of life and increased mental health difficulties in neurotypical youth (Crowley et al., 2018). Clinically, it may be possible to support youth with problems with sleep and target them for intervention. Early identification and sleep health promotion can mitigate long-term sleep problems, which is essential for youth with CP, who are already a vulnerable population.

Strengths and Limitations

The results of our exploratory study should be considered in light of its strengths and limitations. As for the strengths, the results of this study provide important new information on the patterns of sleep and sleep problems in youth with CP. To my knowledge, this is one of a number of only a few studies offering an in-depth characterization of sleep patterns, sleep disturbances, and the factors associated with sleep among youth with CP using subjective and objective measures to assess sleep comprehensively. Second, our sample was more representative of youth across a wide range of ages, which provides a valuable opportunity to explore the diversity and dynamics of sleep in this critical developmental period.

There are also several potential limitations to this study. First, this study was conducted with youth primarily from White and upper-class backgrounds, limiting the findings' generalizability. Furthermore, due to the sample size, the current study was also limited in exploring ethnicity. While existing literature has presented mixed findings, literature has suggested that minority and or ethnic status, specifically among Black and Latinx neurotypical youth plays a role in sleep outcome (Roberts et al., 2000). Empirically, most often, it is the intersectionality between ethnicity status and status differences (e.g., socioeconomic status) that primarily affect sleep outcomes (Roberts et al., 2000). Clearly, more research is needed to determine how the intersectionality between ethnicity or culture and status background affects sleep. Therefore, future research should aim to recruit a more representative sample. Second, the study had a relatively small sample size (< 50), reducing our analyses' statistical power. Thus, nonsignificant findings need to be interpreted with caution. Furthermore, we were limited in our ability to statistically control for factors that likely impact sleep in this population, such as pain and physical activity. Third, it is important to note that the study did not collect specific information regarding children and youth's cognitive ability as well as presence and level of

intellectual disability. This may have impaired their understanding of specific questions and their ability to accurately report on their sleep and mental health experiences. Further research is needed to understand if sleep patterns may be the same or different in people with CP and co-occurring intellectual disability.

Fourth, our study utilizes actigraphy to measure sleep; however, although this tool is sensitive to sleep continuity, it has low specificity for wakefulness. In our sample, the use of actigraphy may have led to an overestimation of sleep variables like sleep duration and an underestimation of SE and WASO. Future work should utilize specific CP algorithms to accurately assess sleep in this population, such as one proposed by Xue and colleagues (2022) who suggest that actigraph placement is important.

Fifth, this study did not include information on the subtype of CP (e.g., spastic, dyskinetic, etc.). The subtype of CP can provide information regarding motor impairments or associated comorbidities that can impact sleep (Horwood et al., 2018; Löwing et al., 2020). For example, hyperkinetic movements, which are unwanted or excess movements, are more commonly seen in the dyskinetic form of CP and can lead to discomfort, pain, and difficulty finding a comfortable sleep position, which may impact both the subjective experience of sleep and the measurement of sleep via actigraphy (Sanger et al., 2010). Moreover, Löwing and colleagues (2020) found that children with dyskinetic CP had significantly higher insomnia severity scores than children with other subtypes regardless of motor functioning. Identifying information on the subtype of CP can provide us with valuable insight in regard to how topographical types can further describe sleep outcomes within this population. Lastly, we also did not include a control group in our study. Future work will need to determine the

characteristics of sleep in youth with CP compared to neurotypical youth and other neurodevelopmental disorders.

Conclusion

The present study contributes significantly to our knowledge and understanding of sleep patterns experienced by youth with CP. The findings demonstrate that youth with CP generally have average sleep duration, reported sleep efficiency, and Wake After Sleep Onset (WASO), aligning with age-based recommendations. However, they are vulnerable to fragmented nighttime sleep and experience poorer sleep quality. Additionally, co-occurring diagnoses may contribute to greater insomnia severity, compromising overall functioning. Overall, this study plays a crucial role in developing our understanding of sleep characteristics among youth with CP. Addressing and managing sleep difficulties in individuals with CP can enhance their sleep quality, promote better physical and cognitive functioning, and improve their overall quality of life.

Chapter 3: Overview

Several children and youth with CP experience mental health issues, including anxiety and depression. In youth without CP, it is well established that poor sleep negatively impacts mood and is significant risk factor for later mental health issues. While a few studies have identified that sleep is associated with mental health issues in children and youth with CP, these studies have all been cross-sectional in nature and have failed to disentangle the directionality of this association. This manuscript aimed to address this gap by evaluating the bidirectional association between sleep and mood in children and youth with CP using a micro-longitudinal research design. The manuscript proposed in this chapter has been prepared for submission to *Developmental Medicine and Child Neurology*.

Chapter 3: Sleep and Mood Among Youth with Cerebral Palsy

Abstract

Background: Cerebral palsy (CP) is one of the most prevalent long-term childhood conditions impacting between 2 to 3 in every 1000 live births (Rosenbaum et al., 2007; Oskoui et al., 2013). Youth with CP often face a variety of mental health difficulties, resulting in lower quality of life and disrupted daily functioning (Whitney et al., 2019; Sandella et al., 2011). Sleep is a known risk factor for both mental health and physiological outcomes (Horwood et al., 2019; Lélis et al., 2016; Owens et al., 2014). Using ecological momentary assessment (EMA), or longitudinal data collection over a short timeframe, researchers have found that poor sleep quality is associated with worse mood in children and youth with and without neurodevelopmental disabilities (Alonzo et al., 2021; Lunsford-Avery et al., 2016; van Rijssen et al., 2023). However, this existing literature has focused on mean patterns across multiple days and has yet to explore sleep's intraindividual variability (IIV), which allows for studying processes that are more dynamic during the day. Investigating IIV allows us to disentangle the mechanisms underlying the role of sleep in mental health and physiological outcomes. Thus, the objective of this study was to extend and replicate previous research on the association between sleep and mental health and investigate the directionality of this association.

Methods: Thirty-two youth (aged 11-17 years; 45.5% female) with CP were included from various health and community agencies in two major centres of Calgary, AB, and London, ON. The youth wore an actigraph and completed daily diaries on sleep and mood for seven days, rating their sleep quality (i.e., 'How would you rate your sleep last night?') and reporting levels of positive and negative affect using the Positive and Negative Affect Scale (PANAS).

Results: Multilevel models were conducted to determine the temporal bidirectional association between sleep and mood with sex, GMFCS, and age controlled for in analyses. Previous day's higher subjective sleep quality was significantly associated with increased next-day positive and decreased negative emotions. Subsequently, greater negative affect, but not positive affect, was associated with worse subjective sleep quality on the following day worse. There were no statistically significant associations between sleep duration and mood. No associations were found between positive and negative affect and next-day sleep duration. **Conclusion:** IIV sleep quality, but not duration, were associated with negative and positive affect. Additionally, negative affect IIV was associated with next-day sleep quality; and thus, negative affect was linked bidirectionally to sleep outcomes. These findings suggest that addressing poor sleep quality may be a mechanism in mood and potentially emotional regulation in youth with CP.

Keywords: Cerebral palsy (CP), children, youth, sleep, intraindividual, mood, positive affect, negative affect, day-to-day, variability.

Introduction

Cerebral palsy (CP) is a brain-based neurodevelopmental disability that results from damage to the developing fetal or infant brain (Rosenbaum et al., 2007; Oskoui et al., 2013). CP is the most common cause of childhood motor disability, impacting approximately 2 to 3 children for every 1000 live births (McIntyre et al., 2022; Oskoui et al., 2013). The phenotype of children with CP can show significant variation, depending on the location and extent of brain damage (Einspieler et al., 2019). As such, CP is classified into five major types to describe different degrees of ambulation and the Gross Motor Function Classification System (GMFCS) is a widely used tool to do this classification. It classifies children from Levels I – V (Palisano et al., 1997; Palisano et al., 2000). Levels I-III are considered ambulatory and capable of independent ambulation, meaning that they can walk independently without minimal assistance. In contrast, individuals at levels IV-V are nonambulatory, meaning they cannot walk or sit without support independently (Palisano et al., 1997; Palisano et al., 2000).

Sleep problems are common in youth with CP, with prevalence rates reported in up to 50% of children and adolescents with CP (Horwood et al., 2019), compared to 25% of neurotypical youth (Alfano et al., 2007; Alfano et al., 2010; Tan et al., 2012). Problems with maintaining sleep throughout the night, frequent awakenings and poor sleep quality are commonly experienced (Horwood et al., 2019). Additionally, initiating sleep is often reported in youth with CP, further contributing to their sleep difficulties (Horwood et al., 2019; Simard-Tremblay et al., 2011). Moreover, staying asleep throughout the night is often fragmented, leading to frequent night wakings and poor subjective sleep quality (Horwood et al., 2019; Hulst et al., 2021; Simard-Tremblay et al., 2011). Thus, youth with CP experience increased daytime sleepiness, fatigue, and reduced alertness, affecting their overall daytime performance and

cognitive functioning (Lélis et al., 2016; Newman et al., 2006; Simard-Tremblay et al., 2011).

Sleep problems also differ based on gross motor functioning, such that youth with a more severe CP phenotype, or those that experience more significant limitations in mobility, experience more sleep problems than children with a milder phenotype (Horwood et al., 2019; Lélis et al., 2016).

In addition to sleep difficulties, individuals with CP are more at heightened risk for experiencing mental health challenges, including anxiety and depression (Whitney et al., 2019). Moreover, symptoms of depression are more prevalent in youth with CP compared to the general population (Whitney et al., 2019). In addition to the high prevalence of depression, youth with CP contend with significant emotional, behavioural, and social difficulties compared to neurotypical youth (Brossard-Racine et al., 2012). These mental health issues are not limited to adolescence, as they are likely to persist and impact youth well into adulthood (McMorris et al., 2021; Smith et al., 2019; Whitney et al., 2020). Studies in adults with CP have indicated a higher prevalence of various mental disorders such as depression, anxiety, behaviour/conduct problems, and multimorbidity (two or more disorders) (Smith et al., 2019; Whitney et al., 2020).

Secondary conditions such as pain, visual impairment, increased muscle tone, and most importantly mental health difficulties, that individuals with CP commonly experience, can exacerbate sleep problems (Engel et al., 2006; Rodby-Bousquet et al., 2021; Sanger et al., 2010). Although only a limited number of studies have investigated the role of sleep on mental health in people with CP, there is evidence that there is interrelationship between physical risk factors (e.g., sleep) and mental health in individuals with CP. For example, Whitney and colleagues (2020) found that physical activity and sleep duration were independently associated with all mental health disorders in adults with CP. However, when they accounted for sociodemographic variables in the model (i.e., sex, age, ethnicity and poverty status), sleep duration was no longer

associated with mental health (Whitney et al., 2020). Similarly, Romeo and colleagues (2014) found that greater sleep disturbance scores were more strongly associated with internalizing symptoms and disorders, such as withdrawal, anxiety, and depression, than with externalizing factors, such as aggression behaviour. Despite this evidence on the association between sleep and mental health issues in youth and young adults with CP, research to date has primarily focused on weekly average sleep patterns (Atmawidjaja et al., 2014; Horwood et al., 2018). While this approach provides valuable insight into the sleep patterns among this population, it overlooks crucial information regarding the variability in sleep patterns (i.e., night-to-night variations), which is essential for understanding the impact of sleep in children and youth with CP (Becker et al., 2017).

Intraindividual variability (IIV) in sleep refers to variations in sleep patterns which can have different magnitudes, frequencies, and structures (Bei et al., 2016). In other words, IIV in sleep captures not only the individual's sleep changes but also the dynamic nature of sleep patterns within an individual over time (Crowley et al., 2018; Bei et al., 2016). Bei and colleagues (2016) highlight that although sleep IIV tends to correlate with other average sleep values like sleep duration and wake time after sleep onset (WASO), IIV provides significantly more information regarding daily sleep fluctuations within individuals over time. Nonetheless, most research to date has failed to examine individual daily experiences of sleep by only focusing on average values, such as sleep duration or sleep efficiency (Horwood et al., 2018; Newman et al., 2006; Simard-Tremblay et al., 2011). There is a strong argument that significant gaps exist in the literature regarding our understanding of the association between sleep and well-being in the general population (Becker et al., 2017; Bei et al., 2016; Dillon et al., 2015). Bei and colleagues (2016) highlight that in order to understand sleep patterns better, several

areas require attention, including shifting our focus from solely examining mean or weekly average sleep timing, duration, and quality, to the sleep IIV. Second, there is a lack of understanding regarding the mechanisms involved when focused on mental health (Bei et al., 2016). For example, it raises the question of whether mental health difficulties are a cause or consequence of sleep IIV or if they have a two-way association (Bei et al., 2016). Third, research to date has focused on specific health conditions rather than examining the overall effects of sleep on overall functioning (Blunden et al., 2016; Becker et al., 2017; Bei et al., 2016). Bei and colleagues (2016) highlight that more research is needed to understand this relation; however, IIV should be integrated as a second dimension in addition to individual means.

