Perinatal Stroke: Functional Abilities, Executive Function, and Modifiable Environmental Factors

by

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ABSTRACT

Background: Perinatal stroke is a vascular brain injury between the 20th gestational week and the 28th postnatal day. Perinatal stroke can lead to significant impairments to daily functional abilities and executive functions (EF: inhibition, working memory, and shifting). Longitudinal research indicates that children with perinatal stroke do not display cognitive deficits until school age, but it is unclear if deficits to EF and functional abilities also change with age.

Modifiable environmental factors, including use of supportive services and movement behaviors (sleep, physical activity, and screen time), may influence EF and functional outcomes for children with perinatal stroke. However, movement behaviors and access to supportive services have been disrupted for many children during the COVID-19 pandemic. Characterizing the engagement of children with perinatal stroke with these modifiable factors, both before and during the COVID-19 pandemic, offers valuable context to developmental trajectories for EF and functional abilities.

Objective I: To describe longitudinal changes to functional abilities and EF behaviors among children with perinatal stroke.

Objective II: To describe engagement with supportive services and movement behaviors among children with perinatal stroke, before and during the COVID-19 pandemic.

Methods: Participants for both studies were identified through the Alberta Perinatal Stroke Project (APSP), a population-based research cohort of individuals with a confirmed diagnosis of perinatal stroke.

For Objective 1: Eight caregivers completed neurobehavioral ratings of their children. At baseline, their children were aged 6-16 years. Caregivers completed follow-up ratings 2.1-3.9

years later. The BRIEF2 was used as the primary measure of EF behaviors and the PEDI-CAT was used as the primary measure of functional abilities. To account for potential impacts of the COVID-19 pandemic, caregivers were also asked to rate the overall impact of the pandemic on their family.

For Objective 2: Thirty-four caregivers of children aged 5-19 years from the APSP completed an online survey: the Wellness Activities Questionnaire (WAQ). The WAQ asks about participation in supportive services and movement behaviors, and about the impact of COVID-19 on these activities.

Results I: All participants displayed reliable worsening of T scores on at least two PEDI-CAT domains. Although participants displayed clinically significant impairment on some BRIEF2 subscales, most changes to BRIEF2 T scores were unreliable. Among this sample, 75% of participants rated the pandemic as having had a negative impact on their family.

Results II: Before the COVID-19 pandemic, 82.4% of children with perinatal stroke had utilized at least one allied health service, while 55.9% typically received some type of educational support. Roughly half of participants indicated that access to allied health services was negatively impacted during the pandemic, whereas 73.5% indicated that access to educational supports did not change during the pandemic. Most children were meeting guidelines for daily sleep and physical activity time before the pandemic, but 63.6% were engaged in more screen time than recommended. During the COVID-19 pandemic, daily sleep and physical activity significantly decreased ($p<0.05$) and daily recreational screen time significantly increased ($p<0.05$).

Conclusions: Children with perinatal stroke displayed slowed development of functional abilities, compared to normative peers. In contrast, development of EF behaviors was more comparable to that of normative peers, as specific deficits persisted but did not worsen over time. Although pre-pandemic patterns of service use and movement behaviors likely provide robust environmental supports for functional and EF development, many of these services and routines were disrupted during the COVID-19 pandemic. It is likely that disruptions to service use and movement behaviors during the pandemic substantially impacted the longitudinal trajectories of EF behaviors and functional abilities reported here.

PREFACE

This thesis is an original work by Leah Hammond. The research projects, of which this thesis is a part, received ethics approval from the University of Alberta Health Research Ethics Board, (Project Name: “Neurobehavioural Outcomes of Children with Perinatal Stroke”, Ethics ID: Pro00066087, March 28, 2017) and from the University of Calgary Conjoint Health Research Ethics Board (Project Name: “APSP: Investigating cognitive, behavioral, and emotional outcomes among children with perinatal stroke”, Ethics ID: REB18-0360, April 2, 2018).

This project is part of a larger research initiative called the Alberta Perinatal Stroke Project (APSP), led by Dr. Adam Kirton at the University of Calgary. Dr. Carmen Rasmussen is a co-investigator of the APSP at the University of Alberta. The Wellness Activities Questionnaire used in Study II was designed by me, with the assistance of Dr. Carmen Rasmussen and other APSP investigators. The introduction, literature review, data analysis, discussion, and conclusions contained herein are my original work.

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INTRODUCTION

Although stroke is commonly considered an adult disease, the most focused lifetime risk of stroke occurs during the perinatal period, from 20 weeks gestation to the 28th postnatal day (Dunbar & Kirton, 2018). Perinatal stroke occurs in roughly 1 in 1,100 term births (Dunbar et al., 2020) and likely at higher rates among preterm births (Benders et al., 2008). Perinatal stroke is often associated with lifelong morbidity and accounts for a substantial global economic burden (Hamilton et al., 2015). It is the leading cause of hemiparetic cerebral palsy (Wu et al., 2006) and many survivors experience long-term comorbidities, such as epilepsy; sensory abnormalities; behavioral problems; and cognitive deficits (Dunbar & Kirton, 2018).

Perinatal stroke lesions are focal and nonprogressive, but some impairments may not emerge until many years after the initial injury (van Buuren et al., 2013; Westmacott et al., 2009). As environmental demands increase, neuroplastic changes which preserve function immediately following a stroke may interfere with typical neural and functional development (Anderson et al., 2011). Consequently, late-emerging deficits are most likely to occur for complex behaviors with prolonged developmental trajectories, such as daily functional abilities and executive functions (EF: inhibition, working memory, and shifting; Anderson et al., 2011). Recent cross-sectional studies have demonstrated that school-aged children with perinatal stroke experience significant deficits to EF (Bosenbark et al., 2018; Khan et al., 2020; Li et al., 2022) and functional abilities (Khan et al., 2020). But longitudinal study is needed to understand the evolving impacts of perinatal stroke on these domains throughout development.

As the effects of perinatal stroke unfurl over time, modifiable environmental factors may modulate outcomes (Anderson et al., 2011; Kirton et al., 2021). Recent studies have demonstrated that factors like access to supportive services and movement behaviors may influence children's EF and functional outcomes (Diamond & Ling, 2016, 2019; Janssen et al., 2017; Mirkowski et al., 2019). Although engagement in such activities has not been characterized among children with perinatal stroke, evidence from other clinical populations indicates these areas could be further leveraged in support of improved outcomes (Arbour-Nicitopoulos et al., 2021; Majnemer et al., 2014; Vyas et al., 2021). During the COVID-19 pandemic, many children have experienced disruptions to movement behaviors and access to services (Paterson et al., 2021; Sutter et al., 2021). Therefore, characterizing the engagement of children with perinatal stroke with these modifiable factors, both before and during the COVID-19 pandemic, may offer valuable context to developmental trajectories for EF and functional abilities.

This thesis includes two parts. Study I was a longitudinal assessment of changes to EF behaviors and functional abilities among school-aged children with perinatal stroke. In Study II, parents of Albertan children with perinatal stroke described their children's movement behaviors and access to supportive services, before and during the COVID-19 pandemic.

Stroke: Definition and Classification

Stroke is an acute, cerebrovascular injury that disrupts blood flow to the brain, causing cell death and damage to downstream neural tissues. Strokes can be classified into subtypes based on three criteria: the mechanism of the injury, the timing of the injury, and when symptoms first become apparent (Kirton & deVeber, 2013).

The primary mechanism of a stroke can be either ischemic or hemorrhagic. In an ischemic stroke, blood flow to a region of the brain is occluded, which restricts oxygen delivery to downstream neural tissues and leads to ischemic infarction (i.e., cell death). In contrast, hemorrhagic stroke is marked by bleeding in the brain, usually due to rupture of a weakened blood vessel. Hemorrhagic stroke can have immediate neurotoxic effects and induce secondary ischemia in downstream tissues. Both ischemic and hemorrhagic strokes can be further delineated based on the type of blood vessel they affect, either arterial or venous (Dunbar & Kirton, 2018).

Strokes can also be classified based on their timing. Any stroke occurring between the prenatal period and 18 years of age falls under the broad umbrella of pediatric stroke (Saver et al., 2012). Based on differences in pathophysiology, incidence, and outcomes, pediatric stroke is often subdivided into perinatal stroke (20 weeks gestation to 28 days postnatally) and childhood stroke (29 days to 18 years of age; Saver et al., 2012). Since the exact timing of an early stroke can be difficult to determine, the terms perinatal stroke and neonatal stroke are often used interchangeably throughout the literature. However, neonatal strokes technically occur between birth and 28 days postnatally (Saver et al., 2012).

Finally, perinatal stroke syndromes can be classified based on when a child first becomes symptomatic. Roughly two-thirds of perinatal strokes present clinically within the neonatal period, from birth to 28 days (Dunbar et al., 2020). These acutely symptomatic cases generally present with focal or generalized seizures within 12-72 hours of the initial injury (Lee, Croen, Backstrand, et al., 2005). The remaining third of perinatal strokes are asymptomatic in the acute neonatal period and are categorized as presumed perinatal strokes. Presumed perinatal strokes generally present with early signs of hemiparesis (i.e., early handedness) within the first year of life (Kirton et al., 2008; Lee, Croen, Lindan, et al., 2005). This thesis will focus on perinatal ischemic stroke, including both acute and presumed perinatal subtypes.

Perinatal Stroke: Diagnosis and Stroke Subtypes

The underlying pathophysiology of ischemic perinatal stroke is often unknown and appears to differ between perinatal stroke subtypes (Mineyko & Kirton, 2011). Diagnosis of a perinatal stroke therefore relies on a combination of clinical indications and evidence of a focal infarction on neuroimaging. Ultrasound and computed tomography scans have been used historically in diagnosis of perinatal stroke, but magnetic resonance imaging is now considered the gold standard (Golomb et al., 2003).

Recent advances in neuroimaging technology have improved detection of perinatal stroke, with recent studies estimating prevalence to be as high as 1:1,100 term births (Dunbar et al., 2020). Furthermore, improved neuroimaging capabilities have been instrumental to furthering research on distinct perinatal stroke subtypes. This paper will focus on three of the most common subtypes of ischemic perinatal stroke: neonatal arterial ischemic stroke (NAIS), arterial presumed perinatal ischemic stroke (APPIS), and periventricular venous infarction (PVI).

Neonatal Arterial Ischemic Stroke (NAIS)

NAIS is the most common type of acutely symptomatic perinatal stroke, with an estimated prevalence of 1:3,000 term births (Dunbar et al., 2020). It is caused by occlusion of an arterial vessel, often the middle cerebral artery (Lee, Croen, Backstrand, et al., 2005). Most NAIS infarctions are unilateral, predominantly affecting the left hemisphere, and occur near term (Lee, Croen, Backstrand, et al, 2005). Pathophysiology is often unclear, but placental thromboembolisms are theorized to be the cause of most NAIS infarctions (Dunbar & Kirton, 2018). NAIS has also been associated with several markers of difficulties with transition and the presence of fetal and maternal prothrombotic factors (Mineyko & Kirton, 2011).

Motor impairment is common following NAIS, with roughly 30% of children receiving a co-morbid diagnosis of cerebral palsy (Lee, Croen, Lindan, et al., 2005; Wagenaar et al., 2018). Given the topography of NAIS infarctions, right-sided hemiparesis is the most common motor outcome, with the upper limb more affected than the lower limb (Kirton & deVeber, 2013). NAIS also frequently leads to language, cognitive, and behavioral impairments (Lee, Croen, Lindan, et al., 2005; Wagenaar et al., 2018), although rates of impairment may vary based on age at assessment (van Buuren et al., 2013; Westmacott et al., 2009).

Arterial Presumed Perinatal Ischemic Stroke (APPIS)

APPIS describes an arterial ischemic stroke with a delayed clinical presentation, after 28 days postnatally. It occurs in roughly 1:7,900 term births (Dunbar et al., 2020). Neuroimaging of APPIS appears similar to that of NAIS (Kirton et al., 2010). Most APPIS infarctions are unilateral, left-sided, and occur in the region of the middle cerebral artery (Ilves et al., 2016; Kirton et al., 2010). APPIS also shares many acute perinatal risk factors with NAIS (Ilves et al., 2016; Kirton et al., 2010). This has led researchers to suggest that APPIS is a consequence of the same type of injury as NAIS but is asymptomatic or unrecognized in the acute neonatal period (Kirton et al., 2010).

Outcomes following APPIS vary based on location of the infarction. Cortical involvement is associated with increased risk of epilepsy and impairments to vision, cognition, and behavior (Kirton et al., 2008). Motor impairment is associated with infarctions involving the basal ganglia and occurs in roughly 80-90% of APPIS cases (Kirton et al., 2008). Compared to NAIS, motor impairment is both more common and more severe following APPIS (Lee, Croen, Lindan, et al., 2005; Wu et al., 2004). However, this may be partially attributable to selection bias, as less serious cases of APPIS may remain unrecognized and undiagnosed.

Periventricular Venous Infarction (PVI)

PVI occurs in 1:6,000 births, accounting for more than half of presumed perinatal ischemic strokes (Dunbar et al., 2020). The initial injury in PVI occurs before 34 weeks gestation in the region of the germinal matrix, a temporary and highly vascularized structure which sits inferior to the lateral ventricles (de Vries et al., 2001; Takanashi et al., 2005). PVI occurs when a germinal matrix hemorrhage causes secondary compression of the medullary veins, producing ischemic infarction of the periventricular white matter (de Vries et al., 2001). Given its early timing, PVI is primarily associated with chronic maternal risk factors, such as hypertension, recurrent miscarriage, antepartum bleeding, or prenatal infection (Ilves et al., 2016; Kirton et al., 2010). In term-born children, PVI is generally asymptomatic in the neonatal period and first presents with motor asymmetries within the first year of life (Kirton et al., 2010).

The primary outcome of PVI is motor impairment in the form of hemiplegic cerebral palsy (Kirton et al., 2008; Lõo et al., 2018). Motor impairment mostly affects the upper limb, although PVI tends to have greater lower limb involvement than other forms of perinatal stroke (Kirton et al., 2008). Due to the relative sparing of cortical tissue in PVI, motor impairments rarely co-occur with non-motor deficits (Kirton et al., 2008; Lõo et al., 2018). However, infrequent cognitive and language impairments may be associated with ipsilesional reductions in grey matter volume (Li et al., 2012).

Theoretical Frameworks for Perinatal Stroke Outcomes

Neuroplasticity, the brain's capacity to adapt to internal and external stimuli, is widely recognized as the primary mechanism of functional recovery following brain injury. In perinatal stroke, neuroplastic recovery must occur alongside, and sometimes in competition with, typical neurodevelopmental processes (Kirton et al., 2021). The unique developmental context of perinatal stroke may produce substantially different recovery mechanisms and long-term outcomes from those documented among older children and adults (Anderson et al., 2011). Two competing theoretical frameworks for recovery following perinatal brain injury have emerged: early neuroplasticity models and early vulnerability models.

Early neuroplasticity models argue that young brains have a greater capacity for neuroplastic change, relative to older brains (Kolb & Teskey, 2012). The effect of this capacity has been distilled into the Kennard Principle: *earlier age at the time of injury is associated with better functional outcomes* (Kennard, 1942; Teuber, 1970). Neuroplasticity models often rest on the idea that the young brain is largely unspecialized, allowing for the uncomplicated substitution of neural functions from the lesion site to nearby uninjured tissues (Anderson et al., 2011).

In contrast, proponents of early vulnerability models posit that early brain injury is more likely to produce poor outcomes, compared to later injury (Hebb, 1942). Although acute neuroplastic reorganization may effectively preserve existing skills, the Crowding Hypothesis argues that reorganization leads to competition for neural space and resources in uninjured tissues (Teuber, 1975). This competition can hamper the ability of uninjured areas to support their typical functions as development continues. Consequently, early reorganization can erase the blueprint for typical neural development, disrupting later emergence of new skills and formation of diffuse neural networks (Anderson et al., 2011; Gogtay et al., 2004; Kolb & Gibb, 2007). Early vulnerability models posit that this altered developmental course leads to a pattern of emerging deficits (Hebb, 1942). Although children with early brain injuries may display few initial impairments, they “grow into their deficits”, making slower developmental gains relative to age-matched peers (Anderson et al., 2011; Westmacott et al., 2009).

On their own, neither early neuroplasticity nor early vulnerability models adequately describe the full range of functional outcomes following perinatal stroke (Kirton et al., 2021). There is a growing recognition that factors other than age at injury play an important role in determining long-term functional recovery (Anderson et al., 2011; Kirton et al., 2021). The recovery continuum model represents early neuroplasticity and early vulnerability as opposing poles on a spectrum of functional outcomes (Anderson et al., 2011). In this model, static (e.g., lesion size, severity, location) and dynamic factors (e.g., therapeutic services, environmental experiences, seizures) help determine where along the "recovery continuum" an individual's recovery trajectory will fall (Anderson et al., 2011; Kirton et al., 2021).

Functional Abilities After Perinatal Stroke

Historically, most research into perinatal stroke outcomes has focused on the level of impairments to body structures and functions and it is often unclear how perinatal stroke affects children's daily lives (Gordon, 2014; World Health Organization, 2007). Investigation of functional abilities following perinatal stroke, including daily activities, mobility, social skills, and independence, reflects an area of emerging research interest (Gordon, 2014). The Pediatric Evaluation of Disability Inventory (PEDI) and its more recent iteration, the PEDI-Computer Adaptive Test (PEDI-CAT), are commonly used, parent-reported measures of functional abilities across four domains: daily activities, mobility, social skills, and responsibility (Haley et al., 2011). Both the PEDI and PEDI-CAT are validated and have been used extensively to describe functional abilities of children with cerebral palsy (Shore et al., 2017, 2019). These measures are also recommended for use among children with pediatric stroke (Gordon, 2014).

Using the PEDI (Galvin et al., 2011) and other measures (Ganesan et al., 2000), researchers have reported that individuals with childhood stroke had worse functional abilities and required more caregiver assistance than expected based on their age. In a study of children with pediatric stroke, Lo et al. (2014) reported significant functional impairments, especially in domains of daily activities and self-care. In several studies, younger age at stroke has been significantly associated with worse functional outcomes (Ganesan et al., 2000; Hurvitz et al., 1999, 2004). Likewise, among children with early brain injury of any etiology, Greenham et al. (2010) found that injuries sustained during the perinatal period were associated with worse social functioning than earlier or later injuries. Consistent with these findings, Khan et al. (2020) reported significant impairments compared to normative values on the PEDI-CAT for daily activities, mobility, responsibility, and social cognitive function among children aged 6-16 years with APPIS, NAIS, and PVI.

In several studies, long-term motor and psychosocial functions were better among children with neonatal stroke, compared to childhood stroke (Cooper et al., 2019; Greenham et al., 2017, 2018). However, these studies all assessed functional outcomes at a fixed time since stroke. As a result, children with perinatal stroke were younger than children with later strokes and it is possible that their functional impairments may not have fully emerged. However, a recent cross-sectional study found that functional abilities were not significantly correlated with age at assessment for children with perinatal stroke (Khan et al., 2020). Longitudinal studies of functional abilities have been conducted in children with cerebral palsy and have produced mixed results. Whereas Smits et al. (2019) reported that longitudinal trajectories on the PEDI plateaued in early school age for children with and without cerebral palsy, Burgess et al. (2020) found that PEDI-CAT scores improved more gradually for children with cerebral palsy, compared to typically developing peers. Therefore, longitudinal study is needed to understand whether the functional impacts of perinatal stroke change over time.

Executive Functions (EF)

EFs encompass a set of skills required to appropriately attend to, organize, and respond to information in the environment (Diamond, 2013). Rather than initiating a reflexive or habitual response, EFs coordinate situation-specific behavioral responses based on environmental cues, existing knowledge, previous experiences, and overarching personal goals (Diamond, 2013). EFs are primarily associated with activity in the prefrontal cortex (Diamond, 2013). However, a vast network of inputs and outputs from other neural regions has been implicated in the development of EFs and their exertion over other processes (Fiske & Holmboe, 2019).

