Neurocognitive Outcome and Psychological Adjustment Following Pediatric Ischemic and Hemorrhagic Stroke

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Abstract

Pediatric stroke is an important cause of acquired brain injury in youth associated with neurological sequelae, including complex neurocognitive impairments. Neurocognitive deficits may impact psychological adjustment post-injury by hindering emotional and behavioural regulation, psychosocial functioning, academic advancement, quality of life, and mental health. Despite awareness of the devastating and long-term sequelae following pediatric stroke, research in this domain is lacking. Using a mixed methods approach, my doctoral dissertation contains two clinical studies that address these gaps. Study 1 used a cross-sectional design to investigate the role of eight factors identified in the literature as possible predictors of neurocognitive outcome in pediatric stroke. Ninety-two patients with a history of pediatric stroke participated in this project. Statistical analyses examined relationships between each predictor and neurocognitive outcome measures. Results indicated that large lesions, ischemic stroke, and lower socioeconomic status were associated with worse neurocognitive outcomes compared to small to medium lesions, hemorrhagic stroke, and higher socioeconomic status. Graphs showed U-shaped trends suggesting worse outcomes across most neurocognitive domains when stroke occurred at five to ten years of age. Participants with seizures had more severe executive functioning impairments than participants without seizures. We found little to no evidence of associations between the other predictors and neurocognitive outcomes. Study 2 used an inductive qualitative methodology to provide a personal lens through which to understand the day-to-day impact of neurocognitive impairments, among other sequelae, on adjustment following stroke. Fourteen adolescents and young adults with a history of childhood stroke were interviewed one-on-one to share their lived experience regarding adjustment and coping. Following thematic analysis, five overarching themes were identified: (1) Processing the

Story, (2) I've Changed, (3) Loss and Challenges, (4) Keys to Recovery, and (5) Adjustment and Acceptance. Findings underscored a need for mental health support for survivors of stroke, as well as important strengths and sources of support drawn upon by survivors. Overall, this dissertation contributed to the advancement of developmental neuropsychology by providing novel insights into neurocognitive outcomes and adjustment following pediatric stroke. Findings should inform clinical practice and the development of services aimed at enhancing recovery and fostering optimal development for youth with stroke.

Pour Charlotte.

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Chapter 1: Overview of Pediatric Stroke

Stroke is an important cause of acquired brain injury in youth and has become increasingly recognized as a significant source of childhood disability (Ferriero et al., 2019). A basic understanding of pediatric stroke is necessary to appreciate the rationale for each study in the current dissertation. This overview presents the definition, prevalence, etiology, risk factors, clinical presentation, and sequelae of pediatric stroke.

Definition and Prevalence

Stroke is defined as a cerebrovascular event of acute onset characterized by a significant disruption of blood flow in the brain due to infarction or hemorrhage. Ischemic stroke includes arterial ischemic stroke and venous infarction caused by cerebral sinovenous thrombosis, while hemorrhagic stroke refers to a bleed from a ruptured vessel or artery. A stroke is deemed pediatric if it occurs perinatally (i.e., 28 weeks' gestation to 28 days after birth) or during childhood (i.e., 29 days old to 18 years old). Perinatal stroke occurs in up to 1 per 2,700 live births (Agrawal et al., 2009) and is more likely to be ischemic than hemorrhagic (deVeber et al., 2017; Ferriero et al., 2019). Childhood stroke affects between 1 and 13 children out of 100,000 (Ferriero et al., 2019; Tsze & Valente, 2011), with ischemic and hemorrhagic strokes occurring at equal rates (Boulouis et al., 2019; Singhal et al., 2013).

Neurophysiology

Understanding the neurophysiology of stroke is key to appreciating its impact on the developing brain. In a hemorrhagic stroke, a ruptured blood vessel causes blood accumulation, which compresses brain tissue. Excessive amounts of calcium present in the overflowing blood lead to cell death. Hemorrhagic stroke is often classified based on location, as intracerebral, meningeal, or intraventricular. The most common subtype is intracerebral, also called intraparenchymal, wherein bleeding occurs within the brain tissue. In a meningeal hemorrhage, bleeding occurs in the epidural, subdural, or subarachnoid areas between the brain and the skull, while an intraventricular hemorrhage takes place in one of the four brain ventricles.

Ischemic stroke occurs when a mass or narrowing vessel causes a restriction of blood flow. The deprivation of blood prevents oxygen and glucose from reaching brain tissues, causing cell death. A thrombotic ischemic stroke occurs when a blood clot (i.e., a thrombus) forms locally and blocks the blood flow, while an embolic stroke occurs when an intravascular mass (i.e., an embolus) detaches from its point of origin and lodges itself into an artery or vessel, occluding blood flow.