IIV plays a crucial role when disentangling the association between sleep and mood (Blunden et al., 2016; Becker et al., 2017; Bei et al., 2016; Kim et al., 2013). Sleep IIV may be associated with sleep restriction and circadian misalignment, which are known to be associated with negative mood and depressive symptoms (Bei et al., 2016; Kahn et al., 2013; Kim et al., 2013). Furthermore, one mechanism by which sleep variability may impact mood and mental health is through sleep onset latency (SOL). It is theorized that regular sleep patterns (i.e., sleeping the same amount each night or going to bed and waking up at the same time) will allow someone to fall asleep quickly (short SOL) based on their natural circadian clock (Bei et al., 2016; Kahn et al., 2013; Kim et al., 2013). By creating variability or fluctuations in sleep, you fight your body's natural circadian clock, subsequently creating more difficulty with falling asleep each night. Consistent with this, Lovato and Gradisar (2014) proposed that increases in wakefulness before initiating sleep (SOL) can promote rumination and reinforce negative thinking styles, which in turn, perpetuates longer sleep latency. Similarly, examining IIV of sleep is crucial as it may contribute to our understanding of the maintenance of sleep problems (Kahn

et al., 2013; Kim et al., 2013). For example, in neurotypical youth, individuals with insomnia have more variable sleep, which further maintains the insomnia symptomology (Kahn et al., 2013; Kim et al., 2013; Molzof et al., 2018). As such, those who sleep poorly on one night may want to catch up by sleeping longer the following night, creating a vicious cycle (Kahn et al., 2013; Kim et al., 2013; Molzof et al., 2018).

Currently, sleep research on IIV is limited in individuals with neurodevelopmental disabilities, and in particular, individuals with CP; however, we can draw insights from studies involving other neurodevelopmental disabilities (Langberg et al., 2019). For example, recent work by Langberg and colleagues (2019) emphasized the important role of sleep IIV in a sample of youth with ADHD. Youth with ADHD (ages 12 and 14 years) exhibited significantly higher variability in total sleep time (TIB), sleep onset, sleep offset, and WASO compared to neurotypical youth. Moreover, on schooldays, youth with ADHD showed greater IIV in TIB, sleep onset, and sleep efficiency (Langberg et al., 2019). Stressful life events and depression can impact nightly fluctuations in sleep, subsequently impacting daily fluctuations in mood and health complaints (Klaiber et al., 2021; Maskevich et al., 2020; White et al., 2012).

In the general population, sleep problems are not only associated with mental health issues but also can exacerbate negative mood or affect, with difficulties in one area perpetuating impairments in the other (Klaiber et al., 2021; Maskevich et al., 2020; White et al., 2012). Affect, which refers to a general dimension of mood and can be broadly classified as positive (PA; positive affect) or negative (NA; negative affect), plays a significant role in subjective well-being, sleep, and emotions (Watson et al., 1988). For instance, a study by van Roekel and colleagues (2015) reported that youth who slept less reported higher negative and lower positive affect. Similarly, they found a significant association between sleep quality and affect, with

participants experiencing increased levels of negative affect and decreased levels of positive affect following nights when they rated their sleep quality lower (van Zundert et al., 2015).

Within the literature, positive and negative affect are seen as unique and independent dimensions; however, they may be experienced simultaneously (Larsen et al., 2001; Watson et al., 1988).

The inverse association has also been found, such that, when individuals experience feelings of irritability, sadness, or anxiety, they are more likely to experience disrupted or inadequate sleep (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Patapoff et al., 2022). Likewise, poor sleep or inadequate sleep can contribute to greater negative mood, creating a cycle where one problem drives the other (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Patapoff et al., 2022). For example, using EMA, Patapoff and colleagues (2022) reported that in individuals with bipolar disorder (BD), those with higher ratings of sadness and anger were associated with lower self-reported sleep quality the next day but not with objective sleep measures (Patapoff et al., 2022). Similarly, more chronic negative trait mood is associated with next day cognitive functioning and health (Phillips et al., 2017). While the association between sleep and mood and how they impact each other is relatively well established in neurotypical populations; less is known about the directionality of this association is unclear in people with CP (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Phillips et al., 2017)

In examining same-day associations, it becomes evident that mood fluctuations can directly impact sleep patterns (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021). For example, Kouros and colleagues (2022) found that neurotypical adolescents who experienced days filled with more negative emotions resulted in higher levels of self-reported sleep/wake problems the next day. Conversely, days with higher than-usual happiness were associated with

reporting fewer sleep/wake problems that evening (Kouros et al., 2015; Kouros et al., 2022). This emphasizes the critical role that daily mood fluctuations may play in shaping sleep outcomes; as such, highlighting the importance of mood fluctuations can shed light on this association (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Phillips et al., 2017). The critical role that mood fluctuations can be further exemplified by how variations in mood can adversely affect evening and next day sleep and that poor sleep on one night can adversely affect the following day, influencing mood and emotional well-being (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Phillips et al., 2017). For example, Kecklund and Åkerstedt (2004) report that daily work stress was associated with subjectively poor sleep quality the next day. This phenomenon can create a vicious cycle wherein sleep problems and negative mood states perpetuate each other (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021; Phillips et al., 2017).

Despite sleep difficulties being more prevalent in children and youth with NDDs compared to same-aged peers, no study has examined the directionality of sleep (duration or quality) in neurodiverse youth using EMA (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019). By capturing data as it happens in real time, we can enhance our understanding of the variations in sleep patterns within and across days of youth (Phillips et al., 2017). This, in turn, enables us to tailor individualized treatment approaches that effectively address these difficulties. Based on previous literature with neurotypical individuals, the current study aims to replicate and extend previous literature by examining the bidirectional association of sleep (i.e., sleep duration and sleep quality with positive and negative mood in children and youth with CP (Bei et al., 2016; Bei et al., 2017; Difrancesco et al., 2021). Specifically, this study aimed to (1a) explore the associations between IIV in sleep duration as a predictor of next-day mood variability (i.e.,

positive and negative affect) and (1b) examine whether IIV in variability in mood (i.e., positive and negative affect) predicts next-day sleep duration. In the second aim, this study investigated the associations between sleep quality and mood variability (i.e., positive and negative affect). Sleep duration and quality are the focus of this study as they have been identified as crucial components of sleep that significantly impact overall well-being and mood (Buysse, 2014). We hypothesized that greater IIV in sleep duration and sleep quality would be associated with lower PA and higher NA total, and higher day-to-day variability in PA and NA would be associated with lower sleep duration and sleep quality. To account for potential confounding factors, age, and Gross Motor Function Classification System (GMFCS) level were included as covariates in the statistical analyses. Age and GMFCS levels were entered as fixed effects in the models to examine their influence on the associations between the predictor variables and the outcome variables.

Paper 2 Methods

Research Design

This study utilized an ecological momentary assessment (EMA) design that captures real-time self-reports of youths' daily experiences in their natural environment (Shiffman et al., 2008). EMA is a longitudinal data method that provides short timeframes over a time period, typically a few weeks, allowing researchers to capture the dynamic nature of behaviours and experiences (Kim et al., 2013; Shiffman et al., 2008). Specifically, in this study, data on sleep (duration and quality) and mood (positive and negative affect) were collected using daily surveys and used in analyses (see Appendix G). Daily surveys were utilized, allowing for a comprehensive understanding of the daily fluctuations in sleep and mood, and how they impact each other in youth with CP.

Secondary Data Analysis

This study is a part of the **Cerebral Palsy, Bodily Reactions & Understanding Mental Health (CereBRUM)** study, examining associations between physiological factors and mental health in children and youth with CP. This project was funded by the HBI Robertson Fund for Cerebral Palsy Research, led by C. McMorris, which took place from September 2019 to August 2021. The study obtained ethics approval from the Conjoint Faculties Research Ethics Board (CFREB, REB19-0481) at the University of Calgary and the Health Sciences Research Ethics Board (HSREB, 115678) at The University of Western Ontario.

Participants

Participants consisted of 45 youth with various GMFCS levels (i.e., functioning ability) recruited from two major Canadian cities, Calgary, AB and London, ON. Health and community sites included the Paediatrician Neuromotor Clinic, Renfrew Educational Services, and Taking

Strides Calgary. For the current study, participants were limited to youth with a formal diagnosis of CP recruited from September 2019 - August 2021. Youth who had diagnoses other than CP, such as epilepsy (not controlled by medication), neurofibromatosis, traumatic brain injury, or other neurodevelopmental disorders, were not considered eligible for participation in the study. These conditions were excluded due to their distinct etiology compared to CP.

Procedure

Potential participants were recruited using advertisements through organizations and agencies that support families with children and youth diagnosed with CP (e.g., Pediatrician Neuromotor Clinic, Renfrew Educational Services, and Cerebral Palsy Association in Alberta), as well as promoting the study through social media channels, such as Facebook advertisements and posts on the research lab's social media accounts. Families who were interested in participating contacted the researchers and underwent a preliminary screening interview to verify their eligibility before providing their consent to participate (see Appendix B for parental consent form and Appendix C for assent form). Youth older than 14 with the cognitive capacity to consent provided their own consent. Furthermore, in order to determine whether youth were capable of consenting, we evaluated their understanding of the study aims and what information would be collected from them, as well as their ability to understand the risks and benefits of participating and the consequences of not participating.

Following this, all the participating families were asked to fill out a demographic and baseline questionnaire (see Appendix E and F). Next, the participants initiated the seven-day survey period. The researchers shared links to the online survey, which the participants were required to complete at a proffered time each day. Following completion of all measures, families received a \$50 gift card as compensation for their time. Due to the coronavirus

pandemic (COVID-19), the study was modified and conducted entirely remotely. As a result, families were able to participate from the comfort of their homes, and they received all the necessary information through web-based platforms (REDCap for questionnaires) (Harris et al., 2019; Harris et al., 2009)

Measures

Sociodemographics. Caregivers reported on their own and their child's age, ethnicity, diagnoses, service utilization, and hospital visits. Sex was reported as female, male, or neither male nor female. It also included questions about caregiver's age, marital status, ethnicity, annual household income, employment status, and highest level of education.

Functional Ability Level. Functional ability level was assessed by the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997; Palisano et al., 2000). Caregivers completed the GMFCS via REDCap. The GMFCS is a reliable and valid tool that uses a simple, five-level, ordinal grading system that classifies children based on the gross motor activities that they can typically accomplish (Wood and Rosenbaum, 2000). Level I corresponds to the highest gross motor function, while level V corresponds to the lowest (Palisano et al., 1997; Palisano et al., 2000; Wood and Rosenbaum, 2000)

The Positive and Negative Affect Schedule (PANAS). Variability in mood was measured using the PANAS. The PANAS measures two constructs of mood involving a 10-item positive affect (PA) subscale and a 10-item negative affect (NA) subscale and consists of two 10-item mood scales (Watson et al., 1988). Youth were asked to rate the extent to which they were experiencing various types of positive and negative affect each day. This included completing the PA subscale, which measures positive emotions such as enthusiasm, inspiration, and joy, as well as the NA subscale, which assesses negative emotions like sadness, anger, and fear. Each item is rated on a scale from 1 to 5 ranging from "Very Slightly or Not at All" to "Very Much". The PANAS has shown acceptable internal consistency with a Cronbach's α of 0.76 for the negative affectivity scale and 0.78 for the positive affectivity scale, among both neurotypical and neurodiverse individuals (Høye et al., 2020; Watson et al., 1988). In our study, the internal

consistency for the PANAS at the daily assessments, as indicated by the average Cronbach's alphas, was 0.80 for negative affect and 0.88 for positive affect.