In adults, EFs are often conceptualized as three interrelated core skills: inhibition, working memory, and shifting (Miyake et al., 2000). The three core EFs serve as a foundation for the development of higher-order EFs, such as reasoning, planning, and problem-solving (Diamond, 2013). This model is often applied to EF in children, although the core EFs develop at different rates and the underlying structure of EF therefore changes throughout development (Huizinga et al., 2006). The foundations of EF begin to emerge within the first year of life (Diamond, 1990), however most EF abilities do not fully mature until late adolescence or early adulthood (Luna, 2009).

EF is generally measured using two approaches: performance-based assessments and rating scales. Performance-based assessments involve administration of a standardized cognitive task by a trained examiner under tightly controlled laboratory conditions. In contrast, rating scales are completed by a parent or other proxy, based on their observations of a child's functioning within their daily environment. The Behavior Rating Inventory of Executive Function (BRIEF) family of instruments, including the BRIEF Second Edition (BRIEF2), are the current gold standard parent-reported measures of EF. These measures describe a child's daily

EF behaviors globally and in three domains: behavioral regulation (inhibition and self-monitoring), emotional regulation (shifting and emotional control), and cognitive regulation (initiating, working memory, planning/organization, task monitoring, and organization of materials).

Limited correlations between performance-based and parent-reported measures of EF have been consistently noted in both typically developing and clinical populations (Krivitzky et al., 2019; Toplak et al., 2013). The lack of correlation between performance-based and parent-reported measures of EF remains incompletely understood, however there are several possible explanations. Performance-based assessments and parent rating scales may measure different aspects of EF (Toplak et al., 2013). Whereas performance-based measures describe EF capacity under optimal laboratory conditions (i.e., “state”-dependent EF abilities), parent ratings may describe more consistent, “trait”-like application of EF in the child’s daily environment (Toplak et al., 2013). This explanation has been supported by research which divides EF into “hot” and “cool” components (Zelazo & Carlson, 2012). Hot EF directs behavior during situations that are emotionally involved, strongly motivated, or tied to personal goals, whereas cool EF manages behavior in tasks which are abstract, depersonalized, and logic driven (Zelazo & Carlson, 2012). Therefore, parent ratings and performance-based assessments may tend to measure hotter and cooler aspects of EF, respectively. The disconnect between parent ratings and performance-based EF has also been attributed to inconsistent responding or responder bias on parent rating scales (Wochos et al., 2014). Likewise, performance-based assessments have been critiqued for a lack of ecological validity, which may compromise their effectiveness at measuring EF (Krivitzky et al., 2019). In this study, we were particularly interested in measuring daily EF behaviors, so EF was assessed using a parent-reported rating scale.

Executive Function Outcomes in Perinatal Stroke

Performance-Based Measures. Children with perinatal stroke experience widespread impairments on performance-based measures of EF. Hajek et al. (2014) reported mild impairments to verbal reasoning, inhibition, working memory, and processing speed among children aged 6–16 years with pediatric arterial ischemic stroke, compared to chronic disease controls. Similarly, children aged 3-16 years with NAIS or APPIS showed the greatest impairments to inhibitory control, but also performed worse than a normative population on measures of attention, planning/organization, processing speed, shifting, and verbal retrieval (Bosenbark et al., 2018). Li et al. (2022) also noted significant impairments to inhibition, shifting, attention, and visuospatial processing in a cohort of children aged 6-16 years with APPIS, NAIS, and PVI.

Though broad impairments on performance-based measures of EF have been widely reported following perinatal stroke, there have been some contradictory findings. Kolk et al. (2011) found that EF was not impaired among children aged 4–10 years with neonatal stroke, despite observing significant impairments across many other neurocognitive domains. Such inconsistencies may be related to key differences between study cohorts. For example, studies which have found mild or no impairments to EF often excluded presumed perinatal stroke subtypes in their cohorts (e.g., Hajek et al., 2014; Kolk et al., 2011). This may be an important distinction as APPIS has been associated with poorer EF outcomes compared to NAIS (Bosenbark et al., 2017).

Furthermore, most studies of EF following perinatal stroke include a wide range of ages at assessment. Given the prolonged developmental trajectory of EF, reported outcomes may differ, in part, due to variations in the precise developmental context of study cohorts. Li et al.

(2022) found only one significant association between age at testing and EF abilities: older age was associated with better visuospatial abilities relative to the normative population. However, in a slightly younger cohort, Bosenbark et al. (2018) found that older age at testing was associated with significantly worse working memory and processing speed. Longitudinal research is needed to further untangle the impact of perinatal stroke on EF throughout development.

Parent-Reported Measures. Among children aged 6-16 years with APPIS, NAIS, or PVI, Khan et al. (2020) reported significant impairments to working memory, shifting, task monitoring, cognitive regulation, and overall EF behaviors on the BRIEF2, compared to normative peers. However, in a cohort of children aged 3-16 years with NAIS or APPIS, Bosenbark et al. (2018) found no significant group-level impairments to EF behaviors compared to normative peers on the BRIEF. Similarly, mean EF behaviors on the BRIEF were comparable to normative values in a cohort of children aged 6-19 years with NAIS, APPIS, and PVI (Larsen et al., 2021). Importantly though, both Bosenbark et al. (2018) and Larsen et al. (2021) noted a wide range of scores on each EF subscale, indicating that some portion of their sample may have been experiencing impaired EF behaviors.

To address discrepancies in parent-reported EF outcomes, several cross-sectional studies have investigated associations between age at testing and parent-reported EF behaviors. Among children aged 3-16 years with NAIS and APPIS, older age at testing was significantly associated with worse parent-rated metacognition and overall EF behaviors on the BRIEF (Bosenbark et al., 2018). Similarly, Larsen et al. (2021) noted older age was systematically associated with worse parent-rated EF behaviors on the BRIEF among children aged 6-19 years with NAIS, APPIS, and PVI. These findings indicate that children with perinatal stroke may make gains to EF behaviors more slowly than their normative peers, resulting in a gradual divergence in developmental trajectories for EF behaviors over time. However, Khan et al. (2020) found no significant correlations between age at testing and any EF behaviors on the BRIEF2. Therefore, there is an ongoing need for longitudinal research in this area to determine the developmental trajectory of EF in children with perinatal stroke.

Modifiable Environmental Factors: Critical Context for Long-Term Outcomes

Real-world activities which challenge EFs, are personally meaningful, are guided by a supportive mentor, and build self-confidence may help improve EFs (Diamond & Ling, 2016, 2019). Programs which help scaffold the development of EF skills and allow children to practice implementing EFs throughout the school day appear to be particularly beneficial (Diamond & Ling, 2019). Although aerobic exercise alone (e.g., walking, running) does not appear to have noticeable impacts on EF, physical activity with a greater cognitive and social component (e.g., organized sports, martial arts) appears to offer meaningful benefits to EF (Contreras-Osorio et al., 2021; Diamond & Ling, 2019). The benefits of EF interventions appear to be greatest for individuals with the lowest baseline cognitive and EF abilities, which may make children with perinatal stroke particularly responsive to the benefits of real-world activities (Diamond & Ling, 2016).

There is an increasing recognition that environmental factors, such as access to therapeutic services and adequate sleep, interact with static factors, such as stroke subtype and lesion characteristics, in determining long-term functional outcomes after perinatal stroke (Anderson et al., 2011; Kirton et al., 2021). Interestingly, there appears to be some overlap between activities which may improve functional outcomes and those which may improve EF outcomes. For example, rehabilitation therapies offer a consistent and supportive context for children to work towards challenging, personally meaningful goals. In addition to building functional skills and self-confidence, engagement in rehabilitation therapies may help build EF skills. Similarly, participation in sports has been associated with improved EF abilities (Contreras-Osorio et al., 2021; Diamond & Ling, 2019), but has also been linked to broad improvements to psychosocial function (Eime et al., 2013). Understanding typical patterns of engagement with modifiable environmental factors is critical to identify service gaps for children with perinatal stroke and guide future resource allocation. Fortunately, preliminary profiles of engagement in such activities among children with perinatal stroke and related clinical conditions are now emerging (e.g., Champigny et al., 2020; Majnemer et al., 2014; Vyas et al., 2021).

Supportive Services

Access to supportive services such as occupational therapy and physical therapy is likely robust for children with perinatal stroke, whereas access to psychosocial supports may be limited. Among children with neonatal/congenital conditions and children with cerebral palsy, roughly 40-60% have accessed physical therapy, occupational therapy, and/or speech language pathology services (Majnemer et al., 2014; Vyas et al., 2021). Among individuals with cerebral palsy, rates of service utilization appear to be lower for adolescents compared to younger children (Majnemer et al., 2014). Likewise, approximately half of children with pediatric stroke receive some type of educational supports (Champigny et al., 2020; O'Keeffe et al., 2017). In comparison, only 6.5% of children with neonatal/congenital conditions were reportedly accessing psychological services (Vyas et al., 2021). More than half of caregivers highlighted limited access to appropriate psychosocial supports for their child and/or family as an ongoing service need (Vyas et al., 2021).

Movement Behaviors

Movement behaviors, including sleep, physical activity, and screen time, are also associated with a wide range of benefits to health, behavior, and psychosocial function (Janssen et al., 2017). *Canada's 24-Hr Movement Guidelines* offers evidence-based recommendations for daily sleep (5-13 years: 9-11 hours/night; 14-17 years: 8-10 hours/night), moderate-to-vigorous physical activity (MVPA; 5-17 years: at least 60 mins/day), and recreational screen time (5-17 years: no more than 2 hrs/day) to promote optimal health outcomes for children and youth (Tremblay et al., 2016). Although there are no specific movement guidelines for children with disabilities, most children with cerebral palsy are encouraged to adhere to the recommendations provided by *Canada's 24-Hr Movement Guidelines* (Verschuren et al., 2016). Unfortunately, children with disabilities may be at particular risk of unhealthy patterns of movement behaviors. Arbour-Nicitopoulos et al. (2021) found only 3.7% of Canadian youth with disabilities were meeting guidelines for MVPA, sleep, and screen time, compared to 17.5% of children and youth from a nationally representative Canadian sample (Roberts et al., 2017). Furthermore, a whopping 18.5% of their sample met none of the three guidelines (Arbour-Nicitopoulos et al., 2021), compared to 10.7% of children and youth from a nationally representative Canadian sample (Roberts et al., 2017). Of the three movement guidelines, youth with disabilities seem least likely to meet recreational screen time guidelines, with only 13.0% meeting this guideline, whereas over 50% met guidelines for MVPA and sleep (Arbour-Nicitopoulos et al, 2021).

Impact of the COVID-19 Pandemic

During the COVID-19 pandemic, access to rehabilitation therapies and daily movement behaviors were disrupted for many children with disabilities (Bertamino et al., 2020; Moore et al., 2021b; Sutter et al., 2021). Caregivers of children with disabilities reported reduced access to rehabilitation services, decreased therapy time, and negative impacts to their child's physical and mental well-being during the pandemic (Sutter et al., 2021). A study of Italian children with pediatric and perinatal stroke replicated these findings and noted worsening clinical courses among participants during Wave 1 of the pandemic (Bertamino et al., 2020). Increases to screen time and decreases to physical activity have been consistently reported for children and youth during the pandemic (Paterson et al., 2021). Disruptions to movement behaviors were shown to persist until at least 6 months into the pandemic (Moore et al., 2021a). Therefore, it is likely that access to supportive services and engagement in movement behaviors have changed substantially for children with perinatal stroke during the pandemic.

Present Study Aims & Hypotheses

Understanding of the evolving functional impacts of perinatal stroke throughout development is currently limited. The goal of this study is to describe developmental trajectories for EF behaviors and functional abilities, and the supportive contexts in which they occur, for school-aged children and adolescents with perinatal stroke. EFs are a strong predictor of a range of functional outcomes, including academic achievement, physical health, and quality of life (Diamond, 2013). Therefore, characterization of longitudinal trajectories for both EF behaviors and functional abilities may further inform long-term outcomes for children with perinatal stroke. Along with describing developmental trajectories, additional contextualization of these trajectories may enable the identification of existing service needs for children with perinatal stroke and areas where daily routines may be harnessed in support of improved outcomes.

This thesis includes two parts. Study I is a longitudinal study of EF behaviors and functional abilities in children with perinatal stroke. The primary aim of Study I was to describe developmental trajectories for EF behaviors and functional abilities in children with perinatal stroke. Study II is a multi-site, cross-sectional survey of supportive services and movement behaviors among children and adolescents with perinatal stroke. The primary aim of Study II was to describe access to supportive services and engagement in movement behaviors among Albertan children with perinatal stroke. A secondary aim of this study was to determine the impact of the COVID-19 pandemic on the supportive services and movement behaviors of Albertan children with perinatal stroke.

Study I

Aim 1. To describe the longitudinal trajectories of functional abilities and EF behaviors in children and adolescents with perinatal stroke.

Hypothesis 1.1: Based on previous cross-sectional research in children with perinatal stroke (Khan et al., 2020) and longitudinal research in children with cerebral palsy (Smits et al., 2019), children with perinatal stroke were not expected to acquire new deficits to functional abilities relative to normative peers over time. This will be marked by unreliable change to PEDI-CAT T scores between Time 1 and Time 2.

Hypothesis 1.2: Consistent with previous research (Bosenbark et al., 2018; Larsen et al., 2021; Westmacott et al., 2009), children with perinatal stroke were expected to show a worsening of parent-rated EF behaviors over time compared to normative peers, especially on measures of cognitive regulation. This will be marked by reliable worsening of BRIEF2 T scores between Time 1 and Time 2 and may lead to the worsening of existing deficits or the emergence of new deficits to EF behaviors.

Hypothesis 1.3: Children with more negative parental ratings of the COVID-19 pandemic were expected to experience worse longitudinal trajectories for parent-rated EF behaviors and functional abilities, compared to children with positive or neutral parental ratings of the pandemic.

Study II

Aim 1. To describe engagement in supportive services and movement behaviors of children and adolescents with perinatal stroke before the COVID-19 pandemic.

Hypothesis 1.1: Based on service utilization patterns among related clinical populations (Champigny et al., 2020; Majnemer et al., 2014; Vyas et al., 2021; Williams et al., 2017), most children and youth with perinatal stroke were expected to utilize physical therapy and occupational therapy services, utilization of psychological supports was expected to be limited, and about half of children with perinatal stroke were expected to receive some type of educational supports.

Hypothesis 1.2: As previously reported among similar clinical populations (Majnemer et al., 2014), service utilization was expected to be greater among younger children, compared to adolescents. Based on differences in clinical outcomes following APPIS, PVI, and NAIS (Kirton et al., 2008; Lee, Croen, Lindan et al., 2005; Lõo et al., 2018), utilization of occupational and physical therapy services was expected to be greater among participants with APPIS and PVI, compared to participants with NAIS. In contrast, utilization of speech/language pathology, psychological services, and educational supports was expected to be greater among participants with APPIS or NAIS, compared to PVI.

Hypothesis 1.3: Consistent with previously reported adherence to 24-Hour Movement Guidelines among children and youth with disabilities (Arbour-Nicitopoulos et al., 2021), children with perinatal stroke were expected to exceed national guidelines for screen time and will not meet minimum daily guidelines for MVPA.

Aim 2. To describe changes to engagement in supportive services and movement behaviors of children and adolescents with perinatal stroke during the COVID-19 pandemic.

Hypothesis 2.1: Consistent with reports from the early phases of the pandemic (Bertamino et al., 2020; Sutter et al., 2021), parents of children with perinatal stroke were expected to report overall reductions in access to all therapeutic services during the pandemic.

Hypothesis 2.2: Based on changes to movement behaviors for children and youth throughout the first year of the COVID-19 pandemic (Moore et al., 2020, 2021a, 2021b; Paterson et al., 2021), children with perinatal stroke were therefore expected to experience significant increases to screen time and sleep time during the pandemic. They were also expected to report significant reductions to MVPA time.

Hypothesis 2.3: More negative parental ratings of the impact of the pandemic were expected to be significantly associated with reduced access to supportive services, increases to screen time and sleep time, and decreases to MVPA time.

STUDY I

METHODS I

Study Overview

Study I was a prospective longitudinal study. Time 1 assessments were completed in 2017-2019 and Time 2 assessments were completed in spring of 2021. Primary data collected from this project was part of a larger study, “Neurobehavioral Outcomes of Children with Perinatal Stroke”, which was approved by the Health Research Ethics Board – Health Panel of the University of Alberta. The aims of this study are aligned with those of the larger study. Due to restrictions on in-person research during the COVID-19 pandemic, in-person neuropsychological assessments could not be completed at Time 2. Therefore, this study will only report on longitudinal changes to parent-reported measures. At both timepoints, consent was obtained from all participants and their caregivers for clinical data to be used in future research.

Participants

Participants were identified through the Northern Alberta Perinatal Stroke Project (N-APSP) registry. The N-APSP is a population-based research cohort of children with perinatal stroke living in northern Alberta. Primary caregivers were selected to participate based on their child’s clinical characteristics. Participant inclusion criteria were: 1) child aged 6-16 years at Time 1; 2) clinico-radiological confirmation of a perinatal stroke diagnosis by a pediatric neurologist; and 3) English as a first language. Based on established diagnostic criteria, perinatal stroke subtypes of NAIS, APPIS, and PVI were considered eligible diagnoses for this study (Kirton et al., 2008; Raju et al., 2007). Exclusion criteria included: 1) premature birth (<37 weeks gestation at birth); 2) age less than 6 years or greater than 17 years at Time 1; and 3) significant medical comorbidity, except for seizures or epilepsy. Exclusionary comorbidities included cerebral hemorrhage not associated with ischemic infarction (i.e., germinal matrix hemorrhage at <32 weeks gestation); hypoxic ischemic event with diffuse or bilateral infarction alone; and neurodevelopmental or psychiatric conditions not explained by stroke.

Data Sources and Test Measures

Data for this study was collected from caregiver-reported measures. At Time 1, all measures were completed in a single-day testing session at the Glenrose Rehabilitation Hospital. At Time 2, due to pandemic restrictions on in-person research, all measures were completed remotely, in an online format. At Time 2, online surveys were administered through RedCap (Harris et al., 2009), QGlobal, and PARiConnect. Study data from both timepoints was managed using RedCap (Harris et al., 2009), an electronic data capture tool hosted and supported by the Women and Children's Health Research Institute at the University of Alberta.

Demographic and Health Information

Current caregiver-reported demographic information was collected at both timepoints. Caregivers reported their child's age, sex, current living situation, family health history, and personal medical history, including epilepsy/seizures. Select caregiver demographic characteristics were also reported, including marital status, level of education, and household income bracket.

Pediatric Evaluation of Disability Inventory – Computer Adapted Test (PEDI-CAT)

The PEDI-CAT is a caregiver-reported measure of functional abilities for children from birth to 21 years of age (Haley et al., 2011). The computer-adapted test format selects questions based on the participant's previous responses. This format keeps the assessment brief by ensuring that caregivers are only asked questions that are most relevant for determining their child's current functional abilities. The PEDI-CAT uses item response theory modelling to reliably estimate overall functional ability. This technique allows scores to be compared between individuals, even if they did not respond to the same set of questions.

The PEDI-CAT measures functional ability in 4 domains: *Daily Activities* (Getting Dressed, Keeping Clean, Home Tasks, and Eating and Mealtime), *Mobility* (Basic Movement and Transfers; Standing and Walking; Steps and Inclines; and Running and Playing), *Social/Cognitive* (Interaction, Communication, Everyday Cognition, and Self-Management), and *Responsibility* (Organization and Planning; Taking Care of Daily Needs; Health Management; and Staying Safe). The Daily Activities, Mobility, and Social/Cognitive domains record responses on a 4-point Likert scale, from “1=Unable” to “4=Easy”. Responses on the Responsibility domain are recorded on a 5-point Likert scale, ranging from “1=Adult has full responsibility” to “5=Child takes full responsibility”.

The PEDI-CAT produces several types of scores. PEDI-CAT scaled scores are raw, unadjusted scores on a 20-80 scale which indicate a child’s functional abilities, independent of their age. Scaled scores are often used to track changes in functional abilities over time for children who may not be expected to achieve functional abilities typical for their age group. An increase in scaled scores over time indicates that a child has acquired new abilities or improved their performance. PEDI-CAT T scores describe a child’s functional abilities compared to the abilities of same-aged peers (M=50, SD=10), where lower T scores reflect worse functional abilities. The PEDI-CAT manual recommends that T scores more than 2 SD below the normative mean should be considered indicative of clinically significant impairment (Haley et al., 2011). However, for this study, a cutoff of more than 1.5 SD below the normative mean (T Score <35) was used for clinically significant impairment to permit comparison to previous studies of functional abilities in children with perinatal stroke (e.g., Khan et al., 2020).

The PEDI-CAT also provides a Fit Score, which indicates whether the responses provided were close to expected values based on item-response theory modelling and the pattern of responses in the standardization samples. Large negative fit scores (-1.65 or lower) indicate a misfit in the pattern of responses. Such a misfit may indicate areas of difficulty for an individual or it may indicate that the validity of the scaled score is questionable.

The PEDI-CAT has been validated for use in children with behavioral, physical, and/or intellectual disabilities. In children with cerebral palsy, domain scores for the PEDI-CAT display excellent test-retest reliability (Intraclass Correlation Coefficients: Daily Activities = 0.96; Mobility = 0.98; Social/Cognitive = 0.99; Responsibility = 0.98; Shore et al., 2019) and excellent discriminant validity based on Gross Motor Functional Classification System and Manual Ability Classification System levels (Shore et al., 2017). The PEDI-CAT also displays convergent validity with other measures of functional abilities in children with cerebral palsy, including the Pediatric Quality of Life – Cerebral Palsy Module (PedsQL-CP) and the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) questionnaire (Shore et al., 2019).

Behavior Rating Inventory of Executive Function, Second Edition (BRIEF2), Parent Report Form

The BRIEF2 Parent Report Form is a 63-item, caregiver-reported measure of EF for children aged 5-18 years (Gioia et al., 2015). The BRIEF2 asks parents to evaluate their child's EF abilities and problem-solving skills in the context of the child's daily environment. The BRIEF2 rates EF abilities in nine areas, which are grouped into three composites. The Behavior Regulation Index (BRI) is composed of two subscales (Inhibit and Self-Monitor) and assesses a child's ability to independently monitor their behavior and inhibit inappropriate behavioral responses. The Emotion Regulation Index (ERI) is composed of two subscales (Shift and

Emotional Control) and assesses a child's ability to control their emotions in response to changing environmental circumstances. The Cognitive Regulation Index (CRI) is comprised of five subscales (Initiate, Working Memory, Plan/Organize, Task Monitor, and Organization of Materials) and assesses a child's ability to control their thoughts and actions in the context of learning, problem-solving, and goal-directed behavior. These three composites are also compiled into a summary score, the Global Executive Composite (GEC), to reflect a child's overall EF behaviors.

The BRIEF2 is scored on a 3-point Likert scale, where 1=Never and 3=Often. The BRIEF2 generates both raw scores and T-scores, standardized against a normative population (M=50, SD=10). Higher T-scores reflect worse EF behaviors compared to the abilities of same-age peers. T scores ≥2 SD above the normative mean (≥70) are considered to reflect *Clinically Significant Elevation*. T scores between 1.5 and <2 SD above the normative mean (65-69) are considered *Potentially Clinically Elevated.*

The BRIEF2 also includes three validity scales to detect unusual or inconsistent responding. The Inconsistency scale (0-16) indicates whether similar items were responded to in an inconsistent fashion, where lower scores indicate greater consistency in responses. The Negativity scale (0-8) detects unusually negative responses, with higher scores indicating more negative responding. The Infrequency scale is comprised of three items that are rarely endorsed, even in cases of severe impairment. Infrequency scores ≥1 indicate atypical responding and were observed in <1% of the normative sample (Gioia et al., 2015).

The BRIEF2 Parent Report Form displays high internal consistency (α=0.76-0.97; Gioia et al., 2015). All composite scores display good test-retest reliabilities, as measured with intraclass correlation coefficients (BRI = 0.83; ERI = 0.82; CRI = 0.89; GEC = 0.88; Gioia et al., 2015). The BRIEF2 Parent Report Form also has moderate to strong concurrent validity with other measures of emotional and behavioral concerns, including the ADHD Rating Scale IV; Behavior Assessment System for Children, Second Edition; Child Behavior Checklist; and Connors Third Edition (Gioia et al., 2015).

COVID-19 Impact Rating

The perceived impact of the COVID-19 pandemic was assessed using a single-item, 5-point Likert scale (“*What do you perceive has been the overall impact of the COVID-19 pandemic on your family?*”; 1 = Profound Negative Impact to 5=Profound Positive Impact). Due to varied pandemic experiences, a single-item, overall rating was selected to allow caregivers to consider the unique combination of impacts the pandemic had on their family. Previous studies have demonstrated that single-item scales display similar psychometric properties as multiple-item scales assessing the same construct (Bergkvist & Rossiter, 2007).

Procedure

Time 1

Participants were initially identified through the N-APSP registry or upon referral to study investigators by N-APSP neurologists. All eligible participants had previously consented to being contacted about research opportunities. Eligible caregivers (n=57) were approached through telephone and/or email to inform them of the study and inquire if they would be interested in participating. Caregivers were provided with information about the nature of the study, neuropsychological testing, informed consent, and voluntary participation, in accordance with University of Alberta Health Research Ethics Board – Health Panel policies. A telephone and/or email script was used to standardize the process.

Time 1 data was collected between May 2017 and March 2019. Consenting families (n=20) completed a single testing session at the Glenrose Rehabilitation Hospital in Edmonton, AB. Children completed a neuropsychological test battery (as part of the larger study "Neurobehavioral Outcomes of Children with Perinatal Stroke"). While children completed assessments, caregiver-reported measures (demographics, BRIEF2, PEDI-CAT) were completed in another room. Caregiver forms were reviewed and scored by trained undergraduate research assistants/graduate students. After the testing session, children received a small gift card for their participation. Families were reimbursed for parking fees during their study visit. Families that drove >50 km to the study site were reimbursed for gas and maintenance fees ($0.50 per km driven).

Time 2

Three participants from Time 1 were lost to follow-up. The remaining 17 participants were invited to take part in Time 2 assessments via telephone or email. One participant declined taking part in Time 2 assessments because they were too busy. Eight participants did not respond to our invitations, despite multiple attempts to contact them by phone and email. Informed consent was gathered through a remote, guided eConsent process. Interested caregivers received access to the study consent forms housed in RedCap via email. The study information letter and consent details were reviewed over the phone with the study coordinator. Caregivers signed consent forms electronically and had the option to download a PDF copy of their completed consent form after signing.

Time 2 data was collected between February and May 2021. Ultimately, eight primary caregivers from Time 1 consented and completed assessments at Time 2. Consenting caregivers were emailed links to complete online surveys on three platforms: 1) RedCap (demographics, COVID-19 Impact rating); 2) QGlobal (PEDI-CAT); and 3) PARiConnect (BRIEF2). Caregivers were provided with a Study ID number, which they were instructed to use in place of their name. To ensure participants were appropriately matched to their Time 1 data, caregivers were required to verify demographic information provided at Time 1 (i.e., child's birthdate). Caregiver forms were reviewed, scored, and data was entered into RedCap by a trained graduate student.

Statistical Analyses

Analyses were performed using IBM SPSS Statistics software for Windows, Version 27.0 (SPSS, Armonk, NY: IBM Corp). Scores from Time 1 and Time 2 were first analyzed separately. BRIEF2 T scores could not be calculated for one participant due to their age at Time 2 (19.5 years), so a sample size of seven was used for all BRIEF2 analyses. Group-level descriptive statistics and the proportion of participants with scores in the clinical impairment range (>1.5 SD below the normative mean on the PEDI-CAT; ≥1.5 SD above the normative mean on the BRIEF2) were reported for composite T scores on each measure at both timepoints.

Group level descriptive statistics were reported for changes to BRIEF2 and PEDI-CAT T scores over time. The proportion of the sample displaying changes by 0.5 SD or greater was also reported. Due to sample size limitations, the significance of changes to EF behaviors and functional abilities at the group level could not be calculated. However, the reliability of within-subject change to EF behaviors and functional abilities over time was calculated using a reliable change (RC) methodology (Jacobson & Truax, 1991; Iverson, 2001).

For each composite of the BRIEF2 and PEDI-CAT, test-retest reliability (r_{xx}) and SD of the composite were used to calculate the standard error of the measurement [SEM; $SEM = SD_{test}\sqrt{(1 - r_{xx})}$]. The SEM was then used to compute the standard error of the difference

[SE_{Diff}; $SE_{Diff} = \sqrt{2(SEM^2)}$]. Next, the reliable change index (RCI) at the 90% confidence interval was calculated using a critical value of 1.64 [Duff, 2012; $RCI_{90\%\,CI} = SE_{Diff} \times 1.64$]. For any composite, an absolute difference in T scores greater than the RCI indicates that the change in T scores is reliable and not likely due to measurement error alone, at the 90% confidence level ($p<0.10$). Practice effects were not considered in calculation of the RCI since both the BRIEF2 and the PEDI-CAT are parent-reported measures that were unlikely to be susceptible to practice effects.

RESULTS I

Demographic and Clinical Characteristics

The primary caregivers of eight children with perinatal stroke completed assessments at both timepoints. Demographic characteristics of the study sample are summarized in Table 1. Average time elapsed between the two assessments was 3.2 years (Range 2.1-3.9; Figure 1). Compared to the general Albertan population (Statistics Canada, 2018), the study cohort was skewed to include primarily participants who were Caucasian, from mid- to high-income families, and whose mothers' completed university/college equivalent education. The study sample also included a greater proportion of APPIS cases (75.0%) and a smaller proportion of PVI cases (0.0%), compared to the typical distribution of perinatal stroke subtypes (APPIS: 12%; PVI: 21%; Dunbar et al., 2020).

Compared to individuals who only completed Time 1 of this study, the study cohort for both timepoints included more participants from mid- to high- income families (T1 only: 50.0%; T1/T2: 87.5%) and whose mothers' completed university/college equivalent education (T1 only: 55.3%; T1/T2: 87.5%). Furthermore, the longitudinal cohort contained a greater proportion of APPIS cases (75.0%) and a smaller proportion of PVI cases (0.0%), compared to participants at

Time 1 only (APPIS: 50.0%; PVI: 16.7%). At Time 1, BRIEF2 and PEDI-CAT outcomes were roughly similar between longitudinal participants and participants at Time 1 only, with two exceptions. Longitudinal participants scored slightly worse on the BRI (59.38, SD: 10.30; 4/8, 50.0% elevated) compared to participants at Time 1 only (49.64, SD: 15.60; 3/11, 27.3% elevated). Longitudinal participants also scored slightly better on the Social/Cognitive domain of the PEDI-CAT (37.50, SD: 9.52; 1/8, 12.5% clinically impaired), compared to participants at Time 1 only (37.55, SD:12.61; 4/10, 40.0% clinically impaired).

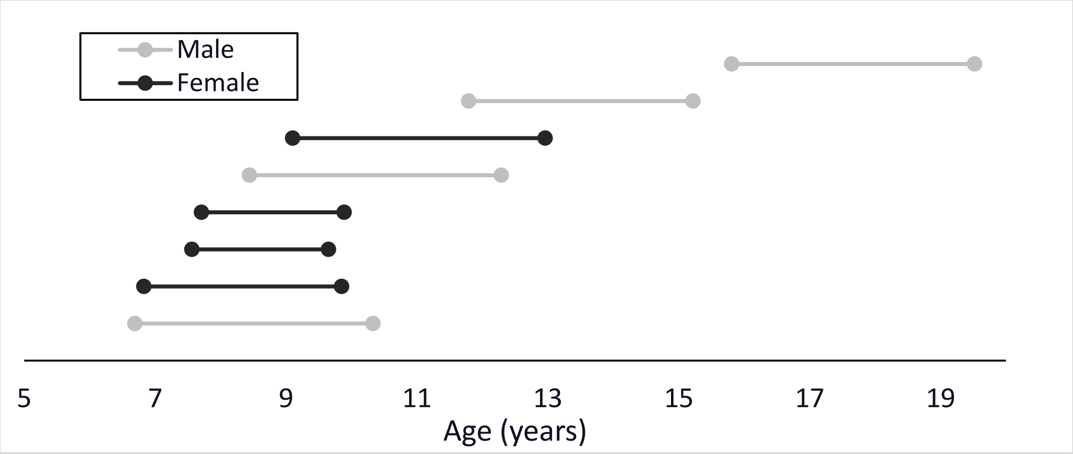
Table 1

Participant Demographics and Clinical Characteristics for Study I.

Demographic Characteristics	**Time 1 N (%)**	**Time 2 N(%)**
Sex (male)	4 (50.0)	4 (50.0)
Age in years, mean (SD)	9.2 (3.1)	12.5 (3.5)
Range	6.7-15.8	9.7-19.5
Ethnicity (Caucasian)	7 (87.5)	7 (87.5)
Maternal education (University/college equivalent)	7 (87.5)	7 (87.5)
Total household gross income (>$70,000)	7 (87.5)	6 (75.0)
Clinical Characteristics		
Stroke presentation		
APPIS	6 (75.0)	6 (75.0)
NAIS	2 (25.0)	2 (25.0)
PVI	0 (0.0)	0 (0.0)
History of seizures	3 (37.5)	5 (62.5)
Comorbid cerebral palsy	7 (87.5)	7 (87.5)
General IQ, mean (SD)	81.9 (10.8)	---
Range	66-97	---

Figure 1

Child Age and Time Between Survey Completion for Study I, by Sex



Note. Circles represent each data collection timepoint, connecting lines represent the time between data collections for each participant, and colors indicate child sex. Eight participants completed data collection at both timepoints, ~2-4 years apart.

Functional Abilities (PEDI-CAT)

Validity

At Time 1, all participants displayed acceptable fit scores (>-1.65) across all four domains of the PEDI-CAT. At Time 2, all participants displayed acceptable fit scores (>-1.65) on the Daily Activities domain, but three participants had low fit scores on other domains. One participant had a low fit score (-1.85) on the Mobility domain, clearly associated with responding indicative of impaired upper limb function and typical lower limb function. This is a common pattern of motor impairment following perinatal stroke but may not have been reflected within the PEDI-CAT standardization sample. Another participant had a low fit score (-3.1) on the Social/Cognitive domain. A review of their responses indicated that everyday math skills and EF behaviors may be areas of difficulty for this individual. These are documented areas of concern for children with perinatal stroke and were consistent with this participant's BRIEF2 responses. Finally, a third participant had a low fit score on the Responsibility domain (-1.8). Responses indicated this individual needed additional adult support with some types of organization and with staying safe in the community.

Time 1

At Time 1, mean T scores on all four PEDI-CAT domains fell below the normative mean for this sample (Table 2). In domains of Daily Activities and Mobility, mean T scores were more than 1.5 SD below the normative mean, falling in the range for *Clinically Significant Impairment.* Most participants had scores >1.5 SD below the normative mean in domains of Daily Activities (4/8; 50.0%) and Mobility (5/8; 62.5%; Table 2).

Time 2

At Time 2, mean T scores on three of the four PEDI-CAT domains (Daily Activities, Mobility, and Social/Cognitive) were >1.5 SD below the normative mean (Table 2). In all three domains, more than half of participants had scores in the range of *Clinically Significant Impairment* (>1.5 SD below the normative mean; Table 2). Mean T scores were highest on the Responsibility domain and only 25% (2/8) had significantly impaired scores.

Longitudinal Analyses

On average, PEDI-CAT T scores decreased from Time 1 to Time 2, on all four domains (Table 2). Individual trajectories for PEDI-CAT T scores are depicted in Figure 2. T scores decreased by ≥0.5 SD for at least half of participants on each of the four domains (Figure 2). On the Daily Activities and Mobility domains, large decreases to T scores (≥1 SD) occurred for more than half of participants (Table 2).

Table 2

PEDI-CAT Domain T Scores and Reliable Changes

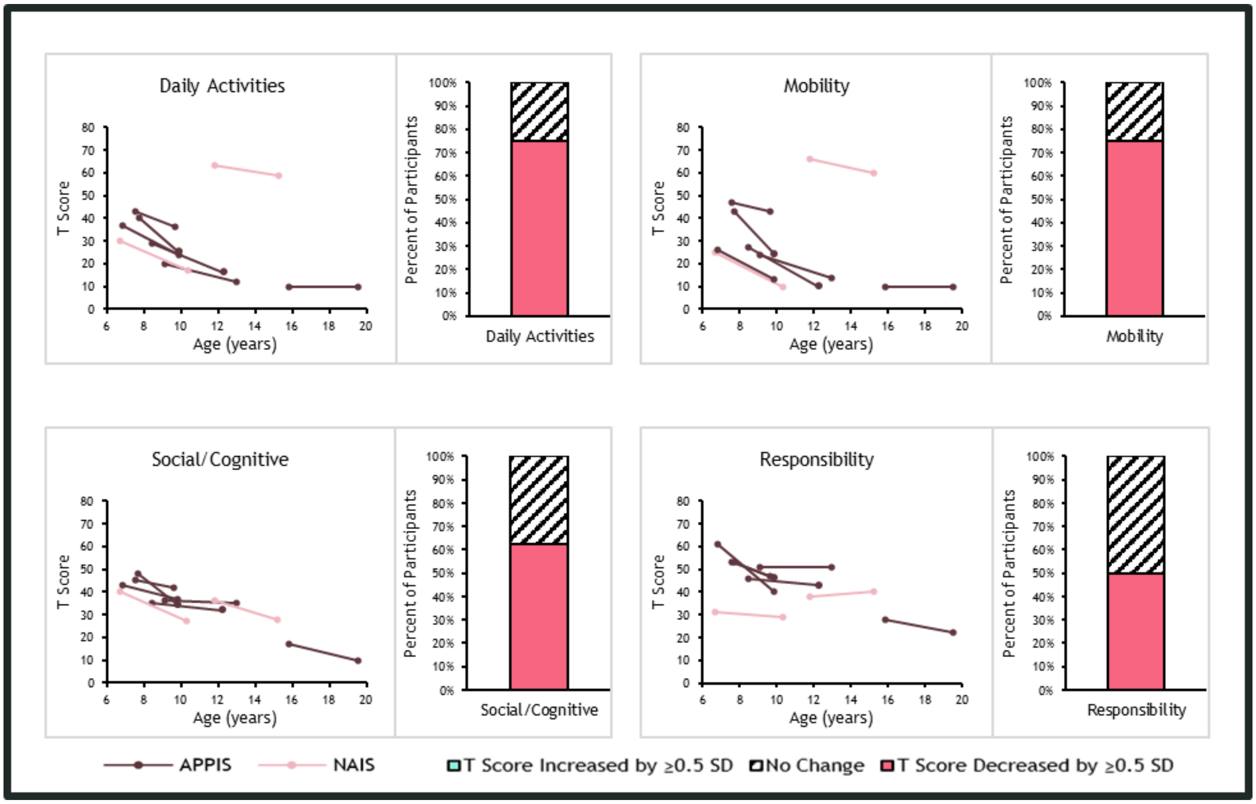
PEDI-CAT Domains	Time 1		Time 2		Difference (Time 2 – Time 1)		RCI	
	Mean (SD)	Impaired* n (%)	Mean (SD)	Impaired* n (%)	Mean (SD)	Decreased by ≥1 SD n (%)	Unreliable n (%)	Worsening n (%)
Daily Activities	34.00 (15.95)	4 (50.0)	24.88 (16.11)	6 (75.0)	-9.13 (5.28)	4 (50.0)	2 (25.0)	6 (75.0)
Mobility	33.50 (17.49)	5 (62.5)	23.00 (18.74)	6 (75.0)	-10.50 (6.70)	5 (62.5)	1 (12.5)	7 (87.5)
Social/Cognitive	37.50 (9.52)	1 (12.5)	30.63 (9.62)	5 (62.5)	-6.88 (4.70)	2 (25.0)	1 (12.5)	7 (87.5)
Responsibility	45.13 (11.68)	2 (25.0)	39.75 (9.71)	2 (25.0)	-5.38 (7.05)	1 (12.5)	4 (50.0)	4 (50.0)

Note. n=8 for all values. Lower scores on the PEDI-CAT indicate worse functional abilities. A reliable worsening may therefore accompany a negative change score (T scores decreasing from Time 1 to Time 2) for this measure. *PEDI-CAT,* Pediatric Evaluation of Disability Inventory – Computer Adaptive Test; *RCI*, reliable change index; *SD,* standard deviation.