Sleep parameters. Youth completed sleep diary data over seven days (see Appendix G). The sleep diary provides a detailed sleep assessment, such as sleep time, awakening time, and quality. Youth participants were asked to rate their sleep quality from the previous night using a slider scale. The slider ranged from 0, indicating the worst possible sleep quality, to 100, indicating the best possible sleep quality. Sleep diaries are shown to provide reliable and valid estimates of subjective sleep parameters (Buysse et al., 2006; Shaffer et al., 2023). Sleep duration was calculated by taking the amount of time elapsed from the time participants reported falling asleep to wake-up time. Sleep variables obtained from the sleep diary included subjective measures of sleep duration and sleep quality.

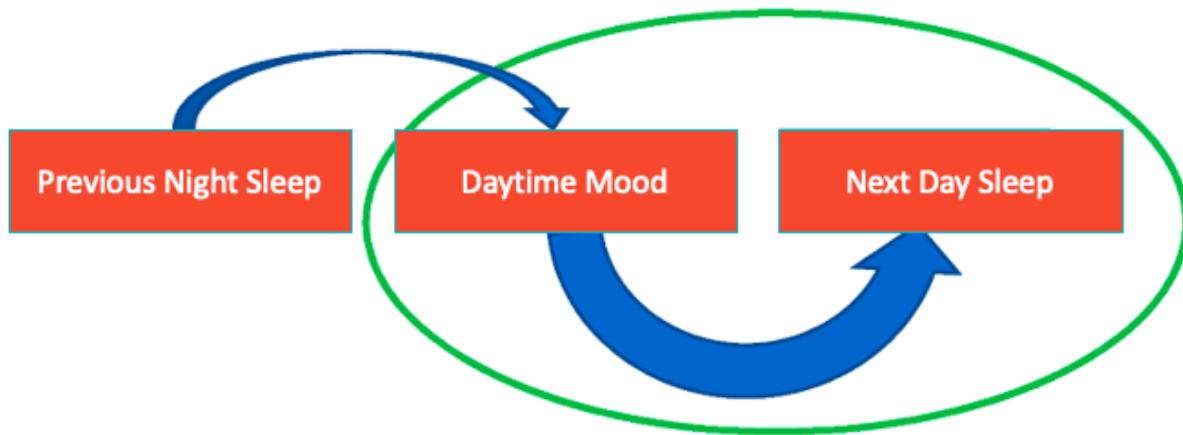
Statistical Analyses

Primary study hypotheses were evaluated using Multilevel modeling (MLM) analyses and were carried out using SPSS statistical software package and restricted maximum-likelihood estimation (IBM SPSS Statistics, Version 26.0; Raudenbush & Bryk, 2002; Raudenbush et al., 2004). We selected a theory-driven model with a random effect for intercept and fixed effects for our predictors of interest. These predictors included daily subjective measures of sleep duration and sleep quality, the age of the youth, parent reported GMFCS level (Gross Motor Function Classification System), and sex. Sex was dichotomously coded as female = 1 and male = 0 for the purposes of the analyses. Throughout these analyses, the Restricted Maximum Likelihood (REML) estimation method was used to reduce response bias. Separate models were conducted to examine the associations between positive affect and negative affect as dependent variables. Specifically, we investigated the effects of sleep (i.e., sleep duration and sleep quality) on next-

day positive and negative affect. Additionally, we explored whether positive and negative affect predicted next-day sleep duration and quality. All predictors recorded across the seven days were centered within subjects. Figure 1 depicts the design and data analysis plan of the current study.

Figure 1

Design and analysis plan of the current study for sleep and mood



Note. Sleep = Sleep Duration and Sleep Quality. Mood = Positive Affect and Negative Affect

Results

Missing Data

In the current study, missing data were analyzed using Little's missing completely at random test. The analysis revealed nonsignificant chi-square values ($p = .58$) for all missing data across levels, indicating that the missing data can be considered Missing Completely at Random (MCAR; Little and Rubin 1989).

Sample Characteristics

A total of 45 youth (40% females) with an average age of 11.6 ($SD = 2.77$) years were recruited as part of the larger study; however, only 32 youth completed all seven consecutive days of daily surveys. In particular, most missing data was due to nine participants who did not provide data beyond the baseline measures (i.e., no daily sleep or mood data was collected). From the 36 children remaining, four youths did not complete more than three nights of daily surveys and were excluded from the sleep analysis. Therefore, the final sample with valid sleep data consisted of 32 youths (45.5% females) with an average age of 11.5 ($SD = 2.80$) years, based on valid sleep data. They were primarily White (75.8%) and biracial or multiracial (18.2%). On average, youth slept 10 hours per day ($SD = 0:59$). In terms of gross motor function, 43.4% of the youth's GMFCS were classified as Level I, 40% as Level II, 6.7% as Level III, 6.7% as Level IV, and 3.3% as Level V. Daily means, standard deviations, and ranges of mood (i.e., Positive Affect and Negative Affect) and sleep variables are presented in Table 6.

Table 6

Daily means, standard deviations and ranges of positive affect, negative affect, sleep duration and sleep quality

	Mean (SD)	Range
Positive affect		
Day 1	31.00 (7.30)	17 – 45
Day 2	29.36 (8.70)	15 – 50
Day 3	31.00 (9.08)	11 – 48
Day 4	30.53 (10.12)	14 – 48
Day 5	30.50 (9.86)	12 – 50
Day 6	30.75 (10.48)	12 – 50
Day 7	29.66 (10.21)	11 – 50
Negative affect		
Day 1	15.00 (5.34)	10 – 30
Day 2	14.67 (5.03)	10 – 29
Day 3	13.57 (5.18)	10 – 37
Day 4	13.67 (5.81)	10 – 38
Day 5	13.41 (4.40)	10 – 29
Day 6	12.39 (4.08)	10 – 29
Day 7	12.59 (3.70)	10 – 25
Sleep duration (hours) ^a		
Day 1	9.40 (1.36)	5.00 – 12.25
Day 2	10.30 (1.06)	8.00 – 13.00
Day 3	9.57 (0.50)	8.25 – 11.50
Day 4	10.13 (1.41)	7.00 – 15.17
Day 5	10.14 (1.47)	4.03 – 13.00
Day 6	9.37 (1.46)	5.03 – 13.00
Day 7	10.07 (1.08)	8.00 – 11.50
Sleep quality ^b		
Day 1	43.66 (26.8)	3 – 97
Day 2	33.08 (27.8)	1 – 100
Day 3	35.42 (25.8)	0 – 100
Day 4	36.03 (27.6)	3 – 100
Day 5	30.91 (22.4)	0 – 81
Day 6	31.61 (24.9)	0 – 98
Day 7	38.19 (29.1)	0 – 97

Note. ^aSleep duration is calculated by taking the amount of time elapsed from the time participants reported falling asleep to wake-up time (hours).

^bSleep quality was reported on a slider scale from 0, indicating the worst possible sleep quality, to 100, indicating the best possible sleep quality.

Primary Analyses

A series of fixed-effect multi-level models were conducted to determine if variability of previous night sleep duration and quality were associated with next-day negative and positive mood over a 7-day period. Age, sex and GMFCS level were entered as between-subjects covariates in all models. GMFCS was significantly related to both sleep duration and sleep quality in all models such that higher GMFCS levels were associated with worst sleep quality ($p < .001$) and decreased sleep duration ($p < .001$). Age was only related to sleep quality such that older youth experienced better sleep quality ($p = .002$) but not sleep duration ($p = .621$).

After controlling for covariates (age, sex and GMFCS), previous day sleep quality was significantly related to both next day negative ($b = -.034 \pm .009, t = -3.820, p < .001$) and positive mood ($b = .042 \pm .021, t = 2.009, p = .046$), as measured by the PANAS, such that increased variability such that higher reported sleep quality was related to lower negative mood and higher reported positive mood the next day. In regard to sleep duration, results did not support our hypothesis such that previous day sleep duration was not significantly related to either next-day negative ($b = -.059 \pm .168, t = -.353, p = .725$) or positive mood ($b = -.335 \pm .410, t = -.817, p = .415$), as measured by the PANAS.

Following this, additional fixed-effects models were then run to determine the directionality of the association between mood and sleep scores. Specifically, the first model examined if within-subjects variability of previous day negative and positive mood was significantly related to next-day sleep duration and quality. After adjusting for the same covariates, only previous day negative mood, not positive affect, was associated with next day

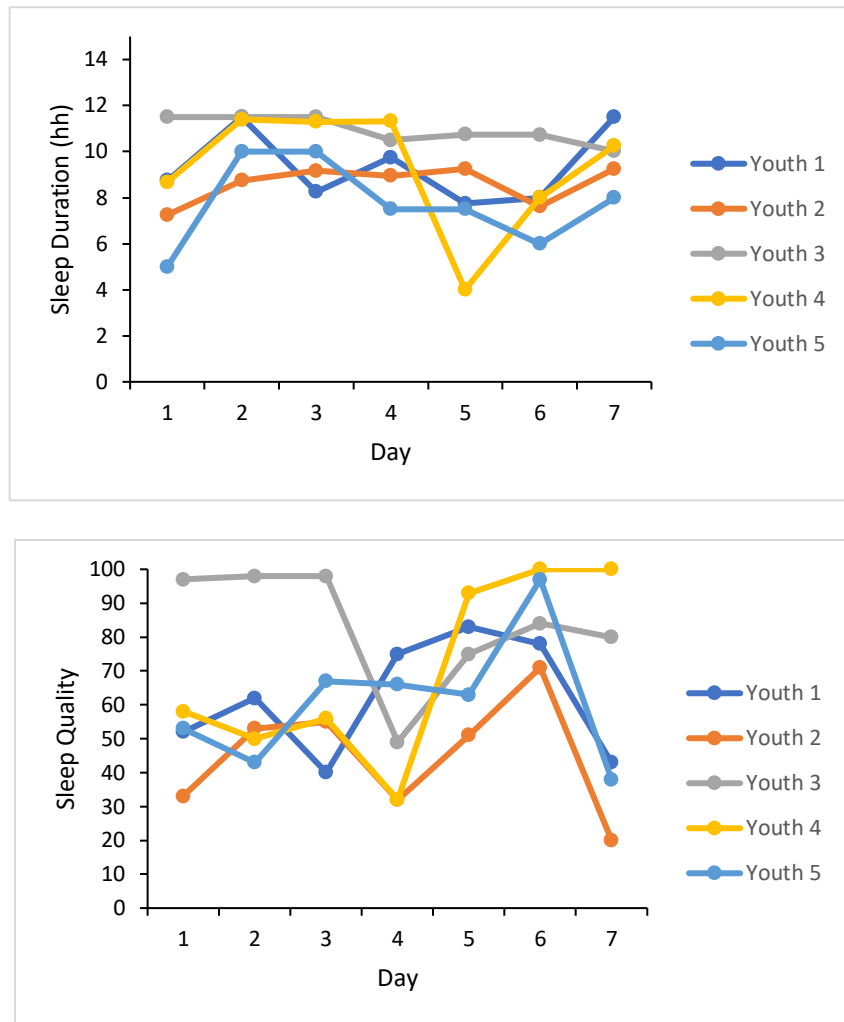
sleep quality ($b = -1.11 \pm .431$, $t = -2.57$, $p = .011$). All other models with mood and sleep variables were not statistically significant.

Visual Representation of IIV

Visual examples of the IIV in five youth with CP are presented in Figure 2. Sleep duration and sleep quality are displayed across seven days. The graph provides a visual representation of how sleep patterns and quality fluctuate within these individuals, highlighting the unique characteristics of their sleep patterns.

Figure 2

Variability in Sleep Duration and Quality: Visual Representation of Individual Differences



Note. Daily parameters for sleep duration (in hours; top) and sleep quality ratings (0-100; bottom), over a seven-day period from five randomly selected participants. Each column and color represent one of the participants.

Discussion

Sleep variability, or daily fluctuations, is common and may be especially characteristic of adolescent sleep (Crowley et al., 2014; Crowley et al., 2018). While no study has investigated this association in youth with CP, previous research in the general population has indicated that

sleep and mood are fundamentally linked (Becker et al., 2017; Bei et al., 2016; Dillon et al., 2015). Using an EMA approach, this study explored the association and directionality between sleep intraindividual variability (IIV) (i.e., duration and quality) and mood (i.e., positive and negative affect). Specifically, this study investigated if subjective sleep duration or quality predicted the next day's mood and, subsequently, if mood predicted the next subjective sleep duration or quality.

Examination of previous day variability in sleep quality and mood showed that nightly better sleep quality ratings were followed by a day of lower negative affect and higher positive affect. This is a novel finding in youth with CP but is consistent with existing literature in neurotypical youth and adults, in which changes in daily subjective sleep quality was associated with subsequent changes in affect (Becker et al., 2017; Bei et al., 2016; Bouwmans et al., 2015; Dillon et al., 2015; Sin et al., 2017). For example, Bouwmans and colleagues (2015) found that when youth with and without depression experienced changes in sleep quality they reported greater next day decreased negative affect and increased positive affect after. While these observations primarily focus on neurotypical youth, it is essential to consider that individuals with CP face a heightened risk of experiencing negative mood states, low self-esteem, and low social support, which may further exacerbate the association between sleep and mood in this population (Becker et al., 2017; Bei et al., 2016; Bouwmans et al., 2015; Dillon et al., 2015; Sin et al., 2017; Whitney et al., 2019). Similarly, McCrae and colleagues (2008) found that in their sample of adults in the general population, those with better subjective sleep quality or less fragmented sleep experienced higher positive and lower negative affect on the following day. Mood was dependent on the quality of sleep experienced the night before by youth in the current sample; thus, highlighting that sleep quality appears to be a significant predictor of the next day

positive and negative mood (McCrae et al., 2008). Taken together, these findings highlight that similar to neurotypical youth and adults, sleep is a restorative function for youth with CP not only for physical functioning but also for our emotional affect and regulation functions (Becker et al., 2017; Bei et al., 2016; Bouwmans et al., 2015; Dillon et al., 2015; McCrae et al., 2008; Sin et al., 2017).

Interestingly, no significant findings emerged from analyses of variability in sleep duration and next-day positive or negative affect (p 's > .05). These null results contradict studies linking sleep duration and mood in neurotypical populations. For example, shorter sleep duration has been shown to significantly increase the odds of youth experiencing heightened negative mood, including anger, positive affect, and negative affect (Shen et al., 2018). Similarly, a recent meta-analysis by Bei and colleagues (2017) found that total sleep time (i.e., sleep duration) was associated with more negative mood in adolescents, and this was more prevalent when sleep was constrained by school or external schedules (e.g., sports training). Although we expect sleep duration to follow the same pattern as sleep quality, a possible explanation for this discrepancy in results compared with similar studies is that sleep duration is a distinct sleep dimension that varies from person to person (Baker et al., 2023; Ferrara & De Gennaro, 2001). Sleep duration is unique to an individual and having a specific “optimal” amount of sleep is complex and not fully understood (Ferrara & De Gennaro 2001). Individuals may feel rested and able to carry out daily functions optimally despite the amount of time asleep (Chaput et al., 2018). Thus, despite these findings, our statistical approach accounts for both between-individual differences and within-individual effects across multiple time points and incorporated a robust level of variability in regarding sleep duration. Additionally, sleep duration is almost always compounded by other factors such as psychological health (Baker et al., 2023; Matricciani et al., 2017). We know that

significant sleep deficiency is detrimental (less than 5 hours) to a myriad of mental and physical functioning such as anxiety, depression and mortality; however, individual sleep duration needs can follow a U-shaped variation (Duncan & Maitre, 2021; Owens et al., 2014). Sleeping too little and excessive sleeping can both have negative effects on health and functioning (Baker et al., 2023; Duncan & Maitre, 2021; Matricciani et al., 2017; Owens et al., 2014). However, within the middle of the U-shaped curve is where individuals experience the ideal amount that varies from person to person based on how it optimizes an individual's outcomes the next day (Owens et al., 2014; Richards et al., 2020).

Sleep quality, unlike sleep duration, is a distinct dimension highly correlated with subjective well-being and other psychological outcomes (Dewald et al., 2010; So et al., 2020; Stewart et al., 2011). When someone experiences good sleep quality, they tend to wake up feeling refreshed, energized, and alert (Dewald et al., 2010; So et al., 2020; Stewart et al., 2011). Youth can experience adequate sleep duration but still have poor sleep quality due to insomnia symptoms, sleep disorders, or even environmental disturbances (i.e., mobile devices) (Castiglione-Fontanellaz et al., 2023)

Although limited, some theories suggest that having good sleep quality is more robustly associated with mood over sleep duration because overall "good" sleep quality allows the brain to restore and regulate the neuronal systems responsible for managing emotions, such as the limbic system (Jamieson et al., 2020; Jamieson et al., 2021). Adequate and restorative sleep quality is linked to better emotional regulation, a more positive outlook, and increased resilience to stress (Kecklund & Åkerstedt, 2004; Klaiber et al., 2021; Maskevich et al., 2020). This is most often found when individuals sleep without awakening or have an environment conducive to sleep (Jamieson et al., 2020; Jamieson et al., 2021). On the other hand, poor sleep quality can

exacerbate feelings of anxiety, depression, and other emotional disturbances (Dewald et al., 2010; Galland et al., 2017; Lang et al., 2021). Overall, the current findings highlight that sleeping longer or shorter may not necessarily mean that it will adversely impact mood if their subjective sleep quality experience is high. However, it is when sleep durations are far outside the 'norm' that we may have more significant effects (Duncan & Maitre, 2021; Owens et al., 2014). While strong research evidence exists to support the causal role of sleep duration in mood, it is more appropriate to say mood is influenced or confounded by an individual's sleep quality (Becker et al., 2017; Brindle et al., 2018; Dewald et al., 2010; Hairston et al., 2022; ; Ong et al., 2017; Stewart et al., 2011). Despite these non-significant findings, these novel findings further our understanding of the relationships between sleep duration and mood in children and youth with CP, who have significant sleep challenges.

Subsequent analyses examined the bidirectional association between sleep and mood, by investigating whether mood, positive and negative affect, impacted youth's following day's sleep quality or duration, and vice versa. These results partially support our hypothesis and demonstrate a partial bidirectional association between affect and sleep quality among youth with CP. These findings are somewhat consistent with existing literature in the general population with neurotypical youth (van Zundert et al., 2015). For example, van Zundert and colleagues (2013) examined the within-person association between affect and the next day's sleep in a sample of 13–16 year-old neurotypical adolescents (59 % female). They found that variability in positive and negative affect during the day affected youth sleep quality and disturbance the following night (van Zundert et al., 2015). Similarly, in their study with young neurotypical adults, Kouros and colleagues (2022) found that higher self-reported positive and negative emotion intensity was associated with self-reported sleep quality. However, inconsistent

with our findings, these authors also showed an association between daily negative mood and happiness ratings and nightly objective sleep minutes or sleep duration (Kouros et al., 2022).

Our findings, along with previous evidence, demonstrate that negative mood may be more robustly linked with sleep than positive affect (Kouros et al., 2015; Kouros et al., 2022). For example, using similar EMA methods and analysis as the current study (e.g., day-level data nested within persons), Stewart and colleagues (2011) found that while negative affect predicted sleep quality, positive affect did not in university students. Given the lack of association between sleep quality and positive affect, Stewart and colleagues argued that it might be that positive affect may be a marker of the absence of negative affect as they are similar concepts (Stewart et al., 2011). Further research is needed to delve deeper into understanding the interplay between positive affect, negative mood, and sleep by capture potential changes in sleep patterns and mood over a longer duration of time.

In terms of mood fluctuation, results revealed that only variability in negative affect (not positive affect) was associated with next-day sleep quality. This may suggest that youth experiencing negative moods during the day may be ruminating at night, a state of cognitive pre-sleep arousal in which youth continuously process thoughts (Hairston et al., 2022; Mills et al., 2019). The association between rumination and mood is well-established (Difrancesco et al., 2021; White & Shih, 2012), and rumination has also been linked to pre-sleep arousal in young adults (Maskevich et al., 2020). Daily stressors may exacerbate emotional and cognitive arousal, which in turn subsequently impair sleep. For example, higher daytime stress is associated with elevated pre-sleep arousal (e.g., racing thoughts), linked to poorer sleep quality (Maskevich et al., 2020). This might even be more pronounced due to the wake of the COVID-19 pandemic, where individuals experienced greater stressors during the day (Klaiber et al., 2021).

Furthermore, it is essential to highlight that negative emotions are more long-lasting, intense and can be more memorable compared to positive feelings (Baumeister et al., 2001; Bower, G. H. (1981). For example, it is believed that adverse events or experiences may keep the memory of the event for a prolonged time and are emotions active for a more extended period of time (Patapoff et al., 2022; Tempesta et al., 2018)

For our prediction that positive and negative affect would be related to next-day sleep duration, neither positive nor negative affect was associated with next-day sleep duration. These findings add to the existing evidence that is quite mixed. For example, while Difrancesco and colleagues (2021) reported that neither positive nor negative affect predicted self-reported sleep duration. Similarly, Kuo and colleagues' (2015) study indicated that Mexican American youth did not show any association between higher depression variability and next day sleep duration. Despite this evidence, other studies have found a connection between sleep quantity (i.e., sleep duration) and mood (Langberg et al., 2019). One study focused on youth with bipolar disorder (BD) and found that hypomanic symptoms such as a sense of happiness, euphoria, and more energy were more closely linked to night-by-night variability in sleep duration (Patapoff et al., 2022). In another study, it was observed that 47 youth who experienced day-to-day fluctuations negative affect obtained significantly less sleep on the weekends (Blunden et al., 2019).

Differences in findings can likely be attributed to several factors, including methodology, the sample size, and the specific measures used. For example, Blunden and colleagues (2019), in their study, had a larger sample size and implemented frequent check-ins to ensure consistent completion of the daily surveys, which may have provided a more rich and valid measures of sleep duration than the current study. Additionally, with a larger sample size, it is possible that we might identify an association between mood variability and sleep duration. Overall, these

contrasting findings highlight the complexity of the association between mood and sleep duration and that mood and mood changes may be more closely related to subjective sleep experiences (i.e., sleep quality) rather than quantitative ones (Blunden et al., 2016; Becker et al., 2017; Bei et al., 2016; Kim et al., 2013)

Findings from the current study must be considered in the context of the COVID-19 pandemic, as a large proportion of the data was collected throughout the pandemic. The onset of COVID-19 saw the introduction of stay-at-home orders causing disruptions in services, support systems, and unpredictability (Fowler & Kumte, 2022; Ostojic et al., 2023). During the pandemic, children with neurodevelopmental disabilities (including CP) experienced increased worry about the stability of living situation (Masi et al., 2021; Ostojic et al., 2023) and many had a loss of supports or a significant decrease in hours per week of supports (Sutter et al., 2021). Moreover, during the pandemic, there was an observed increase in depression symptoms and hopelessness among adolescents with CP (Lai et al., 2022). Other studies also suggest that youth experienced a decrease in positive emotions during this period (Nearchou et al., 2020; Panchal et al., 2021). However, some children and youth with NDDs, such as CP, benefited from the pandemic as they reported to experience less stressors (e.g., going to school, exposed to bullying/victimization) and spent more time with family (Farajzadeh et al., 2021). Thus, it is possible that the mood and sleep patterns reported by youth with CP in the current sample were not an accurate representation of their ‘normal’ functioning.

Children and youth with CP are especially prone to variable sleep and mood patterns due to CP-related symptoms (i.e., pain, and fatigue) and comorbid conditions (i.e., epilepsy) which can be associated with mood difficulties (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019). Therefore, it becomes crucial to take into account individual differences in both sleep

patterns and mood when evaluating their mental health and overall well-being. To improve emotional well-being and mood, future studies should explore personalized interventions targeting sleep, while addressing factors like pain that are known to exacerbate disturbances (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019). Understanding the specific factors that lead to sleep IIV will be critical for the development of prevention and intervention strategies. Given the wide-ranging difficulties experienced by youth with CP, it will also be imperative to examine whether sleep IIV contributes to, or exacerbates, factors such as pain in this population (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019). Similarly, there is growing evidence that sleep is associated with poorer physical activity (Verschuren et al., 2023), as such, important next steps in this line of research include evaluating both predictors and consequences of sleep IIV in relations to physical activity.

Strengths and Limitations

This study has several notable strengths that contribute to our understanding of sleep and mood in youth with CP. To date, few studies have explored the association between sleep and mood and have captured the fluctuations in both sleep and mood (Blunden et al., 2016; Bei et al., 2017; Langberg et al., 2019). The study, therefore, contributes to the limited but growing body of research examining the dynamic association between these factors. Second, this study utilized an innovative, methodological approach of an intensive EMA protocol that provides data on sleep and mood in the youth's natural environment. Studies have shown that even individuals are not always accurate at retrospectively reporting their mood or affect (Bei et al., 2016; Wilson et al., 2002). As such, this is a method for youth to remember feelings and sleeping behaviours that they experienced accurately (Bei et al., 2016; Langberg et al., 2019). Furthermore, obtaining day-to-day measurement of sleep IIV and mood variability over seven days, rather than

collapsing all days into one value, is more representative of the individual (Bei et al., 2016).