* "Impaired" defined as a T score >1.5 SD below the normative mean (i.e., a T score lower than 35)

Figure 2

Individual Changes to PEDI-CAT T Scores Between Time 1 and Time 2



Note. n=8 for all domains. On the PEDI-CAT, a decrease in T scores indicates worsening functional abilities, relative to normative peers. *APPIS,* Arterial Presumed Perinatal Ischemic Stroke; *NAIS,* Neonatal Arterial Ischemic Stroke.

To determine the statistical reliability of the observed changes to PEDI-CAT T scores, RCIs at the 90% confidence level were calculated (Table 2). All participants displayed reliable worsening of PEDI-CAT T scores in at least two domains. Furthermore, 37.5% (3/8) of participants displayed reliable worsening on all four PEDI-CAT domains. This indicates that the observed changes to PEDI-CAT T scores were larger than could be reasonably attributed to incidental variance based on test-retest reliability. No participants displayed reliable improvements to T scores on any of the four PEDI-CAT domains.

PEDI-CAT T scores reflect a child's abilities relative to a normative population of age-matched peers. The reliable decreases to T scores on PEDI-CAT domains indicate that the children in this sample were not keeping up with their typically developing peers when developing functional abilities. However, decreases to T scores might reflect slower achievement of functional abilities, compared to typically developing peers, or they may reflect a loss of functional abilities over time.

To explore absolute changes to functional abilities of children in our sample, we completed a post-hoc analysis of PEDI-CAT scaled scores, which provide a raw unadjusted measure of a child's functional abilities, independent of their age. Overall, changes to PEDI-CAT scaled scores were relatively small. Mean scaled scores increased between Time 1 and Time 2 on the Daily Activities (Mean Difference: 1.00 , SD: 1.07), Social/Cognitive (Mean Difference: 1.13, SD: 1.25), and Responsibility domains (Mean Difference: 2.13, SD: 3.31). At the individual level, most scaled scores on these three domains increased over time or stayed the same (DA: 8/8, 100.0%; SOCOG/RESP: 7/8, 87.5%). Mean scaled scores in the Mobility domain showed a very small decrease over time (Mean Difference: -0.13, SD: 1.64), however 62.5% (5/8) of participants had scaled scores which increased or did not change over time. Overall, PEDI-CAT scaled scores indicated most participants were remaining stable in their functional abilities or gradually acquiring new abilities over time.

Executive Function Behaviors (BRIEF2)

Validity

At Time 1 and Time 2, all responses were within the Acceptable range on all three validity scales of the BRIEF2. This indicates that caregivers' responses were not unusually negative, nor did they endorse atypical items. Furthermore, caregivers were relatively consistent in their responding at both timepoints, indicating that they were taking time to read the test items and respond thoughtfully.

Time 1

At Time 1, mean T scores on the Emotion Regulation Index (ERI) and Cognitive Regulation Index (CRI) fell within the *Average* range (<60) for the children in this sample (Table 3). Mean T scores on the Behavior Regulation Index (BRI) and Global Executive Composite (GEC) fell in the range for *Mild Elevation* (60-64). Time 1 mean T scores on Inhibition (61.14) and Working Memory (60.00) subscales fell in the *Mildly Elevated* range (Table 3). Mean T scores on all other BRIEF2 subscales fell in the *Average* range at Time 1. Although mean scores were generally in the high average range, a subset of the sample had clinically elevated T scores (≥1.5 SD above the normative mean) on each BRIEF2 composite and subscale (except for Shift; Table 3).

Time 2

At Time 2, mean T scores on all BRIEF2 composites, except for the ERI, fell within the *Average* range (<60; Table 3). Mean T scores on the ERI fell in the range for *Mild Elevation* (60-64) and 42.9% (3/7) of the sample had elevated T scores in this domain. Mean T scores were *Mildly Elevated* for both subscales of the ERI (Shift and Emotional Control) and the Self-Monitor subscale, with 42.9-57.2% of the sample scoring ≥1.5 SD above the normative mean (Table 3). On all other BRIEF2 subscales, Time 2 mean T scores fell in the *Average* range with less than one-third of participants scoring ≥1.5 SD above the normative mean.

Table 3

BRIEF2 T Scores and Reliable Changes

BRIEF2 Scales	Time 1		Time 2		Difference (Time 2-Time 1)		RCI	
	Mean (SD)	Elevated* n (%)	Mean (SD)	Elevated* n (%)	Mean (SD)	Change by ≥1SD n (%)	Unreliable n (%)	Worsening n (%)
BRI	**60.86 (10.16)**	**4 (57.1)**	**58.14 (10.29)**	**2 (28.6)**	**-2.71 (5.38)**	**1 (14.3)**	**6 (85.7)**	**0 (0.0)**
Inhibit	61.14 (9.19)	3 (42.9)	55.29 (8.79)	1 (14.3)	-5.86 (6.23)	1 (14.3)	6 (85.7)	0 (0.0)
Self-Monitor	57.00 (12.33)	3 (42.9)	60.43 (16.06)	3 (42.9)	3.43 (8.70)	2 (28.6)	6 (85.7)	1 (14.3)
ERI	**57.14 (8.61)**	**1 (14.3)**	**62.43 (7.53)**	**3 (42.9)**	**5.29 (4.68)**	**1 (14.3)**	**6 (85.7)**	**1 (14.3)**
Shift	57.43 (5.29)	0 (0.0)	62.71 (8.54)	4 (57.2)	5.29 (7.25)	2 (28.6)	6 (85.7)	1 (14.3)
Emotional Control	55.86 (10.49)	2 (28.6)	60.14 (12.19)	4 (57.2)	4.29 (6.26)	1 (14.3)	6 (85.7)	1 (14.3)
CRI	**58.86 (11.63)**	**2 (28.6)**	**57.14 (8.13)**	**1 (14.3)**	**-1.71 (8.98)**	**2 (28.6)**	**4 (57.1)**	**1 (14.3)**
Initiate	56.29 (10.29)	2 (28.6)	55.86 (8.05)	1 (14.3)	-0.43 (5.65)	0 (0.0)	7 (100.0)	0 (0.0)
Working Memory	60.00 (11.78)	2 (28.6)	59.86 (10.27)	2 (28.6)	-0.14 (10.59)	1 (14.3)	3 (42.9)	2 (28.6)
Planning/ Organization	57.86 (12.85)	2 (28.6)	57.43 (10.50)	2 (28.6)	-0.43 (11.56)	2 (28.6)	4 (57.1)	1 (14.3)
Task Monitoring	59.86 (7.80)	1 (14.3)	56.43 (10.20)	2 (28.6)	-3.43 (9.71)	3 (42.9)	6 (85.7)	1 (14.3)
Organization of Materials	53.71 (14.40)	2 (28.6)	48.86 (6.01)	0 (0.0)	-4.86 (11.71)	3 (42.9)	4 (57.1)	0 (0.0)
GEC	**61.14 (8.61)**	**2 (28.6)**	**59.71 (8.40)**	**3 (42.9)**	**-1.43 (4.65)**	**0 (0.0)**	**7 (100.0)**	**0 (0.0)**

Note. n=7. Higher BRIEF2 T scores reflect worse EF behaviors; lower BRIEF2 T scores reflect more robust EF behaviors. A reliable worsening may accompany increasing T scores on this measure *BRI*, Behavior Regulation Index; *CRI*, Cognitive Regulation Index; *ERI*, Emotional Regulation Index; *GEC,* Global Executive Composite; *RCI,* reliable change index; *SD*, standard deviation.

*"Elevated" defined as a T score ≥1.5 SD above the normative mean (i.e., a T score of ≥65). This includes scores falling in the *Clinically Elevated* (≥70) and *Potentially Clinically Elevated* (65-69) ranges.

Longitudinal Analyses

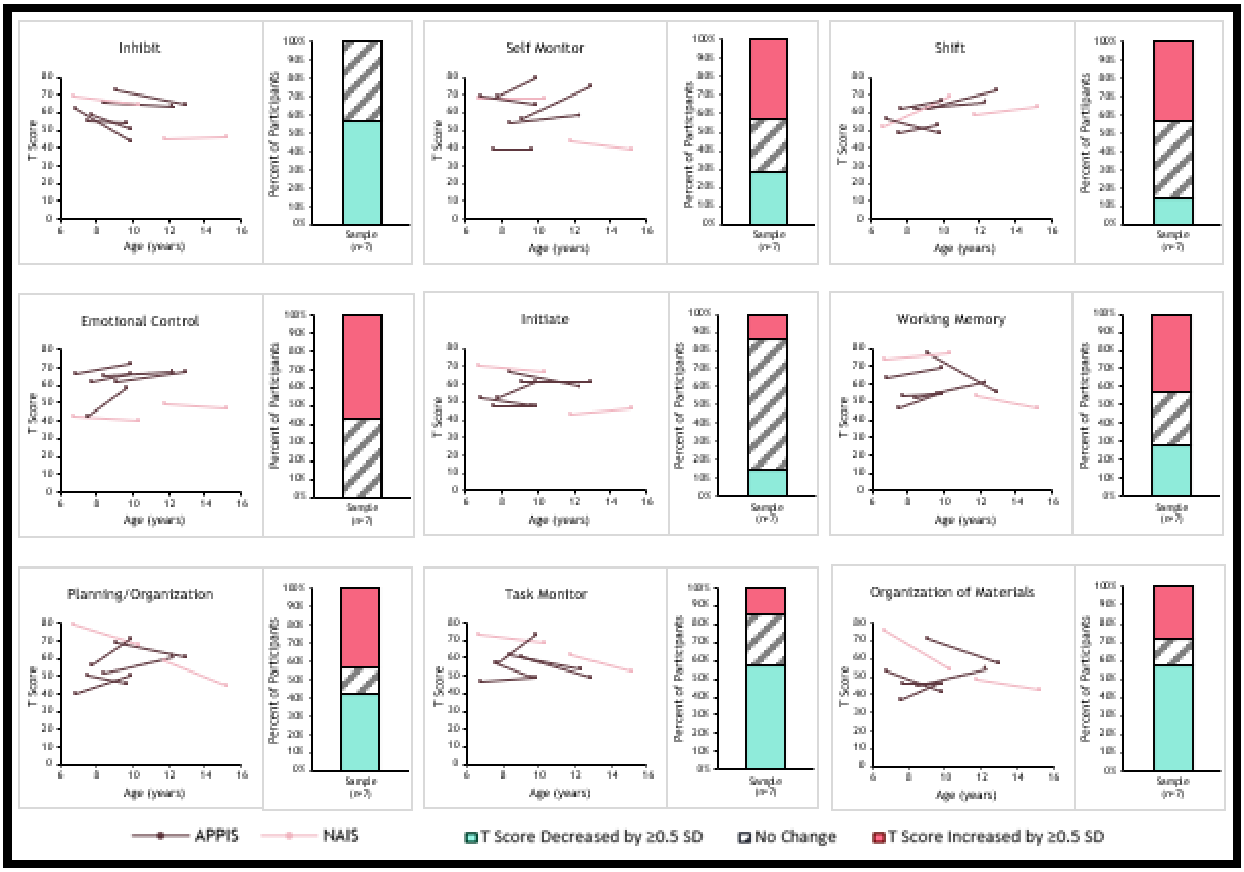
Mean T scores slightly worsened between Time 1 and Time 2 on the Self-Monitor subscale, the ERI, and both ERI subscales: Shift and Emotional Control (Table 3). On all other BRIEF2 subscales and composites, mean T scores improved over time. Individual changes to BRIEF2 T scores were mostly small (Figure 3). On BRIEF2 subscales, up to 71.4% of the sample displayed changes <0.5 SD (Figure 3). Less than 28.6% of the sample had changes to T scores of ≥1 SD on any BRIEF2 composite and on 7/9 subscales (Table 3).

On the BRI, 85.7% of participants (6/7) had T scores change by <0.5 SD, indicating EF behaviors in this domain remained roughly stable relative to normative peers. This pattern likely reflects a balance between relatively consistent improvements to T scores on the Inhibit subscale and more variable changes on the Self-Monitor subscale (Figure 3). In contrast, 57.1% of ERI T scores worsened by ≥0.5 SD. Although 42.9% of the sample had changes <0.5 SD on the ERI, no participants displayed a decrease in T scores on this domain. T scores on both ERI subscales, Shift and Emotional Control, primarily worsened over time (Figure 3). T scores for this sample on the Shift subscale were less variable than those of any other subscale.

Changes to T scores on the CRI and its subscales were more variable than those on the BRI and ERI. On the Initiate subscale, T scores remained roughly stable for most participants (Figure 3). In contrast, large decreases to T scores (≥1 SD) occurred for 42.9% (3/7) of participants on the Planning/Organization and Organization of Materials subscales (Figure 3). Changes to T scores on the final two subscales of the CRI, Working Memory and Task Monitor, were variable (Figure 3).

Figure 3

Individual Changes to BRIEF2 Subscale T Scores Between Time 1 and Time 2



Note. n=7. On the BRIEF2, an increase in T scores indicates worsening daily EF abilities, relative to normative peers. *APPIS,* Arterial Presumed Perinatal Ischemic Stroke; *NAIS,* Neonatal Arterial Ischemic Stroke.

To determine the statistical reliability of individual changes to T scores on BRIEF2 composites, RCIs at the 90% confidence level were calculated (Table 3). Unlike on the PEDI-CAT, where most participants showed reliable worsening of T scores, most changes to BRIEF2 T scores were unreliable. This indicates that changes to T scores over time were so small that they may be reasonably attributed to measurement error. Even on the ERI, which had the largest mean difference in T scores, only 1/7 (14.3%) participants experienced a reliable change to their

T scores. The domain with the most frequent reliable changes was the CRI. Interestingly, of the reliable changes on the CRI, 2/3 (66.7%) were improvements - cases where T scores decreased over time, reflecting an improvement in EF behaviors compared to normative peers.

COVID-19 Impact Rating

COVID-19 Impact Ratings were relatively similar for all participants. Overall, 75.0% (6/8) rated the pandemic as having a negative impact on their family. Of those that provided a negative rating, 5/6 (83.0%) indicated that the pandemic had a *Slightly Negative Impact.* The remaining 25.0% (2/8) rated the pandemic as having *No Change* to their family. Due to the strong skew towards negative ratings of the impact of COVID-19, we were unable to complete any meaningful analyses based on these ratings.

STUDY II

Methods II

Study Overview

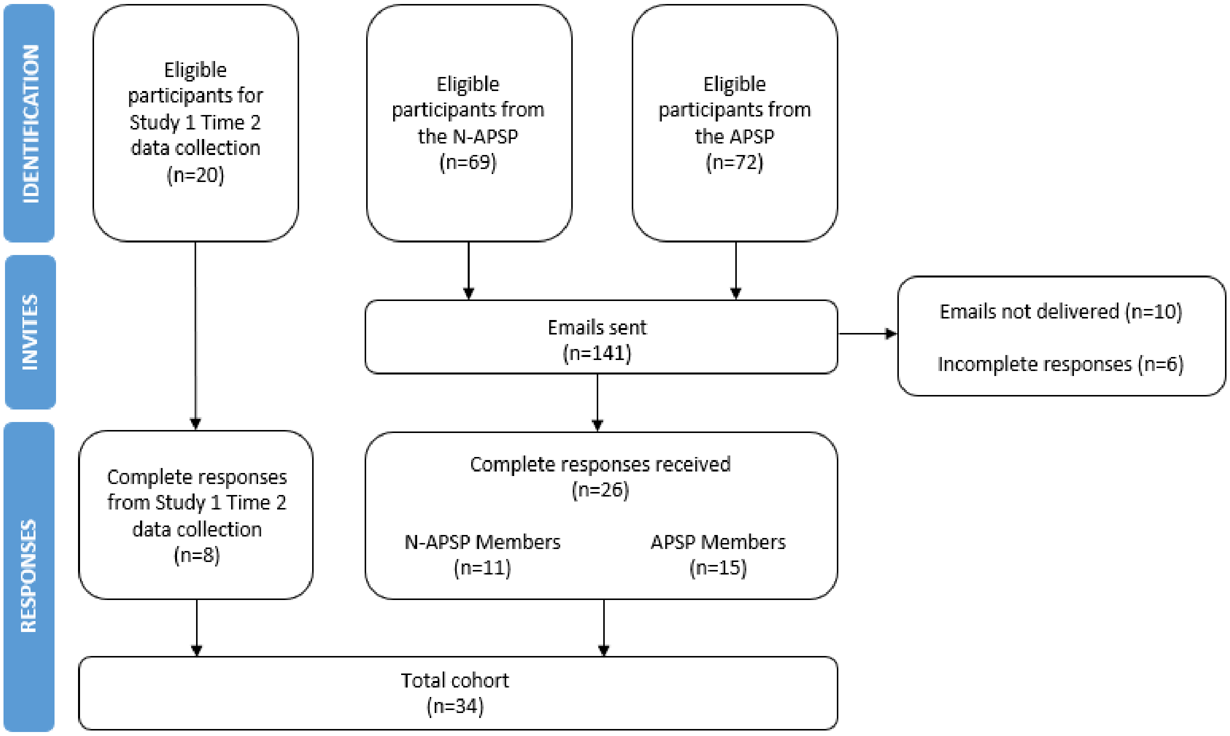
Study II involved the development and delivery of a cross-sectional online survey, the Wellness Activities Questionnaire (WAQ), to caregivers of Albertan children with perinatal stroke. All data collection for this study was completed between February and November 2021, which coincided with Waves 3 (May/June 2020) and 4 (September/October 2021) of the COVID-19 pandemic in Alberta (Government of Alberta, 2022). Study activities involving children from the N-APSP were conducted as part of the larger project “Neurobehavioral Outcomes of Children with Perinatal Stroke” (Pro00066087) and were approved by the Health Research Ethics Board – Health Panel at the University of Alberta. Study activities involving children from the APSP were conducted as part of the larger project “APSP: Investigating Cognitive Behavioral, and Emotional Outcomes Among Children with Perinatal Stroke” (REB18-0360) and were approved by the Conjoint Health Research Ethics Board at the University of Calgary. The aims of this study are aligned with those of the larger studies.

Participants

Participants were identified through the Alberta Perinatal Stroke Project (APSP) registry, based in Calgary, and the Northern Alberta Perinatal Stroke Project (N-APSP) registry, based in Edmonton. The APSP and N-APSP are population-based research cohorts of children with perinatal stroke. Three groups of primary caregivers were invited to participate in this study. A flowchart of participant recruitment for Study II is depicted in Figure 4.

Figure 4

Study II Participant Recruitment Flowchart



Study I Participants

All Study I participants completed the Wellness Activities Questionnaire (WAQ) as part of their Time 2 assessment battery. Recruitment of participants from Study I is described in detail above. This group of participants included primary caregivers of eight children with perinatal stroke, aged 9-19.5 years, initially recruited from the N-APSP. Informed consent was received from all Study I participants for their de-identified study data to be used in collaborations with other APSP and N-APSP projects. Study I participants completed the WAQ between February and May 2021.

N-APSP and APSP Participants

Members of the N-APSP who did not take part in Study I and members of the APSP were also invited to take part in Study II. Inclusion criteria for this group were: 1) child aged 5-18 years; 2) confirmation of a perinatal stroke by a pediatric neurologist; 3) consent to contact about future studies; and 4) current email address on file with the APSP/N-APSP. As in Study I, diagnoses of NAIS, APPIS, and PVI were considered eligible for this study.

Using contact information previously provided to the APSP/N-APSP, all eligible participants for Study II were contacted by email, inviting them to take part in this research study. The invitation email contained a unique hyperlink to the study information letter and online survey. To ensure participants had access to a copy of the information letter for their personal records, the information letter described how to save or print a copy from a web browser. Potential participants were sent up to three reminder emails at four-day intervals, if they did not respond to previous survey invitations.