Youth are likely to experience more variable than constant sleep during adolescence; thus, it is crucial to use statistical methods that accurately capture these relationships (Bei et al., 2016; Spruyt et al., 2011).

A number of limitations should be acknowledged when interpreting results from the current study. First, our study included a large percentage of youth who had higher gross motor functioning (GMFCS levels I and II, 90.1%); hence, the results may only be generalizable to some youth with CP. However, the distribution of ambulatory and non-ambulatory children with CP is similar to other studies examining sleep in this population (86.4%) (Hulst et al., 2021). Second, due to the relatively small sample size were not able to control for additional comorbidities, medication status, pain or ethnicity. Youth with CP who have additional comorbidities such as epilepsy and visual and cognitive impairments or pain have more sleep and mood difficulties than children without comorbidities (Horwood et al., 2018; Jacobson et al., 2020; MacDuffie et al., 2020; McCarthy & Rastogi, 2017). These factors have been associated with sleep disturbances in both neurotypical and neurodiverse populations (Waxmonsky et al., 2017). For example, Horwood and her colleagues (2018) found that pain was the strongest predictor of elevated sleep disturbance scores, as measured by the Sleep Disturbance Scale for Children (SDSC), with odds of 6.5. Additionally, pain was associated with disorders of initiation and maintenance of sleep, with odds of 3.4 (Horwood et al., 2018). Controlling for these variables would have been important to gain a more comprehensive understanding of the specific impact of sleep and mood. As such, future studies should control for the impact of these factors such as pain, and CP subtype (e.g., spastic vs. dyskinetic vs. ataxic-hypotonic vs mixed) (Horwood et al., 2018). Finally, sleep was measured during a period (i.e., the COVID-19

pandemic) when most youth had relatively high control over their sleep, and relatively more significant changes to their sleep occurred (Bigalke et al., 2020; Breda et al., 2023; Klaiber et al., 2021). The COVID-19 pandemic may have shifted youth's sleep timing and increased media use, potentially impacting their sleep quality and quantity. Youth may have experienced later bedtime attributed to virtual schooling or disruption in typical daily schedules the following day.

Second, this study utilized an innovative, methodological approach of an intensive EMA protocol that provides data on sleep and mood in the youth's natural environment. Studies have shown that even individuals are not always accurate at retrospectively reporting their mood or affect (Bei et al., 2016; Wilson et al., 2001). As such, this is a method for youth to remember feelings and sleeping behaviours that they experienced accurately. Furthermore, obtaining day-to-day measurement of IIV sleep and mood variability over seven days, rather than collapsing all days into one value, is more representative of the individual (Bei et al., 2016). Youth are likely to experience more variable than constant sleep; thus, it is crucial to use statistical methods that accurately capture these relationships (Bei et al., 2016; Spruyt et al., 2011). Lastly, this study did not collect any specific information regarding children's cognitive abilities or their level of intellectual disability. Their understanding of the specific questions and their ability to accurately describe their sleep and mental health experiences may be affected.

Conclusion

Given the elevated prevalence of mental health challenges among youth with cerebral palsy, it is crucial to comprehend the factors contributing to poor sleep and emotional well-being to enhance their overall health and quality of life (Downs et al., 2018; Whitney et al., 2019). The results of this study indicate that sleep, particularly sleep quality, is associated with intraindividual variability (IIV) in both negative and positive affect. While a bidirectional

relationship between sleep and mood exists, only negative affect was linked to increased subsequent night's poor sleep. Therefore, this study adds to the limited but expanding body of research examining the dynamic interplay between sleep and mood. Although the reported relationship is only partially bidirectional, the study uncovers a mechanism in which poor sleep quality influences negative affect, which in turn significantly contributes to worse sleep quality.

Overall, this study emphasizes the significance of evaluating the associations between sleep and daily mood, as these associations have implications for psychological well-being. Furthermore, it further supports the importance of considering sleep IIV patterns in youth with CP. Future research should continue to investigate the relationships between sleep and mood, incorporating comprehensive methods (e.g., EMA) and the use of both objective and subjective methods to enhance our understanding of these associations. The current study's findings have implications for how we support sleep in this population and the feasibility of sleep intervention development. From a clinical perspective, it is essential that clinicians treating patients with emotional difficulties not only monitor the youth's sleep but also consider their sleep problems as a crucial target in managing emotions. Furthermore, our findings speculate that targeting either sleep in mood interventions or mood in sleep interventions may indirectly impact youth outcomes, enhancing the potency of these psychological interventions.

Chapter 4: Conclusion

People with cerebral palsy (CP) experience a number of co-occurring mental and physical health conditions, such as a higher incidence of pain, epilepsy, sleep, and mood-related difficulties (i.e., anxiety and depression) (Novak et al., 2012; Horwood et al., 2019; Whitney et al., 2019). While the link between sleep and mood is closely related, our understanding of sleep patterns and their impact on mood has yet to be examined among individuals with CP (Klaiber et al., 2021; Langberg et al., 2019; Maskevich et al., 2020; White et al., 2012). Nevertheless, sleep changes significantly across development, and individual differences in sleep are common (Crowley et al., 2018; Bei et al., 2016). Despite decades of research, our understanding of sleep is still incomplete, and the complexity of intraindividual variability adds to the complex clinical picture (Becker et al., 2017; Bei et al., 2016; Dillon et al., 2015). Sleep experiences are shaped by many factors, including the severity of CP, co-occurring mental health difficulties, and individual personal characteristics (Downs et al., 2018; Horwood et al., 2019; Smith et al., 2019). As such, it is imperative to recognize individual variability to ensure effective treatments and support.

While the literature on sleep in this population is growing, only a limited number of studies have focused on subjectively and objectively characterizing the sleep patterns in this population (Horwood et al., 2018; Lélis et al., 2016). Therefore, this study aimed to extend and replicate previous literature by examining the patterns of sleep experienced by youth with CP. Most of the youth in our sample reported average sleep duration, SE, and WASO as per the guidelines of the National Sleep Foundation (NSF) (Hirshkowitz et al., 2015; Ohayon et al., 2017). Sleep fragmentation was prevalent, with youth experiencing a substantial amount of sleep awakenings, more so than recommended by the NSF (Hirshkowitz et al., 2015; Ohayon et al.,

2017). There was also a significant difference in subjective sleep quality, such that females experienced better sleep quality than males. Not only this, but youth's subjective sleep quality was proportionally worse than the general population, youth with other NDDs, and children who experience chronic pain. There was also a statistically significant association between psychiatric diagnosis and insomnia severity, such that those with a psychiatric diagnosis were statistically more likely to experience greater insomnia symptoms.

Overall, this cohort of youth with CP experienced unique sleep patterns characterized by sleep fragmentation, gender differences in subjective sleep quality, and a significant association between psychiatric diagnosis and insomnia severity, meaning that youth with psychiatric diagnoses were more likely to have more severe insomnia symptoms. Despite these findings, most participants did not meet the criteria for insomnia (ISI score < 8). This study contributes to the growing literature on sleep in this population, shedding light on the need for further research to better understand and address the sleep challenges faced by youth with CP. By objectively and subjectively characterizing their sleep patterns, this study paves the way for future interventions and strategies to improve sleep quality and overall well-being in this population. It is essential to allocate additional resources for sleep research specific to CP, similar to those available for autism and other NDDs.

As an extension to the first paper, the second study aimed to explore the link between sleep and mood, which had yet to be examined in this population. Furthermore, to the best of our knowledge, this is the first study investigating the temporal relationship between sleep and mood among youth with CP. The current study strengthens the claim that specific domains of sleep can directly predict mood in youth with CP. The current findings call attention to the need for clinicians to be aware of the relationships between youth's sleep and mood and to provide sleep

hygiene education. These findings suggest that improving sleep quality may promote better mood and elicit positive and negative affect. This study underscores the important bidirectional contributions of sleep and mood factors in everyday life.

Knowledge gained from the study provides critical information for the development of appropriate and effective prevention and intervention strategies to help improve sleep and, subsequently, the mental health of children and youth with CP (Dewald-Kaufmann et al., 2019; Ma et al., 2018). Moreover, these findings provide support for cognitive behaviour therapy for insomnia (CBT-I) (Dewald-Kaufmann et al., 2019; Ma et al., 2018). CBT-I is a psychological intervention that targets psychological and behavioural maladaptive factors about sleep and yields medium to large effect sizes on self-report measures of sleep in adult and adolescent populations (Dewald-Kaufmann et al., 2019; Ma et al., 2018). CBT-I for sleep in youth may increase positive affect and decrease negative, and thus, provide individuals with the resources that may help regulate daily affective experiences and prevent them from disrupting their sleep. In general, these findings highlight that the association between sleep and mental health is multifaceted and complex, and thus it is important to consider the multitude of factors at play when thinking about what impacts an individual's mood.

Concluding Remarks

Both studies are first of their kind to: 1) examine the patterns of sleep experienced by youth with CP; and 2) explore the temporal link between sleep and mood while accounting for age, sex, and GMFCS. However, sleep is a complex phenomenon, and further investigation is necessary to understand the influence of various other factors, which were not available for this thesis. Ultimately, understanding the sleep patterns among youth with CP and recognizing the detrimental effects of insufficient or subjectively poor sleep is of utmost importance during this

critical stage of physical, emotional, and cognitive development. The prevalence of sleep problems, whether chronic or occasional, combined with significant changes in adolescent development and an increased risk of mental health difficulties, underscores the need to identify sleep problems as a risk factor for mood difficulties in youth with CP. This highlights the significance of promoting the importance of sleep for the overall well-being of adolescents in this pivotal life stage.

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APPENDIX A



Conjoint Health Research Ethics Board
Research Services Office
2500 University Drive, NW
Calgary AB T2N 1N4
Telephone: (403) 220-2297
chreb@ucalgary.ca

CERTIFICATION OF INSTITUTIONAL ETHICS APPROVAL

Ethics approval for the following research has been renewed by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary. The CHREB is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS 2); Health Canada Food and Drug Regulations Division 5; Part C; ICH Guidance E6: Good Clinical Practice and the provisions and regulations of the Health Information Act, RSA 2000 c H-5.

Ethics ID:	REB19-0481_REN4
Principal Investigator:	Carly McMorris
Co-Investigator(s):	Melanie Noel Daniel Kopala Sibley Elizabeth Condliffe
Student Co-Investigator(s):	Christopher Clark Mica Pabia
Study Title:	Anxiety and depression in youth with cerebral palsy: Role of physiological risk factors
Sponsor:	HBI Robertson Fund for Cerebral Palsy Research

Effective: 10-Jun-2023

Expires: 10-Jun-2024

Restrictions:

This Certification is subject to the following conditions:

1. The research as described in the application is approved.
2. Proposed modifications must be approved prior to implementation.
3. An application for renewal must be made annually.
4. Closure requests must be submitted when the research is complete or terminated.

Approved By:

Date:

Kathleen Oberle, PhD, Vice-Chair, CHREB

11-May-2023 2:42 PM

Note: This correspondence includes an electronic signature (validation and approval via an online system).

APPENDIX B

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

SPONSOR: *Hotchkiss Brain Institute (HBI)*

INVESTIGATORS: Carly McMorris, PhD1, Laura Brunton, PhD2, Melanie Noel, PhD1, Daniel Kopola-Sibley, PhD1, Elizabeth Condliffe, PhD1, Benjamin Fong, MSW2, Stephanie Howe1, Hangsel Sanguino1

¹University of Calgary, Werklund School of Education

² Alberta Health Services (AHS)

Contact: enhancelab@ucalgary.ca, 403-441-8473

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. 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.

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 Actigraph 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 review 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. In order to mitigate these risks, our team will take extra care to sanitize these materials and will wear masks and gloves when preparing Actigraph packages. 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.

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 Alberta Health Services or the University of Calgary. Researchers or research staff involved in this study can withdraw

you from the study for any reason. 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 or EverythingCard or Amazon gift code to compensate you for your time. You will receive \$10 when you complete the first set of surveys, \$15 after your at-home assessment (Actigraphy period) and the final amount (\$25) after all other components are done. 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.

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. This organization will treat such information with strict confidentiality.

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.

- ☐ I agree to be contacted about my 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 participation, please contact the Study Coordinator at enhancelab@ucalgary.ca / 403-441-8473 or the Principal Investigator, Dr. Carly McMorris at camcmorr@ucalgary.ca / 403-220-545

If you have any questions concerning your rights as a possible participant in this research, please contact The Chair, Conjoint Health Research Ethics Board, University of Calgary, at 403-220-7990.

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

ASSENT FORM

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

SPONSOR: Hotchkiss Brain Institute (HBI)

INVESTIGATORS: Carly McMorris, PhD1, Laura Brunton, PhD2, Melanie Noel, PhD1,
Daniel Kopola Sibley, PhD1, Elizabeth Condliffe, PhD1, Benjamin Fong, MSW2, Stephanie
Howe1, Mica Pabial, Hangsel Sanguino1, Kate Hall1
1University of Calgary, Werklund School of Education
2 Alberta Health Services (AHS)

Contact: enhancelab@ucalgary.ca; 403-441-8473

Why are we doing this study?

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).

What will happen during the study?

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.

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.

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. Our email address is enhancelab@ucalgary.ca and our phone number is 403-441-8473.

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

APPENDIX D

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. Please put on the Actigraphs on the day that was decided on by you and the research team. If you are not sure about when you are supposed to put your Actigraphs on and take them off, please ask!

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 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.

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.

At the end of the 7 days, you can take the Actigraphs off. In your package, you will have received packaging with our address on it. The postage will be pre-paid so you will not have to pay anything. Please put your Actigraphs and your completed logs into the package and put it in the mail for us.

If you have any questions about the study, please contact:

The ENHANCE Lab

enhancelab@ucalgary.ca

403-441-8473

MONITOR LOG

Wear the Actigraphs for seven (7) consecutive days. 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:

[illegible]

APPENDIX E

DEMOGRAPHIC INFORMATION QUESTIONNAIRE

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

The following questions ask a number of demographic related questions (e.g., age, ethnicity, etc.) for both you and your child. Please read each question below carefully and mark an “X” in the statement that fits you and your child best. Answer each question as best as you can. Thank you!

1. Today's Date: __dd__mm____yr

Section 1: Child's Demographic Information

2. Child's Current Age: _____

3. What is your child's sex: _____ Male _____ Female

4. What is your child's gender: _____ Boy _____ Girl _____ non-binary _____ Other

a. If other, please specify: _____

5. What is your **child's first language**/language most often spoken at home?

☐ English

☐ French

☐ Other. Please specify: _____

6. What is the **ethnic origin of your child**?

☐ White, Anglo, or European Canadian

☐ East Asian (e.g. Chinese, Japanese, Korean)

☐ Southeast Asian (e.g. Filipino, Vietnamese, Thai)

☐ Pacific Islander, and/or indigenous persons of Hawaii, New Zealand, etc.

☐ Indian, Pakistani, Bangladeshi, Nepalese, Sri Lankan, etc.

☐ Hispanic or Latinx, Spanish and/or Portuguese (including Mexican Canadian, Central American, etc.)

☐ Indigenous persons of North America and/or the Metis people

☐ Black, Caribbean, and/or African Canadian

☐ Multiethnic or multiracial (more than one race or ethnicity)

☐ Other. Please describe: _____

☐ I's rather not answer

7. Was your child born in Canada?

☐ Yes

☐ No. If not,

where: _____ Ho
w long have they lived in Canada (in years): _____

8. Please select all statements that describe your child's current educational arrangements (select ALL that apply):

- ☐ My child is home schooled
- ☐ My child is in a mainstream classroom with typically developing peers
- ☐ My child is in a special classroom in a public/catholic school
- ☐ My child is at a special school for children with disabilities
- ☐ My child is in public/catholic school
- ☐ My child is in a private school
- ☐ My child is in regular daycare
- ☐ My child receives specialized services in daycare
- ☐ My child is in a specialized daycare for children with disabilities
- ☐ My child is not in school
- ☐ Other. Please describe: _____

9. If your child is currently **not in school**, please describe what your child does during a typical weekday (e.g., day programming, vocational day program, working, volunteering, etc.)

10. Has your child been diagnosed with any medical or physical health issues (e.g. epilepsy, asthma, diabetes, kidney or urinary problems)? ____Yes ____No

If so, please list them below:

- 1) _____
- 2) _____
- 3) _____
- 4) _____
- 5) _____

11. Is your child currently on any medications to address these physical health concerns?
____Yes ____No

12. If so, please list the specific medications and *why* (i.e. for what condition) they were prescribed to your child

- 1) _____
- 2) _____
- 3) _____

13. My child with CP is:

- a) Younger than 2 years old (0)
- b) 2-4 years old (1)
- c) 4-6 years old (2)
- d) 6-12 years old (3)
- e) 12-18 years old (4)
- f) Older than 18 years old (5)

If, a) is selected, skip to end of section

13.1 [GMFCS Family Report Questionnaire 2-4 years]

If b) is selected:

Please read and select the option that best represents your child's movement abilities.
My child...

- a) Has difficulty controlling head and trunk posture in most positions
and uses specially adapted seating to sit comfortably
and has to be lifted by another person to move about
- b) Can sit on own when placed on the floor and can move within a room
and uses hands for support to maintain sitting balance
and usually uses adaptive equipment for sitting and standing
and moves by rolling, creeping on stomach, or crawling
- c) Can sit on own and walk short distances with a walking aid (such as a walker, rollator, crutches, canes, etc.)
and may need help from an adult for steering or turning when walking with an aid
and usually sits on the floor in a "W-sitting" position and may need help from an adult to get into sitting
and may pull to stand and cruise short distances
and prefers to move by creeping and crawling
- d) Can sit on own and usually moves by walking with an aid
and may have difficulty with sitting balance when using both hands to play
and can get in and out of sitting positions on own
and can pull to stand and cruise holding onto furniture
and can crawl, but prefers to move by walking
- e) Can sit on own and moves by walking without a walking aid
and is able to balance in sitting when using both hands to play
and can move in and out of sitting and standing positions without help from an adult
and prefers to move by walking

13.2 [GMFCS Family Report Questionnaire 4-6 years]

If c) is selected

Please read and select the option that best represents your child's movement abilities.
My child...

- a) **Has difficulty sitting on their own and controlling their head and body posture in most positions**
and has difficulty achieving and voluntary control of movement
and needs a specially-adapted supportive chair to sit comfortably
and has to be lifted or hoisted by another person to move
- b) **Can sit on their own but does not stand or walk without significant support and adult supervision**
and may need extra body/trunk support to improve arm and hand function
and usually needs adult assistance to get in and out of a chair
and may achieve self-mobility using a powered wheelchair or is transported in the community
- c) **Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes, etc.)**
and can usually get in and out of a chair without adult assistance
and may use a wheelchair when travelling long distances or outside
and finds it difficult to climb stairs or walk on uneven surface without considerable help
- d) **Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces**
and can sit in a normal adult chair and use both hands freely
and can move from the floor to standing without adult assistance
and needs to held the handrail when going up or down stairs
and is not yet able to run and jump
- e) **Can walk on their own without using a walking aid, including fairly long distances, outdoors, and on uneven surfaces**
and can move from the floor to a chair to standing without using their hands for support
and can go up and down stairs without needing to hold the handrail
and is beginning to run and jump

13.3 [GMFCS Family Report Questionnaire 6-12 years]

If d) is selected

Please read and select the option that best represents your child's movement abilities.
 My child...

- a) **Has difficulty sitting on their own and controlling their head and body posture in most positions**
and has difficulty achieving any voluntary control of movement
and needs a specially supportive chair to sit comfortably
and has to be lifted or hoisted by another person to move
- b) **Can sit on their own but does not stand or walk without significant support**
and therefore relies mostly on wheelchair at home, school and in the community
and often needs extra body/trunk support to improve arm and hand function
and may achieve self-mobility using a powered wheelchair
- c) **Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)**

- and finds it difficult to climb stairs, or walk on uneven surfaces
and may use a wheelchair when travelling for long distances or in crowds
- d) **Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs**
and often finds it difficult to walk on uneven surfaces, slopes or in crowds
- e) **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**
and walks wherever they want to go (including uneven surfaces, slopes or in crowds)
and can run and jump although their speed, balance, and coordination may be slightly limited

13.4 [GMFCS Family Report Questionnaire 12-18 years]

If e) or f) is selected

Please read and select the option that best represents your child's movement abilities.

My child...

- a) **Has difficulty sitting on their own and controlling their head and body posture in most positions**
and has difficulty achieving any voluntary control of movement
and needs a specially adapted chair to sit comfortably and be transported anywhere
and has to be lifted or hoisted by another person or special equipment to move
- b) **Can sit with some pelvic and trunk support but does not stand or walk without significant support**
and therefore always relies on wheelchairs when outdoors
and can achieve self-mobility using a powered wheelchair
and can crawl or roll to a limited extent to move around indoors
- c) **Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)**
and finds it difficult to climb stairs, or walk on uneven surfaces without support
and uses a variety of means to move around depending on the circumstances
and prefers to use a wheelchair to travel quickly or over longer distances
- d) **Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs**
and therefore walks in most settings
and often finds it difficult to walk on uneven surfaces, slopes or in crowds
and may occasionally prefer to use a walking aid (such as a cane or a crutch) or a wheelchair to travel quickly or over longer distances
- e) **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**
and walks wherever they want to go (including uneven surfaces, slopes, or in crowds)
and can run and jump although their speed, balance, and coordination may be limited

14. Functional Mobility Scale (FMS)

14.1 How does your child usually move around short distances in the house (5m)?

- a) Independent on all surfaces: Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs, etc. and in a crowded environment
- b) Independent on level surfaces: Does not use walking aids or need help from another person. Requires rail for stairs. [If uses furniture, walls, fences, shop fronts for support, please select next option]
- c) Uses sticks (one or two): without help from another person
- d) Uses crutches: without help from another person
- e) Uses wheelchair: may stand for transfers, may do some stepping supported by another person or using a walker/frame
- f) Crawling: Child crawls for mobility at home

14.2 How does your child move around medium distances, such as in and between classes at school (50m)?

- a) Independent on all surfaces: Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs, etc. and in a crowded environment
- b) Independent on level surfaces: Does not use walking aids or need help from another person. Requires rail for stairs. [If uses furniture, walls, fences, shop fronts for support, please select next option]
- c) Uses sticks (one or two): without help from another person
- d) Uses crutches: without help from another person
- e) Uses wheelchair: may stand for transfers, may do some stepping supported by another person or using a walker/frame
- f) Does not apply: For example, child does not complete the distance

14.3 How does your child move around for long distances such as at the shopping center (500m)?

- a) Independent on all surfaces: Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs, etc. and in a crowded environment
- b) Independent on level surfaces: Does not use walking aids or need help from another person. Requires rail for stairs. [If uses furniture, walls, fences, shop fronts for support, please select next option]
- c) Uses sticks (one or two): without help from another person
- d) Uses crutches: without help from another person
- e) Uses wheelchair: may stand for transfers, may do some stepping supported by another person or using a walker/frame
- f) Does not apply: For example, child does not complete the distance

Section 2: Mental Health Issues

15. Has your child been diagnosed by a registered health professional with any psychiatric or mental health diagnoses? ____ Yes ____ No

If so, please select ALL that apply

- ☐ Learning disability
- ☐ Communication disorder (e.g. language disorder, childhood-onset fluency disorder)

[stuttering], speech sound disorder, social [pragmatic] communication disorder)

- ☐ Autism spectrum disorder
- ☐ Tourette's/Tic Disorder
- ☐ Eating/feeding disorder
- ☐ Conduct Disorder/Oppositional Defiant Disorder
- ☐ Substance abuse/misuse
- ☐ Schizophrenia or other psychotic disorder
- ☐ Depression
- ☐ Bipolar Disorder
- ☐ Anxiety disorder (including OCD, social anxiety, or phobias)
- ☐ Sleep disorder
- ☐ Personality disorder
- ☐ Other, please specify: _____

14. Has your child received ***in the past*** any non-medical interventions to address their psychiatric/mental health issues: _____ Yes _____ No

If yes, please indicate which interventions your child or family have received:

- ☐ Individual therapy (e.g., cognitive-behaviour therapy [CBT], play therapy)
- ☐ Group therapy
- ☐ Family therapy
- ☐ Parent coaching/counseling
- ☐ Other, please specify: _____

15. Has your child received ***in the past*** any medical interventions to address their psychiatric/mental health issues: _____ Yes _____ No

If yes: please describe the type of medication and what it was prescribed to treat:

16. Is your child ***currently receiving*** any non-medical interventions to address their psychiatric/mental health issues: _____ Yes _____ No

If yes, please indicate which interventions your child or family have received:

- ☐ Individual therapy (e.g., cognitive-behaviour therapy [CBT], play therapy)
- ☐ Group therapy
- ☐ Family therapy
- ☐ Parent coaching/counseling
- ☐ Other, please specify: _____

17. Is your child ***currently receiving*** any medical interventions to address their psychiatric/mental health issues: _____ Yes _____ No

If yes: please describe the type of medication and what it was prescribed to treat:

Section 3: Parent/Caregiver Demographic Information

18. What is **your relationship to the child/adolescent** with ADHD for whom you are completing this survey? (check off all that apply).