Since no personally identifiable data was collected in the online survey, participants from the APSP/N-APSP provided implied consent to participate in the study through completion and submission of the online survey. Incomplete survey responses were therefore not included in subsequent analyses. Eleven primary caregivers of children from the N-APSP (aged 5-14 years) completed the WAQ between May and August 2021. Fifteen primary caregivers of children from the APSP (aged 5-18 years) completed the WAQ, between September and November 2021.

Data Sources and Test Measures

All data collection for this study was conducted in a remote, online format using RedCap surveys (Harris et al., 2009). This study used demographic and health information previously collected from the APSP/N-APSP and data from an online caregiver-reported survey, the WAQ.

Demographic and Health Information

Key demographic and health information collected at enrollment in the APSP/N-APSP was combined with survey data for this study. This included child sex and stroke subtype. Child age at the time of survey completion was calculated based on date of birth provided to the APSP/N-APSP.

Wellness Activities Questionnaire (WAQ)

The WAQ is an online, caregiver-reported survey developed for this study. It measures service utilization and engagement in movement behaviors among children with perinatal stroke. The WAQ includes question items in three domains: Allied Health Services, Educational Supports, and Lifestyle & Physical Activity. It also includes include questions about the impact of the COVID-19 pandemic on these content areas. A copy of the final version of the WAQ is included in Appendix 1.

Allied Health Services. Caregivers were asked to indicate whether their child had worked with an occupational therapist, physical therapist, speech language pathologist, or psychologist in the past three years. If caregivers indicated that their child had utilized any of the above services, they were asked: (a) how often their child received the service, prior to the COVID-19 pandemic (*Once per month; Twice per month; Four times per month; Other*); (b) approximately how long their child received the service (*One visit; Less than 1 year; 1-2 years; Other*); (c) how the pandemic changed the frequency they were receiving the service (5-pt Likert scale, where 1 ‘*Decreased by a lot’* and 5 *‘Increased by a lot’*); (d) how the pandemic changed the way they were receiving the service (*Changed to tele-practice, e.g., over the phone, over Zoom, etc.,; No change; Other*); and (e) to describe any other ways the pandemic changed their child’s access to the service. To ensure that responses captured the full range of experiences, caregivers were asked to briefly describe any response of *Other.* Caregivers were also asked if their child had ever visited a sleep clinic/sleep specialist or participated in a program to improve their behavior/worked with a behavior specialist. Finally, caregivers were asked to rate how the pandemic affected how their child was able to access allied health services in general (5-pt Likert scale, where 1 ‘*Decreased by a lot’* and 5 *‘Increased by a lot’*) and to comment on how the pandemic changed their child’s access to allied health services.

Educational Supports. Caregivers were asked if their child typically received any modified programming or supports at school, and to describe any supports their child received. They were also asked if their child typically had an aide in their classroom and, if so, how often the aide was there (*All day, 5 days/week; A few days a week; A few hours a week*). Finally, caregivers were asked to rate the impact of the pandemic on their child’s access to educational supports (5-pt Likert scale, where 1 ‘*Decreased by a lot’* and 5 *‘Increased by a lot’*) and to comment on how the pandemic changed their child’s access to educational supports.

Lifestyle and Physical Activity. Caregivers were asked to consider the physical activities their child engaged in most often, both before and during the COVID-19 pandemic. They were then asked who their child usually did those activities with (*Alone; With Family; With Friends; On a Team*), both before and during the pandemic. Based on definitions included in Canada’s 24-Hour Movement Guidelines for Children and Youth (Tremblay et al., 2016), caregivers were asked to indicate how many hours, out of 24, their child spent in moderate-to-vigorous physical activity (MVPA) and sleep on an average day, both before and during the pandemic. Average movement behaviors were reported separately for school days and weekend days. Caregivers were also asked to indicate how many hours their child spent engaged in distinct recreational screen time activities (*Watching videos – TV or online; Texting/social media – Instagram, TikTok, etc.; Playing video games – on any kind of device; Other),* both before and during the pandemic. Online school was not considered recreational screen time. Time reported for each activity was automatically summed to generate the total recreational screen time. Table 4 depicts specific recommendations for sleep time, MVPA, and recreational screen time for individuals aged 5-19 years (Ross et al., 2020; Tremblay et al., 2016). Adherence to 24-Hr Movement Guidelines before and during the COVID-19 pandemic was determined based on age as of March 1, 2020, and age at submission, respectively.

Table 4

Canada 24-Hour Movement Guideline Recommendations for Individuals Aged 5-19 Years

Movement Behavior	**Guidelines for Children and Youth (Tremblay et al., 2016)**		**Guidelines for Adults Aged 18-64 (Ross et al., 2020)**
	5-13 years	*14-17 years*	*18+ years*
Sleep	9-11 hrs/night	8-10 hrs/night	7-9 hrs/night
MVPA	At least 60 mins/day		At least 150 mins/week
Recreational Screen Time	No more than 2 hrs/day		No more than 3 hrs/day

Note. MVPA, moderate-to-vigorous physical activity.

COVID-19 Impact Rating. To capture some of the changes occurring during the COVID-19 pandemic, question items about the impact of the pandemic were embedded within the WAQ. Although the inclusion of a separate COVID-19 impact questionnaire was considered to increase the generalizability of findings, there were no appropriate questionnaires available at the time of ethics submission for this project. In addition to the domain-specific questions about the impact of the pandemic described above, caregivers rated the overall impact of the COVID-

19 pandemic on a 5-point Likert scale (1 '*Profound negative impact'* to 5 '*Profound positive impact'*).

Statistical Analyses

Analyses were performed using IBM SPSS Statistics software for Windows, Version 27.0 (SPSS, Armonk, NY: IBM Corp). Overall means (standard deviations) and n (percentages) for all variables were calculated. Paired samples t-tests were conducted to determine the significance of reported changes to 24-hour movement behaviors during the pandemic. Associations between continuous variables and child age and sex were assessed using Pearson and point-biserial correlations, respectively. Associations between non-continuous variables and child sex were assessed using Fisher's exact tests. One-way ANOVAs were used to assess differences between continuous variables based on stroke subtype. Statistical significance was set at $p < 0.05$. Due to the brevity of responses to open-ended survey items, a quasi-quantitative analysis was conducted, rather than a formal thematic analysis.

Results II

Demographic Characteristics

The primary caregivers of 34 children with perinatal stroke took part in this study. Participant characteristics are summarized in Table 5. The distribution of perinatal stroke subtypes within the sample was relatively consistent with the overall distribution of perinatal stroke subtypes in Alberta (Dunbar et al., 2020). Compared to respondents from the APSP and N-APSP, cases of APPIS were overrepresented among Study I participants. On average, respondents from the N-APSP appeared to be younger than respondents from the APSP or Study I however this difference was not significant ($F(2, 31) = 1.201$, $p = 0.315$).

Table 5

Demographic Characteristics of Study II Participants

Child Characteristics	**Total Sample (n=34)**	**Study 1 Participants (n=8)**	**N-APSP Members (n=11)**	**APSP Members (n=15)**
Age, Mean (SD)	11.85 (3.57)	12.46 (3.46)	10.49 (2.98)	12.53 (3.96)
Sex – Male, n (%)	19 (55.9)	4 (50.0)	6 (54.5)	9 (60.0)
Stroke Subtype, n (%)				
APPIS	11 (32.4)	6 (75.0)	4 (36.4)	4 (26.7)
NAIS	14 (41.2)	2 (25.0)	4 (36.4)	5 (33.3)
PVI	9 (26.5)	0 (0.0)	3 (27.3)	6 (40.0)

Note. APPIS, arterial presumed perinatal ischemic stroke; *APSP,* Alberta Perinatal Stroke Project; *NAIS,* neonatal arterial ischemic stroke; *N-APSP,* Northern – Alberta Perinatal Stroke Project; *PVI,* periventricular venous infarction.

Allied Health

Overall, 82.4% (28/34) of children with perinatal stroke in this sample had utilized at least one allied health service (Table 6). Occupational therapy (OT) and physical therapy (PT) were the most frequently accessed (18/34; 52.9%), although utilization of psychological services was higher than expected (9/34; 26.5%; Table 6). Most children accessing either OT, PT, or speech/language pathology (SLP) services had been doing so for longer than 1 year (Table 6). In contrast, most children who had accessed psychological services had done so for less than one year (55.6%; 5/9) and 22.2% (2/9) specified that their child began receiving psychological services during the pandemic. Most children were receiving allied health services at least monthly prior to the pandemic (Table 6).

Child age was significantly associated with utilization of SLP services (r = -0.457, p = 0.007), indicating that younger children were more likely to be receiving SLP services. Frequency of pre-pandemic OT services was also significantly higher for younger children, compared to older children (r = -0.505, p = 0.032). There were no other significant associations between service utilization and child age or sex (all *p*s > 0.05).

Table 6

Allied Health Service Utilization by Stroke Subtype

Service Type	Total Sample *(n=34)*	APPIS *(n=14)*	NAIS *(n=11)*	PVI *(n=9)*
Number of Allied Health Services Received				
0	6 (17.6)	0 (0.0)	4 (36.4)	2 (22.2)
1	9 (26.5)	4 (28.6)	3 (27.3)	2 (22.2)
2	8 (23.5)	4 (28.6)	1 (9.1)	3 (33.3)
3	8 (23.5)	4 (28.6)	3 (27.3)	1 (11.1)
≥4	3 (8.8)	2 (14.3)	0 (0.0)	1 (11.1)
Occupational Therapy	**18 (52.9)**	**10 (71.4)**	**4 (36.4)**	**4 (44.4)**
Frequency (≥ monthly)	10 (55.6)	6 (60.0)	3 (75.0)	1 (25.0)
Duration (>2 years)	8 (44.4)	6 (60.0)	1 (25.0)	1 (11.1)
Physical Therapy	**18 (52.9)**	**9 (64.3)**	**3 (27.3)**	**6 (66.7)**
Frequency (≥ monthly)	12 (66.7)	7 (77.8)	2 (66.7)	3 (50.0)
Duration (>2 years)	9 (50.0)	6 (66.7)	1 (33.3)	2 (33.3)
Speech Language Pathology	**10 (29.4)**	**6 (42.9)**	**3 (27.3)**	**1 (11.1)**
Frequency (≥ monthly)	9 (90.0)	6 (100.0)	3 (100.0)	0 (0.0)
Duration (>2 years)	5 (50.0)	3 (50.0)	2 (66.7)	1 (100.0)
Psychology	**9 (26.5)**	**3 (21.4)**	**2 (18.2)**	**4 (44.4)**
Frequency (≥ monthly)	5 (55.6)	3 (100.0)	2 (100.0)	0 (0.0)
Duration (>2 years)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Sleep Specialist/Clinic	**5 (14.7)**	**3 (21.4)**	**1 (9.1)**	**1 (11.1)**
Behavior Program/Therapist	**2 (5.9)**	**1 (7.1)**	**1 (9.1)**	**0 (0.0)**

Note. All values are n (%), unless otherwise indicated. *APPIS,* arterial presumed perinatal ischemic stroke; *NAIS*, neonatal arterial ischemic stroke; *PVI,* periventricular venous stroke.

COVID-19 Pandemic Impacts

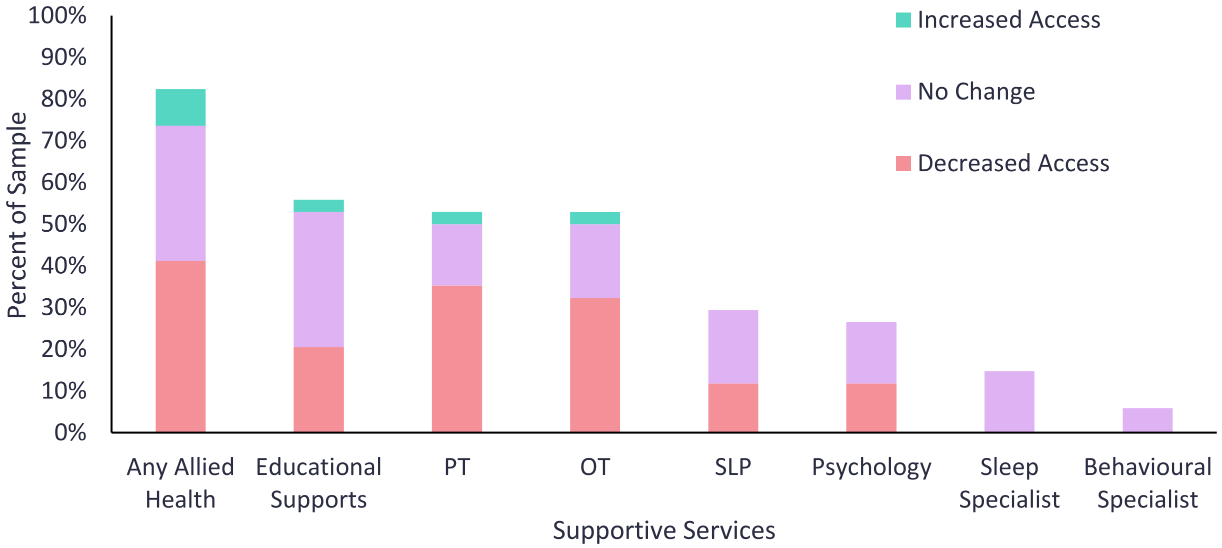
Overall, 41.2% (14/34) of participants indicated that their child was able to access allied health services less often during the COVID-19 pandemic. Of the caregivers who indicated a decrease in access to allied health services during the pandemic, 50.0% (7/14) described issues with unavailability of services and delays in accessing services. Others reported changes to the format of service delivery (3/14; 21.4%), and challenges balancing competing interests when accessing allied health services (2/14; 14.2%) limited their child's access to services. Finally, 14.2% (2/14) indicated that cuts to government funding during the pandemic limited their child's access to allied health services.

Of the 50.0% (17/34) who indicated the pandemic had not changed their child's access to allied health services, 35.3% (6/17) were not utilizing any allied health services before or during the pandemic. Point biserial correlations indicated a significant association between child sex and COVID-19 impact ratings for allied health services (r = 0.385, p = 0.025), with caregivers of female children tending to rate the impact of the pandemic more positively. Child age was not significantly associated with COVID-19 impact ratings for allied health services (r = 0.247, p = 0.160).

Figure 5 depicts changes to the frequency of various supportive services during the pandemic. Most participants reported a decrease in frequency of OT (11/18; 61.1%) and PT (12/18; 66.7%) services during the pandemic. In contrast, most participants reported no change to the frequency of SLP (6/10; 60.0%) and psychological services (5/9; 55.6%). Only a small share of participants indicated that their OT or PT services had completely or partially changed to tele-practice (4/18; 22.2%). Respectively, 40.0% (4/10) and 44.4% (4/9) reported that their SLP and psychological services changed to tele-practice during the pandemic.

Figure 5

Engagement in Supportive Services and Changes to Access During the Pandemic



Note. OT, occupational therapy; *PT*, physical therapy; *SLP*, speech language pathology.

Educational Supports

Just over half of children (19/34; 55.9%) typically received modified programming and/or supports in school. Access to an educational assistant, whether designated for the child or not, was the most reported type of educational support (9/19; 47.4%). Modified academics or Individualized Program Plans (7/19; 36.8%); therapeutic consults and/or integrated therapy during the school day (5/19; 26.3%); and writing accommodations, including extended deadlines, (5/19; 26.3%) were also frequently reported educational supports for the children in this sample. Child age was significantly associated with access to writing accommodations ($r = 0.555$; $p = 0.014$) and access to therapeutic services in the school setting ($r = -0.458$; $p = 0.049$). This indicates that older children were more likely to be receiving accommodations for their writing whereas younger children were more likely to be receiving therapeutic consultation or services within the school setting.

COVID-19 Pandemic Impacts

Among children who were receiving educational supports prior to the pandemic, 57.9% (11/19) of caregivers indicated no change to their child's access during the pandemic (Figure 5). COVID-19 impact ratings for educational supports were not significantly associated with child age or sex (all *p*s > 0.05).

Of the 11.8% (8/25) of caregivers who reported a decrease in their child's access to educational supports during the pandemic, 5/8 (62.5%) described interruptions in their child's support from an aide. Disruptions included difficulty following COVID-19 protocols while delivering one-on-one support, unavailability of aides when needed due to quarantining or cohorting, and limited capacity to connect with an aide virtually. Several caregivers also noted that extra school supports, like lunch hour tutoring, were often unavailable during the pandemic and that their children therefore required additional support at home.

Movement Behaviors

Average daily time spent engaged in sleep, MVPA, and recreational screen time is presented in Table 7. Prior to the COVID-19 pandemic, all participants were meeting at least one 24-Hour Movement Guideline on weekdays and on weekends 97.0% (32/33) were meeting at least one of the guidelines. Likewise, 27.3% (9/33) and 24.2% (8/33) of children in our sample were meeting all three guidelines on weekdays and weekends, respectively. Adherence to 24-Hour Movement Guidelines dropped substantially during the COVID-19 pandemic, with 9.1% (3/33) of children meeting none of the guidelines on either weekdays or weekends. Similarly, the proportion of children meeting all three guidelines dropped to 0.0% (0/33) on weekdays and 6.1% (2/33) on weekends during the pandemic.

Table 7

24-Hour Movement Behaviors, Before and During the Pandemic

Movement Behavior	Pre-Pandemic		Mid-Pandemic		Change (Mid – Pre)	
	Avg. Daily Hours (SD)	n (%) Meeting Guidelines	Avg. Daily Hours (SD)	n (%) Meeting Guidelines	Mean (SD)	p
Sleep						
Weekday	9.57 (1.44)	27 (79.4)	9.24 (1.42)	21 (61.8)	-0.34 (0.91)	0.038*
Weekend	10.15 (1.40)	23 (67.6)	10.12 (1.47)	22 (64.7)	-0.03 (0.72)	0.812
MVPA						
Weekday	1.85 (1.21)	32 (94.1)	1.04 (0.91)	24 (70.6)	-0.81 (1.33)	0.001**
Weekend	2.03 (1.53)	29 (85.3)	1.60 (1.37)	25 (73.5)	-0.43 (1.03)	0.022*
Screen Time†	3.41 (2.11)	12 (36.4)	5.65 (3.38)	4 (12.1)	2.24 (2.16)	<0.001**

Note. n = 34 unless otherwise indicated. *MVPA,* moderate-to-vigorous physical activity.

†n = 33.

*paired sample t-test significant at the 0.05 level (two tailed) **significant at the 0.001 level (two-tailed)

Sleep

Prior to the pandemic, 79.4% (27/34) and 67.6% (23/34) of the children in our sample were meeting 24-Hour Movement Guidelines for sleep time on weekdays and weekends, respectively (Table 7). Older age was significantly associated with shorter average weekday sleep time (r = -0.353, *p* = 0.040). There were no significant associations between sex and pre-pandemic average sleep times. Paired sample t-tests revealed a significant reduction in weekday sleep time during the pandemic (t(33) = -2.166, *p* = 0.038), however there was no significant change to weekend sleep time (t(33) = 0.406, *p* = 0.812). The proportion of children in our sample meeting 24-Hour Movement Guidelines for sleep time decreased during the pandemic, however most were still meeting sleep time guidelines for their age group (Table 7).

Changes to weekday sleep time were negatively correlated with pre-pandemic weekday sleep time ($p = 0.049$; Table 8). This indicates that children with longer weekday sleep times prior to the pandemic tended to display a greater reduction in weekday sleep time during the pandemic. No such association with pre-pandemic values was observed for weekend sleep time ($p = 0.407$; Table 8). Age was significantly associated with change to weekday sleep time ($r = 0.342$, $p = 0.048$). This indicates that older children tended to experience increases to weekday sleep times during the pandemic, compared to pre-pandemic values. There were no other significant associations between changes to sleep times and age or sex (all *p*s > 0.05). There were also no significant differences in changes to sleep time based on stroke subtype (Weekday: $F(2,31) = 0.734$, $p = 0.488$; Weekend: $F(2,31) = 0.817$, $p = 0.451$).