- ☐ Biological parent
 - ☐ Mother
 - ☐ Father
- ☐ Foster parent
 - ☐ Mother
 - ☐ Father
- ☐ Adoptive parent
 - ☐ Mother
 - ☐ Father
- ☐ Step-parent
 - ☐ Mother
 - ☐ Father
- ☐ Grandparent
- ☐ Other relative (e.g., aunt,

cousin)

Please specify:

19. What is your current age:_____

20. What is your marital status:

- ☐ Single
- ☐ Divorced
- ☐ Widowed
- ☐ Married or common-law

21. How would you describe your current family status as it related to your child? (please choose only one). My child lives in a:

- ☐ Two parent family (both biological parents)
- ☐ Two parent family (two adoptive parents)
- ☐ Two parent family (one biological parent, one non biological-parent)
- ☐ Single parent family
- ☐ Other. Please specify:_____

22. What is the highest level of education **you have completed**?

- ☐ Elementary school
- ☐ High school
- ☐ Some college/university
- ☐ Trade, technical, vocational school or business/community college (e.g., SAIT, NAIT)
- ☐ University undergraduate degree

- ☐ Masters degree
- ☐ PhD

23. What is the highest level of education **your partner has completed**?

- ☐ Elementary school
- ☐ High school
- ☐ Some college/university
- ☐ Trade, technical, vocational school or business/community college (e.g., SAIT, NAIT)
- ☐ University undergraduate degree
- ☐ Masters degree
- ☐ PhD

24. How long have you been living in Canada (in years)? _____

25. Please estimate your average annual household income:

- ☐ Prefer not to say
- ☐ Under \$20,000
- ☐ \$20,000 and over
- ☐ \$25,000 and over
- ☐ \$35,000 and over
- ☐ \$50,000 and over
- ☐ \$75,000 and over
- ☐ \$100,000 and over

26. What is the best way to describe the size of your community?

- ☐ We live in a remote area of the country
- ☐ We live in a rural area of the country
- ☐ We live in a suburban area of the country
- ☐ We live in an urban area of the country

27. How would you describe your current work/employment situation:

- ☐ Working for pay for an individual or a company
- ☐ Self-employed
- ☐ Attending school
- ☐ Volunteering
- ☐ At-home parent

28. How many people usually live with your child at this address, including you and your child:_____

29. How many children do you have, in total? (please include all children that you have guardianship of or legal responsibility for, even those how are not biologically related):__

30. How many of your children have a developmental, mental health, or physical disability? ____

31. What are the ages of the children that live at your home currently (in years):

Child 1: _____

Child 2: _____

Child 3: _____

Child 4: _____

Child 5: _____

Section 4: Service Utilization

*Next, I'd like to understand a little more about the specific services you needed and the services you received in the **last year**. Please put Y (for Yes) or N (No) if you have needed this type of service in the **last 12 months**.*

*Next, please rate the **need of that service**, from 1 to 3, with 1 being some need, 2 being reasonably strong need and 3 being very strong need.*

*Following, that, please **indicate Yes (Y) or No (N)** you received that support, and then rate how helpful that support was to you, from 1 to 3, 1 being not at all helpful, 2 being somewhat helpful but not enough and 3 being very helpful*

TYPE	NEED (Y/N)	NEED? (1-3)	RECEIVED? (Y/N)	RATE HELPFUL? (1-3)
Friendly ear for you to talk to				
Parent support group				
Information				
Activities for the family member with CP				
Respite care				
Practical or material help				
Mental health care for the family member with CP				

Other Specify: _____				
-------------------------	--	--	--	--

BARRIERS TO ACCESSING SERVICES

Next, please indicate if your family has experienced any of the below barriers to accessing the services you wanted or needed. Mark an 'X' under Yes if your family has experience this barrier.

<u>TYPE OF BARRIER?</u>	<u>YES</u>	<u>NO</u>
The problem was not so serious that you didn't look for help		
Want to handle problems themselves		
Problem was considered temporary		
Negative experiences with professional help		
Didn't know where to find help		
Fear of being too big a burden		
Busy / other priorities		
Steps to seek help are too overwhelming		
Having difficulties in describing the problems and needs		
Other people did not want the family to seek help		
No trust in professional help		
Fear of labeling / stigma		
Distance too far to get help		
Waitlists too long		
No services available		
Language/communication difficulties		
Parent/caregiver mental health		

Other Specify: _____		
---------------------------------	--	--

EMERGENCY ROOM

Next, I would like to ask you some questions related to your experiences with the Emergency Room.

Have you ever had to visit the ER (Y/N) because of your son or daughter's mental health issues?
Y/N

IF YES:

What was the main reason you went to the ER? _____

Did you have any concerns or challenges going to the ER? _____

What could be done to prevent another ER visit, if anything?_____

What could have helped you after an ER visit, if anything?

APPENDIX F

ADOLESCENT QUESTIONNAIRE PACKAGE

(AGES 12 AND UP)

Includes Youth Pain Questionnaire, FISSA, ISI, ASWS, PROMIS-25, PedsQL teen report, CRPB-30, & SBI

YOUTH PAIN QUESTIONNAIRE

1. In the past 7 days, how often have you had aches or pains?
 - ☐ Not at all
 - ☐ 1 time per week
 - ☐ 2 to 3 times per week
 - ☐ 4 to 6 times per week
 - ☐ Daily

2. In which part of your body did you experience the most aches and pains? (Select all that apply)
 - ☐ Stomach
 - ☐ Head
 - ☐ Muscles and joints
 - ☐ Legs
 - ☐ Chest
 - ☐ Other (please specify): _____

3. How long do your aches and pains usually last?
 - ☐ Less than 1 hour
 - ☐ A few hours
 - ☐ Half of the day
 - ☐ All day

4. When you have aches or pain, how much hurt so you usually have?

0											10
no	1	2	3	4	5	6	7	8	9		worst pain
pain											possible
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. How much do aches and pains bother or upset you?

Not at all	A little	Between a little and a lot	A lot	Very Much
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the Past 7 days...

	Never	Almost Never	Someti mes	Often	Almost Always
6. I had trouble sleeping when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Never	Almost Never	Someti mes	Often	Almost Always
7. It was hard for me to pay attention when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. It was hard for me to run when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. It was hard for me to walk one block when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Now think about the past several months.

10. Have you had pain for at least 3 months in a row?

- ☐ Yes
☐ No

I have had this pain for...

_____ years and _____ months.

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.

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

Fatigue interferes with...

	Completely Disagree 1	Somewhat Disagree 2	Neither Agree or Disagree 3	Somewhat Agree 4	Completely Agree 5
1. My general everyday activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. My ability to move around indoors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. My ability to do things on my own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Completely Disagree 1	Somewhat Disagree 2	Neither Agree or Disagree 3	Somewhat Agree 4	Completely Agree 5
4. My ability to move around my community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My ability to get outside of my house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. My ability to finish things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. My participation in social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. My ability to start things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. My ability to take care of myself (examples: dressing, eating, bathing, brushing my teeth/hair, toileting, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In addition,

	Completely Disagree 1	Somewhat Disagree 2	Neither Agree or Disagree 3	Somewhat Agree 4	Completely Agree 5
10. I use adaptive equipment to manage my fatigue (examples: a walker, manual wheelchair, power wheelchair, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I have to reduce my work responsibilities outside of my home because of fatigue (examples: school work, job-related work, volunteering, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. I have to reduce my responsibilities at home because of fatigue

☐ ☐ ☐ ☐ ☐

Using the scale given with each question, please think about the **last 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 most** fatigued:

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

No Fatigue		Moderate Fatigue		Severe Fatigue
1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

None	A Quarter of the Day	Half of the Day	Three Quarters of the Day	All Day
1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. For how many days **last week** did you feel fatigued for at least part of the day?

1	2	3	4	5
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fatigue interferes with...

Completely Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Completely Agree
1	2	3	4	5

18. My enjoyment of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My leisure and recreational activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. The length of time I can be physically active	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. My balance and coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Completely Disagree 1	Somewhat Disagree 2	Neither Agree or Disagree 3	Somewhat Agree 4	Completely Agree 5
22. My motivation to do physical activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. My motivation to participate in social activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In addition,

	Completely Disagree 1	Somewhat Disagree 2	Neither Agree or Disagree 3	Somewhat Agree 4	Completely Agree 5
24. My muscles ache when I am fatigued	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Long periods of inactivity increase my fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Stress increases my fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Fatigue increases my stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. I pace my physical activities to manage my fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. I think about fatigue when I plan my day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. I limit my physical activity to manage my fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. I stop and rest during activity to manage my fatigue ☐ ☐ ☐ ☐ ☐

Additional Questions:

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

- ☐ Yes
☐ No

If yes, what time of day is your fatigue the worst?

- ☐ Early morning
☐ Mid-morning
☐ Noon
☐ Late afternoon
☐ Evening

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

- ☐ Yes
☐ No

If yes, on which day of the week are you most fatigued?

- ☐ Monday
☐ Tuesday
☐ Wednesday
☐ Thursday
☐ Friday
☐ Saturday
☐ Sunday

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 you reduce your fatigue?

INSOMNIA SEVERITY INDEX (ISI)

Please rate the **current (i.e. last two weeks) severity** of your insomnia problems.

None
0

Mild
1

Moderate
2

Severe
3

Very
Severe
4

1. Difficulty falling asleep ☐ ☐ ☐ ☐ ☐
2. Difficulty staying asleep ☐ ☐ ☐ ☐ ☐
3. Problems waking up too early ☐ ☐ ☐ ☐ ☐

4. How satisfied/dissatisfied are you with your **current** sleep pattern?

Very Satisfied	Satisfied	Moderately Satisfied	Dissatisfied	Very Dissatisfied
0	1	2	3	4
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. How **noticeable** to others do you think your sleep problem is in terms of impairing the quality of your life?

Not at all Noticeable	A little	Somewhat	Much	Very Much Noticeable
0	1	2	3	4
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. How **worried/distressed** are you about your current sleep problem?

Not at all Worried	A little	Somewhat	Much	Very Much Worried
0	1	2	3	4
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. To what extent do you consider your sleep problem to **interfere** with your daily functioning (e.g. daytime fatigue, mood, ability to function at work or school/daily chores, concentration, memory, etc.) **currently**?

Not at all interfering	A little	Somewhat	Much	Very Much Interfering
0	1	2	3	4
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

ADOLESCENT'S SLEEP-WAKE SCALE (ASWS)

	Always	Frequent ly-if not always	Quite often	Sometim es	Once in a while	Never
<i>Going to bed</i>						

- [illegible]

	Always	Frequently-if not always	Quite often	Sometimes	Once in a while	Never
<i>Falling asleep</i>						

- [illegible]

medication, or have
someone else in the
bed with me.

11. I fall asleep quickly. ☐ ☐ ☐ ☐ ☐ ☐

		Frequent ly-if not always	Quite often	Sometim es	Once in a while	Never
<i>Maintaining sleep</i>	Always					

12. During the night, I
toss and turn in my
bed. ☐ ☐ ☐ ☐ ☐ ☐

13. During the night, I am
very restless. ☐ ☐ ☐ ☐ ☐ ☐

14. During the night, I
moan, groan, or talk
in my sleep. ☐ ☐ ☐ ☐ ☐ ☐

15. During the night, my
legs kick or jerk. ☐ ☐ ☐ ☐ ☐ ☐

16. During the night, I
wake up more than
once. ☐ ☐ ☐ ☐ ☐ ☐

17. I sleep soundly
through the night. ☐ ☐ ☐ ☐ ☐ ☐

		Frequent ly-if not always	Quite often	Sometim es	Once in a while	Never
<i>Reinitiating sleep</i>	Always					

18. After waking up
during the night, I
have trouble going
back to sleep. ☐ ☐ ☐ ☐ ☐ ☐

19. After waking up
during the night, I
have trouble getting
comfortable. ☐ ☐ ☐ ☐ ☐ ☐

20. After waking up
during the night, I ☐ ☐ ☐ ☐ ☐ ☐

wake up another
family member.