Table 8

Correlations Between Pre-Pandemic Average Daily Movement Behaviors and Change to Average Daily Movement Behaviors During the Pandemic

Pre-Pandemic Movement Behaviors	**Change to Movement Behaviors (Mid – Pre)**				
	Sleep, Weekday	Sleep, Weekend	MVPA, Weekday	MVPA, Weekend	Recreational Screen Time†
Sleep, Weekday	**-0.34***	-0.22	0.16	0.10	-0.18
Sleep, Weekend	-0.16	-0.15	0.13	-0.10	-0.05
MVPA, Weekday	-0.07	-0.25	**-0.75****	-0.09	**0.39***
MVPA, Weekend	-0.24	-0.27	-0.07	**-0.48****	0.08
Recreational Screen Time†	**0.36***	0.15	-0.27	0.24	0.25

Note. n = 34 unless otherwise indicated. *MVPA,* moderate-to-vigorous physical activity.
†n = 33.
* significant at the 0.05 level (two-tailed). ** significant at the 0.01 level (two-tailed).

Moderate-to-Vigorous Physical Activity (MVPA)

Before the pandemic, nearly all the children in this sample were reportedly meeting or exceeding 24-Hour Movement Guidelines for MVPA (Table 7). Furthermore, 58.8% (20/34) were primarily participating in physical activity with their peers. Of those, 75.0% (15/20) were engaged in physical activity as part of a team. Average weekday MVPA time was significantly associated with sex ($r = -0.410$, $p = 0.016$), which indicates that MVPA time tended to be longer for males. There were no other significant associations between age or sex and average MVPA time prior to the pandemic (all *p*s >0.05). Average MVPA time prior to the pandemic did not differ based on stroke subtype (Weekday: $F(2,31) = 0.906$, $p = 0.415$; Weekend: $F(2,31) = 0.384$, $p = 0.684$).

Paired sample t-tests revealed a significant reduction to time spent in MVPA during the pandemic, compared to recalled pre-pandemic values, on both weekdays ($t(33) = -3.557$, $p = 0.001$) and weekends ($t(33) = -2.41$, $p = 0.022$; Table 7). Likewise, the proportion of children meeting guidelines for MVPA dropped dramatically during the pandemic, particularly for weekday MVPA (Table 7). Alongside a reduction in average daily MVPA, the proportion of children engaging in physical activity with their peers dropped from 58.8% (20/34) to 11.7% (4/34) during the pandemic.

Changes to average daily MVPA were strongly correlated with pre-pandemic average daily MVPA, for both weekdays ($p < 0.001$) and weekends ($p = 0.004$; Table 8). More time spent in MVPA, on average, prior to the pandemic was associated with a larger reduction in daily average MVPA time during the pandemic. There were no significant associations between changes to average daily MVPA and either age or sex (all *p*s >0.05).

Recreational Screen Time

Before the COVID-19 pandemic, 63.6% (22/33) of the children in this sample were exceeding the maximum guideline for daily recreational screen time (Table 7). On average, the children in our sample spent most of their recreational screen time watching videos (1.89 hrs, SD: 1.13) and playing video games (1.26 hrs, SD: 1.29). Older age was associated with more time spent texting or on social media ($r = 0.410$, $p = 0.018$). There were no other significant associations between pre-pandemic daily recreational screen time and age or sex (all *p*s >0.05).

Average daily recreational screen time increased substantially during the pandemic, with 87.9% (29/33) of children exceeding the maximum guideline (Table 7). Paired samples t-tests revealed a significant increase to average daily recreational screen time during the pandemic, compared to recalled pre-pandemic values ($t(32) = 5.959$, $p < 0.001$). Pre-pandemic recreational screen time was not significantly associated with changes to recreational screen time during the pandemic (Table 8). However, pre-pandemic weekday MVPA was significantly associated with changes to recreational screen time ($p = 0.024$; Table 8). This indicates that children who spent more time in MVPA on weekdays before the pandemic tended to see a greater increase in daily average recreational screen time during the pandemic. There were no significant associations between change to average daily recreational screen time and age or sex (all *p*s > 0.05).

Overall COVID-19 Pandemic Impacts

On a 5-point Likert based scale, 50.0% (17/34) of respondents indicated that the COVID-19 pandemic has had a *Slight Negative Impact* on their family overall. A further 14.7% (5/34) indicated that the pandemic had a *Profound Negative Impact* on their family. Unexpectedly, 17.6% (6/34) of respondents rated the pandemic as having a *Slight* or *Profound Positive Impact* on their family. COVID-19 impact ratings were not significantly associated with child age or sex (all *p*s >0.05), nor was there any difference based on stroke subtype (F(2,31) =2.082, *p* = 0.142).

COVID-19 impact ratings were not significantly associated with changes in access to allied health services during the pandemic (p >0.05). Overall, negative COVID-19 impact ratings were strongly correlated with greater increases to average daily recreational screen time (r = -0.636, *p* <0.001). Contrastingly, positive COVID-19 impact ratings were correlated with increases to average weekend MVPA (r = 0.432, *p* = 0.011).

DISCUSSION

Study I

The primary aim of Study I was to describe longitudinal changes to functional abilities and EF behaviors among children and youth with perinatal stroke.

Longitudinal Changes to Functional Abilities

In direct contrast to my initial hypothesis, children with perinatal stroke displayed worsening of existing functional impairments and emergence of new functional impairments compared to same-age peers, especially in domains of Daily Activities, Mobility, and Social/Cognitive function. All participants displayed reliable worsening of T scores on at least two functional domains, which indicates that these changes were not likely to be an artifact of repeated PEDI-CAT administration. Together, these findings indicate that children with perinatal stroke in this study acquired new functional abilities at a more gradual rate than normative peers.

Daily Activities & Mobility. Several recent studies have reported similar trajectories on the Daily Activities and Mobility domains of the PEDI and PEDI-CAT among individuals aged 1-21 years with cerebral palsy (Burgess et al., 2020; Smits et al., 2019). Even though functional trajectories differed significantly based on degree of gross motor impairment, children with independently ambulatory cerebral palsy made functional gains to Daily Activities and Mobility at a slower rate than typically developing peers (Smits et al., 2019). Likewise, Burgess et al. (2020) found that children with cerebral palsy had worse baseline Daily Activities scores than normative peers, on average. Smits et al. (2019) found that functional development on the PEDI plateaued around 7 years of age for children with cerebral palsy and their typically developing peers. However, Burgess et al. (2020) described a widening gap between the Daily Activities abilities on the PEDI-CAT throughout childhood and adolescence, as children with cerebral palsy acquired new functional skills more gradually than their typically developing peers. Results from this study are largely consistent with these findings. Most participants displayed incremental functional gains to PEDI-CAT scaled scores throughout childhood and adolescence, leading to a reliable worsening of functional abilities compared to normative peers, as described by PEDI-CAT T scores.

Slowed functional development compared to normative peers in domains of Daily Activities and Mobility is also consistent with current research surrounding neural control of motor development following perinatal stroke (Kirton et al., 2021). NAIS and APPIS lesions often affect regions of the motor cortex and further implication of subcortical motor structures is associated with poor motor outcomes (Dinomais et al., 2015; Mercuri et al., 1999). Early damage to motor structures following perinatal stroke can disrupt activity-dependent plasticity and lead to atypical development of motor organization. For example, in typical early motor development, upper motor neurons of the corticospinal tract project to the spinal cord bilaterally (Eyre et al., 2001). Within the first 2 years of life, activity-dependent synaptic plasticity favours preservation of contralateral corticospinal projections and the redundant ipsilateral pathways are mostly withdrawn (Eyre et al., 2001). Further developmental plasticity and refinements to neural motor control systems continue into adulthood (Guzzetta et al., 2007).

In perinatal stroke, contralateral projections from the lesioned hemisphere are less competitive and ipsilateral corticospinal projections from the non-lesioned hemisphere are often preserved beyond their usual developmental shelf life (Eyre et al., 2007; Kirton et al., 2021). Though this type of developmental plasticity may prevent immediate major motor deficits in the affected limbs, preservation of ipsilateral corticospinal projections has been associated with long-term development of functional motor impairments in the affected limbs (Zewdie et al., 2017) and impaired function of the less affected limbs compared to typically developing peers (Rich et al, 2017). In line with the early vulnerability hypothesis, immediate neuroplastic changes following perinatal stroke not only contribute to long-term motor deficits like hemiplegia, but likely continue to impede functional motor development throughout childhood and adolescence.

Social Cognitive Function. Children with perinatal stroke in this study displayed worsening of existing impairments and emergence of new impairments to Social/Cognitive function, compared to normative peers. These results are consistent with those of Voorman et al. (2010), who found that 9-11-year-olds with cerebral palsy experienced similar worsening social function compared to normative expectations over a three-year period. However, results contrast with those of a Dutch study that found children with cerebral palsy alone achieved typical levels of social functioning by adolescence/early adulthood, whereas children with cerebral palsy and comorbid intellectual disability experienced slower development of social function and never achieved the same developmental limits as their peers (Tan et al., 2020). Social/cognitive trajectories for children with perinatal stroke in this study resemble trajectories for children with cerebral palsy and intellectual disability, even though 75% of the Study I sample did not meet the operational definition for intellectual disability used by Tan et al. (2020). A variety of factors, including limited generalizability of the longitudinal sample for Study I; difficulties accurately rating social/cognitive function during the COVID-19 pandemic; and regional variations in community inclusivity and opportunities for social participation (Fauconnier et al., 2009), likely contributed to this discrepancy in findings.

Although some researchers have concluded that brain injury during the perinatal period carries distinct risk of poor social outcomes (Anderson et al., 2014; Greenham et al., 2010), others have argued that perinatal or neonatal strokes carry a reduced risk of social impairment compared to children with later strokes (Greenham et al., 2017, 2018). However, studies which found limited social impairment among children with perinatal stroke often completed assessments at a standard time since stroke, meaning that children with perinatal stroke were significantly younger than children with later strokes (Greenham et al., 2017, 2018). Results from Study I indicate that difficulties with social function likely emerge throughout childhood and adolescence following perinatal stroke. Likewise, preliminary evidence indicates that foundational social/cognitive skills, such as theory of mind, are vulnerable to disruption by perinatal stroke and may contribute to long-term impairments to social function (Ryan et al., 2021). Overall, the relatively poor social functioning of participants by Time 2 of Study I adds strength to the suggestion that children with perinatal stroke may be at risk of poor social outcomes later in development (Anderson et al., 2014; Greenham et al., 2010).

Responsibility. Changes to Responsibility were less consistent than changes to other functional domains. Although mean T scores worsened over time, average T scores were higher on the Responsibility domain than any other functional domain of the PEDI-CAT at both timepoints. Likewise, the proportion of the sample with clinically significant impairments to

Responsibility did not change and only half of the sample showed reliable worsening of Responsibility T scores over time. This is unsurprising since the Responsibility domain is more challenging and displays a more linear, protracted developmental course among typically developing children compared to other domains of the PEDI-CAT (Haley et al., 2011). Gradual improvements to mean Responsibility scaled scores are present throughout childhood and adolescence in the PEDI-CAT normative sample (Haley et al., 2011). However, most major changes to Responsibility are not expected until later adolescence or early adulthood when individuals undergo major life transitions (Schmidt et al., 2019; van Gorp et al., 2019). It is therefore likely that difficulties in this domain had not yet emerged for the participants in this study, although further study is needed to confirm this supposition.

Longitudinal Changes to EF Behaviors

At both timepoints, mean T scores for all BRIEF2 domains and subscales were in the *Average* or *Mildly Elevated* ranges, however most children in our sample displayed *Clinically Elevated* or *Potentially Clinically Elevated* T scores on at least one BRIEF2 domain or subscale. This is consistent with the findings of both Bosenbark et al. (2018) and Khan et al. (2020), who reported that some children with perinatal stroke experienced clinically significant impairments to EF behaviors, but that mean scores were within normative ranges. Likewise, previous reports of cognition and academic skills among children and youth with stroke have demonstrated general abilities in the low-average range, with occasional specific impairments (Jacomb et al., 2018; Westmacott et al., 2009).

Contrary to my initial hypothesis, most longitudinal changes on the BRIEF2 did not indicate worsening of EF behaviors compared to normative peers. Mean T scores and the proportion of children with clinically elevated T scores either improved or remained stable, on nearly all composites and subscales. Furthermore, most individual changes to BRIEF2 T scores were unreliable based on the 90% RCI, suggesting that most of the observed changes were an artifact of repeated administration of the BRIEF2, including on subscales where mean T scores worsened over time. Overall, children with perinatal stroke may experience specific impairments to a range of EF behaviors, compared to normative peers, however these do not appear to worsen throughout childhood and adolescence.

EF has previously been highlighted as an area which may be prone to emerging deficits and most previous research has provided support for the early vulnerability model of recovery. In line with the theory that development of high-order, late-developing cognitive functions depends on the functional integrity of early maturing areas (Gogtay et al., 2004; Kolb & Gibb, 2007), previous longitudinal studies have described emerging cognitive deficits between preschool and school-age among children with perinatal stroke (van Buuren et al., 2013; Westmacott et al., 2009). Likewise, several cross-sectional studies have found older age at testing was significantly associated with worse performance-based EF (Bosenbark et al., 2018; Li et al., 2022) and parent-rated EF behaviors on the BRIEF (Bosenbark et al., 2018; Larsen et al., 2021) among children with perinatal stroke.

Contrary to these expectations though, results from Study I were generally consistent with neuroplasticity models of recovery. Several studies have reported relative stability of cognitive abilities throughout childhood and adolescence following pediatric stroke compared to normative peers, even if specific deficits are present. For example, O'Keeffe et al. (2014) found that neuropsychological abilities, including EF behaviors on the BRIEF, remained roughly stable over a period of 19-31 months for children and adolescents with childhood stroke. Although their sample excluded children with perinatal stroke, they also reported that younger age at stroke was associated with better EF behaviors on the BRIEF (O’Keeffe et al., 2014). Since cognitive development is particularly dependent on functional integrity of brain structures during critical developmental periods (Kolb & Gibb, 2007), it is possible that early neuroplasticity may help mitigate the impacts of neural injury on functions with late critical periods, such as EF (Selemon et al., 2013). Studies which have demonstrated emerging deficits to general cognition over time following perinatal stroke have focused on developmental changes between preschool and school age (van Buuren et al., 2013; Westmacott et al., 2009). Similarly, Bosenbark et al. (2018) included children as young as 3 years old in their sample, when they found that older age at testing was associated with worse EF behaviors on the BRIEF. In contrast, participants in this study were at least 6 years of age at Time 1. It may be that impairments to EF behaviors first emerge during early critical periods (in the preschool years; Diamond, 2013) and persist, but do not worsen, during later development for children with perinatal stroke. Further study is needed to explore this hypothesis; however, this would be consistent with findings from this study and those of Khan et al. (2020), who reported no significant associations between age and BRIEF2 EF behaviors among children aged 6-16 years with perinatal stroke.

Considering the limited correlations between parent-rated and performance-based EF in children with perinatal stroke (Krivitzky et al., 2019), it is also possible that parent-rated EF behaviors have a more stable developmental trajectory, compared to performance-based EFs. Although the optimal laboratory setting of performance-based measures may permit detection of subtle longitudinal changes that may be missed on parent-reported measures, most cross-sectional studies have reported relatively few significant correlations between performance-based EFs and age at testing (Bosenbark et al., 2018; Li et al., 2022). Longitudinal study of performance-based EFs in children with perinatal stroke is certainly needed.

Most of the longitudinal evidence for early vulnerability of children with perinatal stroke has been derived from research into general cognitive abilities (van Buuren et al., 2013; Westmacott et al., 2009). Therefore, perinatal stroke may have differential effects on general cognitive and higher cognitive functions, like EF. In a pediatric stroke study, Jacomb et al. (2018) found that most children and youth did not display reliable changes to IQ or memory over an average follow-up period of 5.55 years. Although younger age at stroke was significantly associated with greater changes to IQ over time, age at stroke did not have any significant effects on changes to memory over time (Jacomb et al., 2018). Therefore, it is possible that relatively typical development of higher order cognitive functions, like EF, may co-occur with slowed development of general cognitive functions, as described by Westmacott et al. (2009), following perinatal stroke.

It is still surprising that worsening of EF behaviors was not observed among the participants in our sample, given that Time 2 data collection was completed nearly one year into the COVID-19 pandemic. Experiences such as stress, loneliness, sadness, and suboptimal movement behaviours are all associated with negative impacts to EF (reviewed in Diamond & Ling, 2016) and may be more common during the pandemic. Findings from Study II confirm that many children with perinatal stroke experienced disruptions to service access and physical activity, which may have limited opportunities for children and youth to practice and improve EF abilities within a structured and supportive context. Some researchers have noted that children and youth had more opportunities for self-directed and unstructured play during the pandemic (Moore et al., 2021a; Paterson et al., 2021), which may help mitigate negative impacts to EF (Stucke et al., 2021). However, due to the impacts of the pandemic, it is possible that Study I illustrates worse trajectories to EF behaviors than are typical for children and youth with perinatal stroke.

Impacts of the COVID-19 Pandemic on Longitudinal Trajectories

Children and youth with more negative parental ratings of the COVID-19 pandemic were expected to display worse longitudinal trajectories for functional abilities and EF behaviors, compared to those whose parents rated the impact of the COVID-19 pandemic as neutral or positive. There was a strong skew towards negative ratings in our sample which, coupled with the sample size of Study I, precluded any meaningful analyses based on COVID-19 impact ratings. Although it is unfortunate that further analyses based on COVID-19 impact ratings could not be completed, the ratings still provide important context for the longitudinal changes described in this study.

In early waves of the COVID-19 pandemic, parent perception of the pandemic was identified as a key predictor of child and parent wellbeing (Spinelli et al., 2020). Though parents may not consider factors such as increased financial instability or greater workplace stress to have direct impacts on their children, such factors can increase parental stress, affecting the quality of intrafamilial relationships and producing considerable impacts on the child (Prime et al., 2020). In this study, most parents rated the pandemic as having an overall negative impact on their families. Therefore, the longitudinal trajectories reported in this study may reflect both developmental changes and changes due to the impact of the COVID-19 pandemic. As a result, it is possible that the longitudinal trajectories described in this study are worse than would typically be expected based on developmental changes alone. This uncertainty should encourage further longitudinal study of neurobehavioral outcomes in children and youth with perinatal stroke to determine the contribution of developmental changes to outcomes observed here.

Study II

The aim of Study II was to describe engagement with supportive services and movement behaviors among Albertan children and youth with perinatal stroke, both before and during the COVID-19 pandemic, to further contextualize the developmental trajectories reported in Study I.

Pre-Pandemic Supportive Services

Overall, responses from the WAQ indicated that Albertan children and youth with perinatal stroke had robust access to a range of allied health and educational supports, including greater use of psychological supports than expected. As predicted, OT and PT services were the most accessed allied health services by children and youth with perinatal stroke. Since motor deficits are common, easily detectable, and have been well described following perinatal stroke (Dunbar & Kirton, 2018), it is understandable that allied health services aimed at improving motor function, namely OT and PT, would be most utilized among this sample. About one-third of participants had accessed SLP services. Although most children with perinatal stroke display typical language abilities by school age (Lai et al., 2015), utilization of SLP services was consistent with prevalence of language delays in children with perinatal stroke, which occur in <10% of children with PVI (Kirton et al., 2008) and 20-30% of children with NAIS or APPIS (Lee, Croen, Lindan et al., 2005). Utilization of OT, PT, and SLP services in this study were largely consistent with utilization among children and youth with cerebral palsy (Majnemer et al., 2014) and children with other early brain injuries, including neonatal stroke (Vyas et al., 2021).

Unexpectedly, utilization of psychological services was relatively robust compared to previous reports. Just over one quarter of participants in this study had utilized psychological services, whereas only 6-15% of children and youth in related clinical populations have reportedly accessed psychological supports (Majnemer et al., 2014; Vyas et al., 2021). It is possible that increased utilization of psychological services reflects a response to the outstanding needs of this population and emerging research on neurobehavioral outcomes following perinatal stroke. Families of children with early brain injuries have previously highlighted increased access to psychological services as a critical and ongoing need (Vyas et al., 2021). Though reports of poor mental health outcomes have been inconsistent throughout the perinatal stroke literature (Lo et al., 2014; Max et al, 2010; Williams et al., 2017), it has been suggested that perinatal stroke may increase risk of later mental health concerns as a combined consequence of neurological injury and lived experience with a chronic disability (Williams et al., 2017). Therefore, the increased utilization of psychological services in this study is an encouraging finding. However, this uptick may also be related to the COVID-19 pandemic, as most participants had been receiving psychological services for less than one year at the time of survey completion. A variety of factors, including increased mental health concerns and increased public awareness of the importance of mental health during the pandemic, may have contributed to the high utilization of psychological services by children with perinatal stroke reported here.

Most children and youth in this study typically received some form of educational supports. This is an encouraging finding, since children with perinatal stroke may face a variety of challenges in the classroom. In addition to difficulties performing fine-motor tasks, such as writing, children with perinatal stroke may also struggle academically. Li et al. (2022) found that math skills of children with perinatal stroke were significantly impaired, compared to normative peers. Several studies have also reported significant impairments to core academic skills, including reading, comprehension, spelling, and math, among children with pediatric stroke (Champigny et al., 2020; Deotto et al., 2019). Furthermore, Champigny et al. (2020) reported that as many as 41.4% children with pediatric stroke received a formal diagnosis with a learning disability, compared to just 8.8% of controls. Access to educational supports may mitigate the impact of such concerns. Champigny et al. (2020) found that grade point averages of children with pediatric stroke did not significantly differ from controls, despite significant differences in academic skills. Considering nearly two-thirds of the pediatric stroke sample received some form of educational support, the discrepancy between grades and academic skills may reflect the beneficial impacts of educational supports for children with stroke (Champigny et al., 2020). In this study, children and youth with perinatal stroke appeared to receive a variety of educational supports, based on their individual needs.

Overall, children and youth with perinatal stroke in this study were well-supported by allied health services and educational supports prior to the COVID-19 pandemic. In addition to addressing the functional needs of children and youth with perinatal stroke, access to these services offers children and youth the opportunity to work towards challenging, personally meaningful goals in a supportive and consistent context, which may directly or indirectly support EFs (Diamond & Ling, 2016, 2019). Indeed, this consistent supportive context for children and youth with perinatal stroke may be one of many factors contributing to better-than-expected developmental trajectories for EF behaviors reported in Study I.

Differences Based on Age. Compared to school-aged children with cerebral palsy, adolescents with cerebral palsy are less likely to use OT and PT services and utilize fewer rehabilitation services overall (Majnemer et al., 2014). In this study, SLP utilization was significantly more likely among younger children with perinatal stroke. This association is consistent with reports that language concerns often resolve throughout school age when appropriately addressed among children with perinatal stroke (Ballantyne et al., 2008). The proportion of adolescent participants utilizing OT and PT services was comparable to that of school-aged peers, however adolescents tended to engage with OT and PT services less frequently. Early intervention is strongly recommended for children with perinatal stroke, to take advantage of enhanced neuroplastic potential during critical periods for motor development (Basu et al., 2014). With age, it becomes less likely that underlying neural motor circuitry will change. Therefore, it is understandable that younger children may have more frequent delivery of OT and PT services, whereas OT and PT for adolescents may be more consultative and focus on addressing the evolving functional impacts of a child's motor impairment (Majnemer et al., 2014).

Although access to educational supports did not significantly differ based on age, differences in the types of educational supports reported between school-aged children and adolescents likely also reflect the emphasis of early therapeutic intervention following perinatal stroke. School-aged children often received therapeutic supports integrated throughout the school day, whereas adolescents reported receiving accommodations and writing supports in the classroom more often. Overall, the continued engagement of adolescents in this sample with supportive services is a promising indication that adolescents with perinatal stroke were able to access appropriate rehabilitation services. Considering results from Study I, which indicated slowed development of functional abilities throughout childhood and adolescence compared to normative peers, continued engagement with supportive services may be more important than previously considered.

Differences Based on Stroke Subtype. Participants with APPIS and PVI, which almost always lead to motor impairment (Kirton et al., 2008), were expected to utilize OT and PT services more often than participants with NAIS, which only leads to motor impairment in about 30% of cases (Lee, Croen, Lindan et al., 2005). Results from Study II supported this hypothesis and revealed a further pattern of OT and PT utilization among participants with APPIS and PVI. A greater proportion of participants with APPIS utilized OT services compared to PT services, whereas the reverse was true for participants with PVI. This pattern of service utilization is consistent with patterns of motor impairment in the two stroke subtypes. Whereas motor impairment following APPIS primarily affects the upper limbs, PVI often leads to greater involvement of the lower limbs with relative sparing of upper limb function (Fehlings et al., 2021; Kirton et al., 2008). Accordingly, OT services tend to focus on improving daily activities and therefore involve a greater focus on upper limb function, whereas PT services generally focus on movement and mobility concerns and hence focus on lower limb function.

Utilization of SLP, psychological, and educational supports was expected to be greater among participants with NAIS and APPIS compared to those with PVI, which is primarily associated with isolated motor deficits (Kirton et al., 2008). Consistent with this hypothesis, participants with NAIS and APPIS utilized SLP services more often than participants with PVI. Utilization of educational supports was also similar across all three stroke subtypes, although there may be differences in the types of educational supports received. Contrary to my initial hypothesis though, utilization of psychological services was greatest among children with PVI. Although mild cognitive deficits have recently been reported in children with PVI, non-motor outcomes are less common than in APPIS or NAIS (Lõo et al., 2018). It is possible that greater utilization of psychological supports is related to the comparative visibility of PVI-associated motor deficits. In a previous qualitative study of adolescents with cerebral palsy, many individuals reportedly had mental health concerns, often associated with the stress of life with a chronic disability (Hanes et al., 2019). However, some individuals with mild motor impairment described difficulties accessing mental health supports (Hanes et al., 2019). Whether increased utilization of psychological services is related to the specific impacts of PVI, to easier referral for psychological services, or is simply an artifact of the relatively small sample size in Study II, this is an interesting finding that warrants further investigation. Overall, differences in service utilization based on age and stroke subtype indicate that most children and youth in this sample were accessing appropriate supportive services for their developmental stage and specific clinical needs.

Pre-Pandemic Movement Behaviors

Based on pre-pandemic movement behaviors among Canadian children with disabilities (Arbour-Nicitopoulos et al., 2021), most children and youth with perinatal stroke were expected not to meet minimum daily guidelines for MVPA and to exceed daily guidelines for recreational screen time. Due to the lack of research evidence regarding sleep following perinatal stroke, we had no specific hypothesis regarding adherence to sleep guidelines. Most participants were engaged in too much daily screen time and over half were meeting sleep guidelines for their age. However, nearly 95% of participants in Study II were reportedly meeting or exceeding guidelines for daily MVPA, which is substantially greater than previously reported among Canadian children and youth (36.0% meeting MVPA guidelines; Roberts et al., 2017) and among children and youth with disabilities worldwide (19-55%; Arbour-Nicitopoulos et al., 2021; Burghard et al., 2018; Case et al., 2020).

Compared to objective measures of MVPA, like those used by Roberts et al. (2017), parent reports tend to overestimate actual time spent in MVPA by roughly 40 minutes (Colley et al., 2012). When parent-reported pre-pandemic MVPA was adjusted to account for this difference, pre-pandemic daily MVPA (55% meeting guideline) was more consistent with previously reported, actigraphy-based MVPA among Canadian children (Roberts et al., 2017). Sleep time and screen time were not adjusted similarly since previous studies also relied on parent- or self-reported measures for these movement behaviors (Arbour-Nicitopoulos et al., 2021; Roberts et al., 2017). The relative consistency of adjusted parent-reported MVPA with previously reported values suggests that parent-reported pre-pandemic estimates were likely influenced by considerable recall and social desirability bias. The potential influence of these factors on parent estimates for pre-pandemic sleep and screen time should not be underestimated.

Parent reports of movement behaviors tend to report time spent in an activity, rather than time spent at a specific movement intensity, as is captured by objective measures like actigraphy (Adamo et al., 2009; Colley et al., 2012). Therefore, even though parents may have overestimated the time their children spent in actual MVPA, their responses imply that children and youth were routinely engaged in activities that incorporated some degree of MVPA. This may have additional positive implications since most children and youth were primarily participating in physical activity with their peers or on a team. In addition to the many health benefits of physical activity (Carson et al., 2016), participation in team sports has been associated with broad psychosocial benefits, including improved self-esteem, mental health, and social interaction (Eime et al., 2013). Furthermore, physical activity provides a play-based context for improving gross and fine motor skills, which may lead to functional benefits for children with physical disabilities, such as perinatal stroke (Clutterbuck et al., 2019). Finally, emerging evidence indicates that participation in activities which include cognitive or social components, are guided by a supportive mentor, and which build self confidence, such as team sports, may help support improved EFs (Contreras-Osorio et al., 2021; Diamond & Ling, 2019). Therefore, robust participation in physical activity overall, especially alongside peers, is likely of psychosocial and functional benefit to children with perinatal stroke, even if parent reports overestimated MVPA time in this study.

In contrast, most participants in Study II were taking part in far more daily recreational screen time than recommended. Consistent with previous reports that youth with disabilities are more likely to exceed guidelines for screen time (Arbour-Nicitopoulos et al., 2021; Burghard et al., 2018), the proportion of Study II participants meeting daily screen time guidelines (36.4%) was less than the proportion from a nationally representative sample of Canadian youth (49.3%; Roberts et al., 2017). However, a greater proportion of our sample were reportedly meeting daily screen time guidelines (36.4%) than previously reported for Canadian children with disabilities (13.0%; Arbour-Nicitopoulos et al., 2021). As with MVPA, recalled pre-pandemic recreational screen time likely reflects an idealized perception of participants' screen time.

Given that parents likely underestimated their child's actual recreational screen time, it is concerning that nearly two-thirds of children and youth in this sample were reportedly engaged in more screen time than recommended. Although children with disabilities often engage in more screen time than their peers, excessive screen time has been linked with poorer physical and psychosocial outcomes and with worse overall quality of life (Saunders & Valance, 2017). Furthermore, displacement of time for activities which may promote improved functional abilities in favour of screen time may contribute to poorer functional outcomes for children with perinatal stroke. Therefore, the excessive pre-pandemic screen time of children with perinatal stroke is cause for concern and may be hampering some of the robust efforts to support healthy development in children with perinatal stroke.

Changes to Supportive Services During the COVID-19 Pandemic

Access to all supportive services was expected to be negatively impacted during the pandemic. This hypothesis was partially supported; access to allied health services was often negatively affected during the pandemic, whereas access to educational supports appeared to be considerably less affected. Disrupted access to allied health services, particularly to OT and PT services, was broadly reported for children with disabilities in the early phases of the pandemic (April-May 2020: Bertamino et al., 2020; May-July 2020: Murphy et al., 2021; Sutter et al., 2021). However, the consistency of findings from this study with previous reports is particularly concerning given that data collection was conducted between February and November of 2021, over one year into the COVID-19 pandemic. Although some families indicated that their services had returned to usual, this was not the case for many participants. Given that functional abilities and child wellbeing were already suffering for children facing service disruptions in May-July 2020 and that OT and PT services were disproportionately affected compared to other allied health services (Murphy et al., 2021; Sutter et al., 2021), such sustained disruptions may have had substantial impacts on the functional abilities of children and youth with perinatal stroke. It is possible that disrupted access to services contributed to the overall slowed functional development observed for children and youth with perinatal stroke in Study I.

Few allied health services were expected to transition to telepractice, although the necessity of telepractice for continuity of care was highlighted during the initial months of the COVID-19 pandemic (Prvu Bettger et al., 2020). Transition to telehealth occurred more frequently for SLP and psychological services, compared to OT and PT services. This is consistent with the status of research on telerehabilitation interventions before the pandemic. A 2020 systematic review found that telerehabilitation had been robustly investigated for psychological services, whereas the body of research into telerehabilitation for OT and PT services was relatively limited (Camden et al., 2020). Although there have been some conflicting reports of parental satisfaction with telehealth (Masi et al., 2021; Murphy et al., 2021), the general failure of OT and PT services to be offered virtually is unfortunate, as telehealth may have offered an opportunity to mitigate the functional impacts of service disruptions.

Educational supports appeared to be less impacted during the pandemic overall. Since Study II data was not collected during any of the phases of mandated online learning in Alberta, this study likely did not capture disruptions to educational supports which occurred during periods of at-home learning. However, the relative stability of educational supports compared to outpatient allied health supports has been described elsewhere (Murphy et al., 2021). It should be noted that considering previous reports of parental dissatisfaction with educational supports during the pandemic (Murphy et al., 2021), it is unlikely that the relative stability of educational supports was sufficient to mitigate negative outcomes associated with disruptions to allied health services.

Changes to Movement Behaviors During the COVID-19 Pandemic

During the COVID-19 pandemic, significant increases to recreational screen time and significant decreases to MVPA have been widely reported for children and youth (Paterson et al., 2021), including among Canadian children and youth with (Moore et al., 2021b) and without disabilities (Moore et al., 2020, 2021a). Consistent with these previous reports, recreational screen time increased significantly and MVPA decreased significantly during the COVID-19 pandemic for participants in this study. Mid-pandemic sleep, recreational screen time, and overall adherence to movement behaviors in this study were all comparable to values reported for Canadian children and youth with disabilities (Moore et al., 2021b). It is important to note that the increase to recreational screen time reported during the pandemic in this sample did not include time participating in online learning. Although there was no provincial mandate for online learning when data collection for Study II was completed, classrooms have experienced occasional shifts to online learning throughout the 2020-2021 school year due to local COVID-19 outbreaks and difficulties with staffing. Therefore, the total daily screen time of children and youth in this sample is likely considerably higher than the recreational screen time reported here.

Compared to pre-pandemic estimates, weekday sleep time decreased significantly in this study. A recent scoping review reported that most studies described significant increases to sleep duration for children and youth during the COVID-19 pandemic, however, they also noted that changes to sleep were more variable than changes to MVPA or screen time (Paterson et al., 2021). Two studies conducted in Canadian children and youth indicate that changes to sleep time have evolved over time (Moore et al., 2020, 2021a). Though average sleep time increased compared to pre-pandemic estimates in April 2020, by October 2020 average sleep time had decreased compared to the first month of the pandemic (Moore et al., 2020, 2021a). Therefore, it is possible that decreases to sleep time, as observed in this study, may be more common in later waves of the pandemic. Despite these differences, most children and youth with perinatal stroke were reported to still be meeting guidelines for sleep time, which is comparable to reports among other Canadian children and youth (Moore et al., 2020, 2021a, 2021b).

Although parent reported MVPA decreased significantly during the pandemic, reported adherence to MVPA guidelines among the Study II sample (70.6%) was substantially higher than reported elsewhere, despite similar parent reported methods (5-18%; Moore et al., 2020, 2021a, 2021b). Some of the differences in adherence may be related to differences in operationalization of the MVPA guideline provided by Tremblay et al. (2016). Whereas this study considered a reported average daily MVPA time of ≥60 minutes to be adherent to the guideline, the large-scale Canadian studies conducted by Moore et al. (2020, 2021a, 2021b) asked participants how many days per week their child participated in ≥60 minutes of MVPA and considered responses of six or more days to meet the guideline. Some of the discrepancy in MVPA adherence may also be related to the comparatively small sample size and the use of an unvalidated survey designed for this study. Many other studies have used unvalidated, investigator-designed survey measures of movement behaviors throughout the COVID-19 pandemic, yet no other studies (reviewed in Paterson et al., 2021) have reported average MVPA or adherence to MVPA guidelines as high as in this one. Regardless, the fact that children and youth with perinatal stroke experienced significant declines to reported MVPA time during the pandemic is consistent with most other reports of changes to physical activity during the pandemic (Moore et al., 2020, 2021a, 2021b; Paterson et al., 2021).

As with disruptions to supportive services, the consistency of findings from Study II with existing research reflects a worrying persistence of changes to movement behaviors for children with perinatal stroke during later phases of the COVID-19 pandemic. This persistence is supported by the findings of Moore et al. (2020), who found that fewer children and youth were meeting guidelines for sleep and MVPA six months into the pandemic, compared to the first month of the pandemic. Reduced adherence to movement guidelines, as observed during the pandemic, is associated with negative impacts to physical health and psychosocial outcomes (Janssen et al., 2017). Therefore, reduced adherence to movement guidelines one year into the pandemic may place children with perinatal stroke at risk of even further negative functional impacts. Changes to the type of physical activities children and youth in this study were engaged during the pandemic may further compound limitations on the functional benefits being derived from physical activity. During the pandemic, the proportion of children and youth with perinatal stroke primarily participating in physical activity with peers or on teams dropped from over half to just 11%. Participating in physical activity alone or with family does not produce the same psychosocial and potential EF benefits as physical activity in a team or peer-supported environment (Eime et al., 2013). Together, this constellation of changes to movement behaviors reflects a loss of time spent in activities with robust functional and psychosocial benefits for children and youth with perinatal stroke. Since significant changes to movement behaviors coincided with substantial disruptions to supportive services, it is unsurprising that children and youth with perinatal stroke displayed such consistently poor trajectories for functional abilities in Study I. But as children and youth in this study reported decreased engagement in activities which may confer additional benefits to EF, it is even more remarkable that developmental trajectories for EF behaviors were so comparable to those of normative peers .

COVID-19 Impact Ratings and Changes to Supportive Services/Movement Behaviors

More negative parental impact ratings in this study were significantly associated with greater changes to recreational screen time and weekend, but not weekday, MVPA. The COVID-19 pandemic has had disproportionate impacts on populations with previous socio-economic vulnerabilities and changes to movement behaviors appear to be greatest for those groups. For example, children and youth from two-parent households, higher income households, detached homes, and less urban settings all experienced smaller reductions in physical activity time, compared to peers (Paterson et al., 2021). However, associations between parent impact ratings and changes to MVPA and screen time may also be related to parent perceptions of the pandemic. Previous research has illustrated that parental perceptions of the pandemic are important predictors of the impact on their children (Prime et al., 2020; Spinelli et al., 2020). Parents who felt a sense of control and capable of supporting their children during the pandemic reported less perceived stress (Brown et al., 2020) and fewer negative impacts to their child (Morelli et al., 2020; Spinelli et al., 2020). Similarly, among Canadian children and youth with disabilities, parent-rated capacity and opportunity to support healthy movement behaviors were associated with more physical activity and less screen time overall (Moore et al., 2021b). It may be that parents who perceived the pandemic more negatively had less capacity to support healthy movement behaviors for their children, than parents who rated the pandemic more positively. Either way, associations between parent impact ratings and changes to movement behaviors in Study II indicate that Study I participants likely experienced considerable changes to movement behaviors, as 75% of Study I participants rated the pandemic as having had a negative impact on their family.

Limitations

These studies included several key limitations. Participant recruitment for both studies was challenging and may limit generalizability of the results. Only 40.0% of the initial Study I sample was retained at Time 2. Compared both to participants at Time 1 only and to Albertan children with perinatal stroke (Dunbar et al., 2020), the longitudinal sample contained a disproportionately high percentage of children with APPIS. Since APPIS is associated with worse motor (Wu et al., 2004) and EF outcomes compared to other stroke subtypes (Bosenbark et al., 2017), it is likely that outcomes in the longitudinal sample were worse than outcomes among participants at Time 1 only and were not representative of the broader population of children with perinatal stroke. Similarly, the Study I sample was recruited from a single tertiary hospital and disproportionately contained individuals from high socioeconomic backgrounds, which limits generalizability. Likewise, the response rate for Study II (27.2%) was relatively low for clinical research. Therefore, it is possible that study participants differed substantially from non-responders. The low response rate was likely related to the recruitment method for Study II. Potential participants were approached by the study team via email to facilitate easy responding. However, recruitment through email alone is notoriously challenging and it is possible that many of our invitations were never read by the intended individuals.

Participant recruitment during the COVID-19 pandemic was associated with a unique set of challenges. During the pandemic, parents of children with disabilities have experienced a disproportionate increase in caregiving burden due to combined disruptions to supportive services, schooling, and daily routines (Sutter et al., 2021). Therefore, capacity to participate in research studies may be limited, especially among parents of children with the most severe stroke outcomes. As a result, it is possible that the outcomes reported in both studies are not generalizable to the broader population of children with perinatal stroke. Collection of additional demographic information for the Study II sample would been useful to determine the likely generalizability of the sample. Mid-pandemic recruitment challenges were not unique to this study. Other observational studies recruiting parents of children with disabilities during the pandemic have had similarly low response rates as in Study II (e.g., Murphy et al., 2021; Sutter et al., 2021).