21. After waking up during the night, I need help to go back to sleep (for example: I need to watch television, read, or sleep with another person).

○ ○ ○ ○ ○ ○

22. After waking up during the night, I feel scared.

○ ○ ○ ○ ○ ○

23. After waking up during the night, I roll over and go right back to sleep.

○ ○ ○ ○ ○ ○

		Frequent				
		ly-if not	Quite	Sometim	Once in	
<i>Returning to wakefulness</i>	Always	always	often	es	a while	Never

24. In the morning, I wake up and feel ready to get up for the day.

○ ○ ○ ○ ○ ○

25. In the morning, I
wake up feeling rested
and alert.

○ ○ ○ ○ ○ ○

	Always	Frequently-if not always	Quite often	Sometimes	Once in a while	Never
<i>Returning to wakefulness</i>						

26. In the morning, I wake up and just can't get going.

○ ○ ○ ○ ○ ○

27. I need help waking up in the morning (for example: from an alarm clock or other person).

○ ○ ○ ○ ○ ○

28. I have trouble getting out of bed in the morning. ☐ ☐ ☐ ☐ ☐ ☐

PATIENT-REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM

(PROMIS)

PEDIATRIC PROFILE-25 (V2)

<i>In the past 7 days...</i>	With no trouble 5	With a little trouble 4	With some trouble 3	With a lot of trouble 2	Not able to do 1
1. I could do sports and exercise other kids my age could do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I could get up from the floor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I could walk up stairs without holding on to anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I have been physically able to do the activities that I enjoy most	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<i>In the past 7 days...</i>	Never 1	Almost never 2	Sometimes 3	Often 4	Almost Always 5
5. I felt like something awful would happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I felt nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I felt worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I worried when I was at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<i>In the past 7 days...</i>	Never 1	Almost never 2	Sometimes 3	Often 4	Almost Always 5
9. I felt that everything in my life was wrong	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I felt lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. I felt sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. It was hard for me to have fun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>In the past 7 days...</i>	Never 1	Almost never 2	Sometimes 3	Often 4	Almost Always 5
13. Being tired made it hard for me to keep up with my schoolwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I got tired easily	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I was too tired to do sports or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I was too tired to enjoy the things I like to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>In the past 7 days...</i>	Never 1	Almost never 2	Sometimes 3	Often 4	Almost Always 5
17. I felt accepted by other kids my age	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I was able to count on my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My friends and I helped each other out	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Other kids wanted to be my friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>In the past 7 days...</i>	Never 1	Almost never 2	Sometimes 3	Often 4	Almost Always 5
21. I had trouble sleeping when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. It was hard for me to pay attention when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. It was hard for me to run when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. It was hard for me to walk one block when I had pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In the past 7 days...

How was your pain on average?

No
pain

Worst pain
you can think
of

0 1 2 3 4 5 6 7 8 9 10
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

PEDIATRIC QUALITY OF LIFE INVENTORY (PEDSQL)

	Never 0	Almost Never 1	Sometim es 2	Often 3	Almost Always 4
<i>About my health and activities</i>					
1. It is hard for me to walk more than one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. It is hard for me to run	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. It is hard for me to do sports and activities or exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. It is hard for me to lift something heavy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. It is hard for me to take a bath or shower by myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. It is hard for me to do chores around the house	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I hurt or ache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I have low energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>About my feelings</i>	Never 0	Almost Never 1	Sometim es 2	Often 3	Almost Always 4
9. I feel afraid or scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I feel sad or blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I feel angry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I have trouble sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I worry about what will happen to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>How I get along with others</i>	Never 0	Almost Never 1	Sometim es 2	Often 3	Almost Always 4
14. I have trouble getting along with other teens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Other teens do not want to be my friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Other teens tease me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. I cannot do things that other teens my age can do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. It is hard to keep up with my peers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>About school</i>	Never 0	Almost Never 1	Sometim es 2	Often 3	Almost Always 4
19. It is hard to pay attention in class	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I forget things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I have trouble keeping up with my schoolwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I miss school because of not feeling well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I miss school to go to the doctor or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CHILDREN'S REPORT OF PARENT BEHAVIOUR INVENTORY (CRPB-30)

Please read each statement of the following pages and circle the answer that most closely describes the way each of your parents act towards you.

My mother is a person who...

	Not like 1	Somewhat like 2	A lot like 3
1. Makes me feel better after talking over my worries with her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Tells me all of the things she has done for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Believes in having a lot of rules and sticking with them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Smiles at me often.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Says, if I really cared for her, I would not due things that cause her to worry.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Insist that I must do exactly as I am told.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Is able to make me feel better when I'm upset.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Is always telling me how I should behave.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Is very strict with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. Enjoys doing things with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not like	Somewhat	A lot like
	1	like 2	3
11. Would like to be able to tell me what to do all the time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Gives hard punishment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Cheers me up when I am sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Wants to control whatever I do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Is easy with me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Gives me a lot of care and attention.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Is always trying to change me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Lets me off easy when I do something wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Makes me feel like the most important person in her life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Only keeps rules when it suits her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not like	Somewhat	A lot like
	1	like 2	3
21. Gives me as much freedom as I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Believes in showing her love for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Is less friendly with me if I do not see things her way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Lets me go anyplace I please without asking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Often praises me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Will avoid looking at me when I have disappointed her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Lets me go out any evening I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Is easy to talk to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- | | | | |
|--|-----------------------|-----------------------|-----------------------|
| 29. If I have hurt her feelings, stops talking to me until I please her again. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 30. Lets me do anything I like to do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

My father is a person who...

- | | Not like
1 | Somewhat
like
2 | A lot like
3 |
|---|-----------------------|-----------------------|-----------------------|
| 1. Makes me feel better after talking over my worries with him. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Tells me all of the things he has done for me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 3. Believes in having a lot of rules and sticking with them. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Smiles at me often. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Says, if I really cared for him, I would not due things that cause him to worry. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Insist that I must do exactly as I am told. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Is able to make me feel better when I'm upset. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Is always telling me how I should behave. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Is very strict with me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Enjoys doing things with me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- | | Not like
1 | Somewhat
like
2 | A lot like
3 |
|---|-----------------------|-----------------------|-----------------------|
| 11. Would like to be able to tell me what to do all the time. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Gives hard punishment. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Cheers me up when I am sad | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Wants to control whatever I do. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Is easy with me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Gives me a lot of care and attention. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 17. Is always trying to change me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

18. Lets me off easy when I do something wrong.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Makes me feel like the most important person in his life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Only keeps rules when it suits him.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not like 1	Somewhat like 2	A lot like 3
21. Gives me as much freedom as I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Believes in showing his love for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Is less friendly with me if I do not see things his way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Lets me go anyplace I please without asking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Often praises me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Will avoid looking at me when I have disappointed him.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Lets me go out any evening I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Is easy to talk to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. If I have hurt her feelings, stops talking to me until I please him again.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Lets me do anything I like to do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SOCIAL BEHAVIOUR INVENTORY (SBI)

Please rate the extent to which you did the following things when you **interacted with your parent today**. If you're unsure, please take your best guess.

	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
1. I listened attentively to my parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I tried to get my parent to do something else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- | | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 3. I let my parent make plans or decisions | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. I confronted my parent about something I did not like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. I expressed affection with words or gestures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. I spoke in a clear, firm voice | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. I withheld useful information | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. I did not say how I felt | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. I compromised about a decision | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. I took the lead in planning/organizing the activity | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- | | | | | | |
|--|-----------------------|---------------------------|-----------------------|-----------------------|-----------------------|
| | Not at all
1 | Very
occasionally
2 | Somewhat
3 | Often
4 | All the
time
5 |
| 11. I avoided taking the lead or being responsible | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. I ignored my parent's comments | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. I criticized my parent | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. I smiled and laughed with my parent | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. I spoke softly | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. I made a sarcastic comment | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

17. I expressed an opinion ☐ ☐ ☐ ☐ ☐

18. I complimented or praised
my parent ☐ ☐ ☐ ☐ ☐

19. I did not express
disagreement when I
thought it ☐ ☐ ☐ ☐ ☐

20. I gave incorrect
information ☐ ☐ ☐ ☐ ☐

Not at all Very Somewhat Often All the
1 occasionally 3 4 time
 2

21. I got immediately to the
point ☐ ☐ ☐ ☐ ☐

22. I made a concession to
avoid unpleasantness ☐ ☐ ☐ ☐ ☐

23. I did not state my own
views ☐ ☐ ☐ ☐ ☐

24. I showed impatience ☐ ☐ ☐ ☐ ☐

25. I went along with my
parent ☐ ☐ ☐ ☐ ☐

26. I raised my voice ☐ ☐ ☐ ☐ ☐

27. I gave information ☐ ☐ ☐ ☐ ☐

28. I expressed reassurance ☐ ☐ ☐ ☐ ☐

29. I gave in ☐ ☐ ☐ ☐ ☐

30. I demanded my parent do
what I wanted ☐ ☐ ☐ ☐ ☐

Not at all Very Somewhat Often All the
1 occasionally 3 4 time
 2

31. I set goals for my parent or for us	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. I pointed out where there was agreement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. I spoke only when spoken to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. I waited for my parent to act or talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. I stated strongly that I did not like or that I would not do something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. I assigned my parent to a task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. I exchanged pleasantries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. I did not say what was on my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. I did not respond to my parent's questions or comments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. I made a suggestion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
41. I showed sympathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. I did not say what I wanted directly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. I discredited what my parent said	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. I asked my parent to do something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

45. I spoke favourably of my parent when they were not present

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
1. My parent listened attentively to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. My parent tried to get me to do something else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. My parent let me make plans or decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. My parent confronted me about something he/she did not like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. My parent expressed affection with words or gestures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. My parent spoke in a clear, firm voice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. My parent withheld useful information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. My parent did not say how he/she felt	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. My parent compromised about a decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. My parent took the lead in planning/organizing the activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
11. My parent avoided taking the lead or being responsible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. My parent ignored my comments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. My parent criticized me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. My parent smiled and laughed with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. My parent spoke softly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. My parent made a sarcastic comment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. My parent expressed an opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. My parent complimented or praised me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. My parent did not express disagreement when he/she thought it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. My parent gave incorrect information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
21. My parent got immediately to the point	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. My parent made a concession to avoid unpleasantness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. My parent did not state his/her own views	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. My parent showed impatience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. My parent went along with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. My parent raised his/her voice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. My parent gave information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. My parent expressed reassurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. My parent gave in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. My parent demanded I do what he/she wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
31. My parent set goals for me or for us	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. My parent pointed out where there was agreement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. My parent spoke only when spoken to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. My parent waited for me to act or talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. My parent stated strongly that he/she did not like or that he/she would not do something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

36. My parent assigned me to a task	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. My parent exchanged pleasantries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. My parent did not say what was his/her my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. My parent did not respond to my questions or comments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. My parent made a suggestion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not at all 1	Very occasionally 2	Somewhat 3	Often 4	All the time 5
41. My parent showed sympathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. My parent did not say what he/she wanted directly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. My parent discredited what I said	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. My parent asked me to do something	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. My parent spoke favourably of me when I was not present	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

You have reached the end of the questionnaire booklet.

Thank you for your time!

APPENDIX F

Page 1

Daily Survey 1

Please complete the survey below.

Thank you!

-
- 1) Email (optional) _____
-
- 2) How much pain did you experience today?
- No Pain Worst Possible Pain
- =====
- (Place a mark on the scale above)*
-
- 3) How much did pain interfere with your day?
- Not at all Pain interfered with all activities
- =====
- (Place a mark on the scale above)*
-
- 4) How much fatigue did you experience today?
- No Fatigue Worst Possible Fatigue
- =====
- (Place a mark on the scale above)*
-
- 5) How much did fatigue interfere with your day today?
- Not at all Fatigue interfered with all activities
- =====
- (Place a mark on the scale above)*
-
- 6) How would you rate your sleep last night?
- Best Sleep Possible Worst Sleep 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? _____
-