Small sample sizes limited the statistical analyses, particularly for Study I. A larger sample size for Study I would have permitted further group-level statistical analyses to be conducted, such as exploring differences in developmental trajectories based on age at assessment, stroke subtype, seizure status, or lesion characteristics. However, small sample sizes are common in research conducted among children with specific and unique neurodevelopmental conditions, especially for longitudinal research. Further, examination of individual trajectories using the RCI methodology was not impacted by power or sample size and generated novel insights into longitudinal changes to functional abilities and EF behaviors for youth with perinatal stroke.

Neither of these studies included a control group. For Study II, inclusion of a typically developing comparison group may have been useful to define base rates of service utilization among the general population and to reduce the impact of bias in recalled pre-pandemic movement behaviors. However, results from Study II were largely compared to robust large-scale studies of movement behaviors among Canadian children and youth with and without disabilities, both before (Arbour-Nicitopoulos et al., 2021; Roberts et al., 2017) and during the COVID-19 pandemic (Moore et al., 2020, 2021a, 2021b). Though findings from Study II show some evidence of social desirability bias and/or “good old days” bias (Gunstad & Suhr, 2001), they are largely consistent with those of previous large-scale Canadian studies. In Study I, parent-rated functional abilities and EF behaviors were compared to age-standardized normative means published in the test manuals. Comparison to normative values is common in clinical neuropsychological research and allowed inferences to be drawn about the abilities of children with perinatal stroke compared to a large, representative sample of age-matched peers. But inclusion of a well-matched, typically developing control group may have minimized confounding of developmental changes among the clinical cohort due to the impact of the COVID-19 pandemic on parent perceptions and on participant’s functional abilities and EF behaviors. Although we planned to control for the impact of the pandemic using parental COVID-19 impact ratings, this was not possible since all the caregivers rated the impact of the pandemic similarly. Given the restricted sample size of Study I, any control group would have been equally small and therefore would have been subject to the same concerns regarding generalizability and representativeness as the clinical cohort.

Since data collection was completed during the pandemic, all data collection was conducted in a remote format to mitigate risk of potential COVID-19 exposure and study design was tailored to limit burden on families. To those ends, both studies relied almost entirely on parent-reported measures. Although parent-reported measures are commonly used in observational research, it is generally considered best practice to combine parent-reported measures with more objective measures when describing EF and movement behaviors. In general, parents often overestimate the amount of time their children spend sleeping and in MVPA and to underestimate time spent sedentary, compared to objective measures (Colley et al., 2012). Discrepancies between parent-reported and objectively measured movement behaviors may arise through a combination of differences in what is being measured and social desirability bias (Adamo et al., 2009; Colley et al., 2012). To minimize social desirability bias in Study II, parents were not informed of the recommendations provided in the 24-hr movement guidelines and questions about movement behaviors did not include predefined response options.

Study II relied on a parent-reported questionnaire developed for this study, rather than a previously validated questionnaire. Use of a previously validated questionnaire was considered, however a suitable questionnaire which encompassed all three relevant domains (allied health services, educational supports, and movement behaviors) could not be found. Likewise, inclusion of more objective measures of movement behaviors, such as actigraphy or activity journals, was rejected to reduce burden on families. Finally, at the time of study design, existing questionnaires measuring the impact of the pandemic were not available, although incorporating an existing questionnaire may have increased the generalizability of Study II findings. Indeed, many studies conducted during the COVID-19 pandemic have relied on previously unvalidated, investigator designed survey measures (Paterson et al., 2021). Although the use of a unique and previously untested questionnaire introduced additional uncertainty to the results from Study II, most findings from Study II were comparable to those of previous studies conducted with more objective and previously validated measures.

In the absence of a comparison group for either study, the use of parent-reported measures within the context of the COVID-19 pandemic introduced additional uncertainty. Even previously validated parent-reported measures depend on parent observations and perceptions of their child’s behavior. During the COVID-19 pandemic, many daily activities shifted to the home environment and parents may have had fewer opportunities to compare their child’s behaviors to those of same-age peers. It is not clear how such social upheaval has impacted the validity of parent rating scales such as the PEDI-CAT and BRIEF2, but the possibility that parent reporting was different during the pandemic than during normal circumstances should not be overlooked. Therefore, Time 2 ratings for Study I should be interpreted with caution and will require replication under more typical circumstances to confirm their validity.

Recollections of pre-pandemic movement behaviors in Study II may have been further affected by the “good old days” bias, which describes the tendency to idealize one’s past health and problems after a trauma, injury, or other negative event (Gunstad & Suhr, 2001). The “good old days” bias has primarily been applied to clinical scenarios with clearly defined pre- and post-event periods, like traumatic brain injury (Iverson et al., 2010). However, given that most participants in this study rated the COVID-19 pandemic as having a negative impact on their families and that pre- and post-pandemic periods can be clearly differentiated, it is likely that the "good old days" bias applied to recalled pre-pandemic movement behaviors in Study II. Despite the many limitations of these studies, both provide novel insights into the experiences of children and youth with perinatal stroke, particularly during the COVID-19 pandemic.

Clinical Implications

Further study with larger sample sizes is needed to confirm that results from this project (particularly Study I) are generalizable, however several key clinical implications can be drawn. Although most participants displayed specific impairments to EF behaviors, most EF behaviors developed at a similar rate to normative peers for the children with perinatal stroke in this sample. Given that the COVID-19 pandemic has heightened stress, increased loneliness, and disrupted healthy routines, the maintenance of a relatively typical developmental trajectory is a testament to the resilience of EF development. Clinically, these findings reinforce the importance of conducting neuropsychological assessments for children with perinatal stroke at early school age, as previously noted by others (e.g., Bosenbark et al., 2018; Li et al., 2022; Westmacott et al., 2009). Completion of such assessments will allow EF deficits to be identified and appropriate interventions/supports put in place during the years where EF development is ongoing, and children are still likely to benefit from enhanced plasticity of EF systems.

Secondly, the functional impacts of perinatal stroke continue to evolve throughout childhood and adolescence. COVID-19-related disruptions to allied health services and healthy movement behaviors likely exacerbated the worsening of functional abilities compared to normative peers reported in Study I. However, the growing gap between the functional abilities of participants in this study and their typically developing peers emphasizes that individuals with perinatal stroke should be followed by rehabilitation services throughout childhood and adolescence, even after the window for early motor interventions has closed. Luckily, results from Study II indicate that most older children with perinatal stroke are still accessing allied health services. But some older children with perinatal stroke will likely require more frequent services, especially in the wake of the COVID-19 pandemic.

In general, children with perinatal stroke appear to have had relatively robust access to multidisciplinary supports in the community prior to the COVID-19 pandemic. Although utilization of psychological services was elevated compared to previous reports (Majnemer et al., 2014; Vyas et al., 2021), utilization remains relatively limited compared other supportive services and it is possible that these findings reflect a temporary increase in utilization of psychological services during the COVID-19 pandemic. Though recommendations for non-motor intervention and/or rehabilitation following perinatal stroke are limited (Teasell et al., 2020), psychological supports have been shown to benefit children with traumatic brain injury and their families (Chapman et al., 2000). Furthermore, parents of children with perinatal stroke have clearly voiced a desire for increased access to psychological supports (Vyas et al., 2021). Clinicians should consider referral to a psychologist for children and/or their families as part of standard multi-disciplinary rehabilitation services for children with perinatal stroke.

Many families have experienced disrupted access to supportive services during the COVID-19 pandemic. Such disruptions may have had functional implications, so increased monitoring of functional abilities is warranted in the short-term. Results from Study II indicated that reasons for service interruptions are multifaceted and likely cannot be addressed by one-size-fits-all solutions. Therefore, clinicians may need to draw on their creativity and work collaboratively to support the ongoing clinical needs of children with perinatal stroke while considering the unique circumstances of individual families.

Most children with perinatal stroke were reportedly engaging in healthy amounts of sleep and MVPA before the pandemic, although many children were engaged in more recreational screen time than recommended. During the COVID-19 pandemic, most children have experienced significant changes to physical activity, sleep, and recreational screen time. These changes to movement behaviors were widely reported throughout the initial lockdowns, early, and later waves of the pandemic (Paterson et al., 2021; Moore et al., 2021a). However, it is important to be aware that movement behaviors may still be affected for children and youth with perinatal stroke. Adherence to guidelines for sleep, MVPA, and screen time are associated with better mental and physical health (Janssen et al., 2017), therefore it may be necessary to offer education on the recommendations included in the 24-hr Movement Guidelines, particularly for recreational screen time, and to offer strategies or resources to help rebuild healthy routines. Emphasis should be placed on increasing daily MVPA and reducing recreational screen time, particularly passive screen time. Parental perceptions of capability to support healthy movement behaviors have also been identified as key determinants of healthy movement behaviors for children with disabilities during the pandemic (Moore et al., 2021b). Therefore, providing education to parents, offering encouragement, and connecting them with helpful resources may be simple but effective strategies to promote a return to healthy movement behaviors.

Future Directions

Study I produced several novel findings regarding long-term development for children with perinatal stroke. However, future studies are needed to determine the replicability of these findings with larger, more representative samples and in the absence of major confounds, like the disruptions caused by the COVID-19 pandemic. Longitudinal study with larger samples would enable trajectories to be compared based on clinical characteristics, including stroke subtype, seizure status, and lesion location, and environmental factors, including socioeconomic status and health system differences.

As with other children and youth, individuals with perinatal stroke have experienced substantial disruptions to service access and movement behaviors during the pandemic. Other researchers have called for comprehensive plans and resources to help rebuild patterns of healthy movement behaviors for children and youth. However, there are very few resources available that address the specific needs of children and youth with disabilities. Even before the pandemic, there was a dearth of information about how *Canada's 24-Hr Movement Guidelines* apply to children and youth with disabilities and how healthy movement behaviors can be achieved for children with disabilities. As the pressure to "return to normal" progresses, research focused on these specific gaps is urgently needed to address the disruptions experienced by children and youth with perinatal stroke and other disabilities during the pandemic.

CONCLUSIONS

Overall, most children with perinatal stroke in Study I displayed slowed development of functional abilities, compared to normative peers, which frequently resulted in clinically significant functional impairments. In contrast, development of EF behaviors was more comparable to that of normative peers, with specific deficits persisting, but not worsening over time. A planned comparison of longitudinal changes based on parental COVID-19 impact ratings was precluded by a small sample size and a strong skew towards negative impact ratings.

Results from Study II indicate that typical pre-pandemic patterns of service use and movement behaviors among children and youth with perinatal stroke likely provide robust environmental supports for functional and EF development, although increasing access to psychological supports and replacing some recreational screen time with other activities may be areas for further optimization. However, many of these beneficial services and routines have been disrupted during the COVID-19 pandemic. Given that the beneficial effects of interventions for EF and functional abilities deteriorate rapidly once consistent practice ends (Diamond & Ling, 2016), it is likely that disruptions to service use and movement behaviors during the pandemic substantially impacted the longitudinal trajectories reported in Study I.

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APPENDIX I: WELLNESS ACTIVITIES QUESTIONNAIRE (WAQ)

Allied Health Services:

1. In the past three years, has your child worked with an occupational therapist (OT)? **Yes** **No**

   a. If yes, how often did your child receive occupational therapy, prior to the COVID-19 pandemic?

   Once a month **Twice a month** **Four times a month** **Other:**

   b. Approximately how long did your child receive occupational therapy?

   One visit **Less than 1yr** **1-2 years** **Other:**

   c. How has the COVID-19 pandemic changed how often your child receives occupational therapy?

   Decreased a lot **Decreased a little** **No change** **Increased a little** **Increased a lot**

   d. How has the COVID-19 pandemic changed the way your child receives occupational therapy?

   Changed to Tele-Practice (eg. over the phone, over Zoom, etc.) **No change** **Other:**

   e. Has the COVID-19 pandemic changed your child's access to occupational therapy in any other ways?

   ____

   ____

2. In the past three years, has your child worked with a physical therapist (PT)? **Yes** **No**

    a. If yes, how often did your child receive physical therapy, prior to the COVID-19 pandemic?

    Once a month **Twice a month** **Four times a month** **Other:**

    b. Approximately how long did your child receive physical therapy?

    One visit **Less than 1yr** **1-2 years** **Other:**

    c. How has the COVID-19 pandemic changed how often your child receives physical therapy?

    Decreased by a lot **Decreased by a little** **No change** **Increased by a little** **Increased by a lot**

    d. How has the COVID-19 pandemic changed the way your child receives physical therapy?

    Changed to Tele-Practice (eg. over the phone, over Zoom, etc.) **No change** **Other:**

    e. Has the COVID-19 pandemic changed your child's access to physical therapy in any other ways?

    ____

    ____

3. In the past three years, has your child worked with a speech language pathologist (SLP)? **Yes** **No**

    a. If yes, how often did your child receive speech/language therapy, prior to the COVID-19 pandemic?

    Once a month **Twice a month** **Four times a month** **Other:**

b. Approximately how long did your child receive speech/language therapy?

One visit **Less than 1yr** **1-2 years** **Other:**

c. How has the COVID-19 pandemic changed how often your child receives speech/language therapy?

Decreased by a lot **Decreased by a little** **No change** **Increased by a little** **Increased by a lot**

d. How has the COVID-19 pandemic changed the way your child receives speech/language therapy?

Changed to Tele-Practice (eg. over the phone, over Zoom, etc.) **No change** **Other:**

e. Has the COVID-19 pandemic changed your child's access to speech/language therapy in any other ways?

____

____

4. In the past three years, has your child worked **Yes** **No** with a psychologist?

a. If yes, how often did your child receive psychological services, prior to the COVID-19 pandemic?

Once a month **Twice a month** **Four times a month** **Other:**

b. Approximately how long did your child receive psychological services?

One visit **Less than 1yr** **1-2 years** **Other:**

c. How has the COVID-19 pandemic changed how often your child receives psychological services?

Decreased by a lot **Decreased by a little** **No change** **Increased by a little** **Increased by a lot**

d. How has the COVID-19 pandemic changed the way your child receives psychological services?

Changed to Tele-Practice (eg. over the phone, over Zoom, etc.)	**No change**	**Other:**

e. Has the COVID-19 pandemic changed your child's access to psychological services in any other ways?

____

____

5. Has your child ever visited a sleep clinic or sleep specialist? **Yes** **No**

   a. If yes, please tell us about it in a few words:

____

6. Has your child ever participated in a program designed to improve their behavior or worked with a behavior specialist? **Yes** **No**

   a. If yes, please tell us about it in a few words:

____

7. Overall, how has the COVID-19 pandemic affected how often your child is accessing the health services listed above?

Decreased by a lot	**Decreased by a little**	**No change**	**Increased by a little**	**Increased by a lot**

8. Overall, how has the COVID-19 pandemic changed your child's access to the health services listed above?

____

____

School:

9. Did your child attend an early education or preschool program? **Yes** **No**
    a. If yes, please tell us about the type of preschool program your child attended in a few words (eg. Montessori, Reggio, play-based, bilingual, or inclusive program [like 100 Voices]):

    b. Please tell us how often your child attended this program, by circling below:

       5 days/week **3 days/week** **2 days/week** **Other:**

    c. How long did your child attend this program?

       1 school year **2 school years** **3+ school years** **Other:**

10. Did your child receive any of the following early education supports? (circle all that apply)

    Program Unit Funding (PUF) **Specialized Services** **Developmental Supports**

    a. If so, how long did your child receive these services:

       1 year **2 years** **3 years** **Other:**

    b. How often did your child receive these services?

       1x/week **2x/week** **3x/week** **Other:**

11. Does your child typically receive any modified programming or supports at school? **Yes** **No**
    a. If yes, please tell us about it in a few words:

12. Does your child typically have an aide in their classroom? **Yes** **No**
    a. If yes, how often is the aide there?

All day, 5 days/week **A few days a week** **A few hours a week**

13. Overall, how has the COVID-19 pandemic affected your child's access to educational supports?

Decreased by a lot	**Decreased by a little**	**No change**	**Increased by a little**	**Increased by a lot**

14. Overall, how has the COVID-19 pandemic changed your child's access to educational supports?

____

____

Lifestyle & Physical Activity:

15. Has your child had any opportunities to meet other children with perinatal stroke (e.g. Summer camps, peer support groups)? **Yes** **No**
    a. If yes, please tell us about it in a few words:

____

16. Have you or your child's other caregiver(s) had the opportunity to meet with other caregivers of children with perinatal stroke (eg. Support groups, parent education programs)? **Yes** **No**
    a. If yes, in what format did you meet with other caregivers?

       In Person **Online** **Other**

    b. If yes, please tell us about it in a few words:

____

17. What are some physical activities that your child enjoys? Circle the ones they like or write in your own.

Walking
Running
Hiking
Biking
Skiing
Snowboarding
Skating
Dancing
Soccer
Basketball
Football
Hockey
Swimming
Going to the Gym
____
____

18. Prior to the COVID-19 pandemic, what physical activities did your child do most often?

____

19. Prior to the COVID-19 pandemic, who did your child usually do these activities with?

Alone **With Family** **With Friends** **On a Team**

20. During the COVID-19 pandemic, what physical activities does your child do most often?

____

21. During the COVID-19 pandemic, who does your child usually do these activities with?

Alone **With Family** **With Friends** **On a Team**

22. Does your child participate in any of the following activities which incorporate mindfulness or visualization practice?

Tae Kwon Do
Karate
Yoga
Meditation
Other: ____________
Other: ____________

Questions 23-25 will ask you to consider how your child spends their time ON AN AVERAGE DAY, both prior to and during the COVID-19 pandemic.

23. Please indicate how many hours, out of 24, your child spends in each of the following activities on an average day, prior to and during the COVID-19 pandemic.

ON A SCHOOL DAY		
Activity	**Hours Spent**	
	Before COVID-19	**During COVID-19**
Sleep: uninterrupted sleep		
Step: structured and unstructured light physical activity (eg. Walking the dog, playing outdoors)		
Sweat: moderate to vigorous physical activity (eg. hockey, biking, dancing)		
Sit: time spent sitting, including recreational screen time		
Total	**24 hrs**	**24 hrs**

ON A WEEKEND DAY		
Activity	**Hours Spent**	
	Before COVID-19	**During COVID-19**
Sleep: uninterrupted sleep		
Step: structured and unstructured light physical activity (eg. Walking the dog, playing outdoors)		
Sweat: moderate to vigorous physical activity (eg. hockey, biking, dancing)		
Sit: time spent sitting, including recreational screen time		
Total	**24 hrs**	**24 hrs**

24. Please indicate how many hours your child spends engaged in the following recreational screen time activities on an average day, both before and during the COVID-19 pandemic.

Recreational Screen Time Activity	**Hours Spent**	
	Before COVID-19	**During COVID-19**
Watching Videos (TV or Online)		
Texting/Social Media (Instagram, TikTok, etc)		
Playing Video Games (on any kind of device)		
Other (please specify)		
Total Recreational Screen Time		

25. What do you perceive has been the overall impact of the COVID-19 pandemic on your family?

Profound negative impact	**Slight negative impact**	**No change to my family**	**Slight positive impact**	**Profound positive impact**

Note: The WAQ was developed from January to August 2020. Multiple rounds of internal review (involving the graduate student and supervisor/principal investigator) were conducted from January to March 2020. Several rounds of external review, involving consultation with other APSP and N-APSP investigators, were conducted from March to August 2020. This interdisciplinary team includes researchers and clinicians with expertise in perinatal stroke, including pediatric neurologists, clinical psychologists, a developmental pediatrician, and a neuropsychologist. Pilot testing and consultation with a small sample of caregivers was discussed, however, delays due to the COVID-19 pandemic meant this was not feasible within project timelines. In the absence of formal pilot testing, the WAQ was first administered to the eight caregivers from Study I. Their responses were closely inspected to ensure that all survey items were responded to appropriately. No question items were changed based on the response patterns of Study I participants.