Occasionally, an ischemic stroke can weaken blood vessels and cause them to rupture, leading to a secondary hemorrhage. A hemorrhagic stroke can also cause a secondary ischemic infarct through mass effect from the bleeding or, in the context of a subarachnoid hemorrhage, through an arterial spasm that leads to vasoconstriction (Fullerton et al., 2007).

Etiology and Risk Factors

Neonates and children have a more diverse and larger number of risk factors for stroke than adults do, the latter being predominated by hypertension, diabetes, and atherosclerosis (Tsze & Valente, 2011). Furthermore, pediatric hemorrhagic and ischemic strokes are susceptible to different risk factors.

Vascular malformations, most commonly arteriovenous malformations but also aneurysms and cavernous malformations, account for most pediatric hemorrhagic strokes (Boulouis et al., 2019; Ferriero et al., 2019; Fullerton et al., 2007; Guédon et al., 2018; Liu et al., 2015; Lo et al., 2008; Singhal et al., 2013). Hemorrhage can also be triggered by intracranial vascular diseases, especially Moyamoya disease-associated angiopathy and sickle cell disease-associated angiopathy, though these are more often associated with ischemic stroke (Earley et al., 1998; Kim et al., 2010). Bleeding disorders (e.g., hemophilia) represent another risk factor for hemorrhagic stroke, predominantly in the first years of life (Boulouis et al., 2019). Causes of brain hemorrhage in newborns commonly include coagulopathy, thrombocytopenia, and trauma (Ferriero et al., 2019). The frequent use of anticoagulation drugs prescribed to youth with cardiac diseases increases the risk of hemorrhage (Giang et al., 2018). In rare cases, tumours have caused hemorrhagic stroke (Boulouis et al., 2019). Lastly, about 10% of pediatric hemorrhagic strokes are idiopathic, or unexplained (Ferriero et al., 2019).

In infants, risk factors for ischemic stroke can be maternal and neonatal (Ferriero et al., 2019). Maternal factors include a history of infertility, chorioamnionitis, oligohydramnios, premature rupture of membranes, vacuum extraction, emergency caesarean section, coagulation disorders, and preeclampsia (Lee et al., 2005). Neonatal factors include thrombophilia, cardiac lesions, coagulation disorders, infection, trauma, and asphyxia (Günther et al., 2000; Nelson & Lynch, 2004; Rodan et al., 2012). The leading risk factor for ischemic stroke in childhood is arteriopathy, most commonly focal cerebral arteriopathy (Amlie-Lefond et al., 2009; Beslow & Jordan, 2010; Ganesan et al., 2003; Mackay et al., 2011), as well as Moyamoya disease-associated angiopathy, sickle cell disease-associated angiopathy, vasculitis, and arterial dissection (Ganesan et al., 2003; Mackay et al., 2011). Other risk factors of ischemic stroke include cardiac disorders (e.g., congenital heart disease), acute systemic conditions (e.g., dehydration, lasting fever), and infection (e.g., meningitis) (Fullerton et al., 2015; Mackay et al., 2011). At least 10% of ischemic infarctions are idiopathic (Greenham et al., 2016).

Youth with ischemic stroke are likely to have multiple risk factors (Mackay et al., 2011) and are at increased risk of recurrence, with rates nearing 50%, compared to those with hemorrhagic stroke, whose recurrence rates are about 10% (deVeber et al., 2000; Fullerton et al., 2007).

Clinical Presentation

Symptoms at onset of pediatric stroke depend on a variety of factors, such as the stroke type and age of the child. Newborns with ischemic stroke often present with focal motor seizures, which can sometimes go unnoticed because of resemblance to normal infant movements (deVeber et al., 2017; Grunt et al., 2015; Kirton et al., 2010). A number of cases of perinatal stroke are diagnosed prior to birth, when signs of encephalopathy are detected on routine prenatal ultrasounds (Ferriero et al., 2019). Lastly, some young children receive brain imaging because they present with early handedness, motor asymmetry, delayed motor milestones, or epilepsy, which leads to the diagnosis of a remote infarction presumed to have occurred perinatally (Golomb et al., 2001; Grunt et al., 2015; Kirton et al., 2008).

Childhood stroke symptomatology differs from infant stroke symptomatology. In cases of hemorrhagic stroke, headache is frequently reported at onset, as well as vomiting, altered mental status, and seizures (Liu et al., 2015; Yock-Corrales et al., 2011). Some children may experience transient or subtle symptoms such as migraine or irritability (Roach et al., 2008). Youth with ischemic stroke tend to present with focal limb weakness, facial weakness, and speech disturbance (Yock-Corrales et al., 2011).

Neuroprotective intensive care and hyperacute management strategies are crucial for best clinical outcomes following pediatric stroke (Roach et al., 2008). However, delays in diagnosis are common, limiting opportunities for rapid medical intervention (Braun et al., 2006; Cárdenas et al., 2011). One study found that time from clinical onset to first medical contact averaged 28.5 hours, and the time to diagnosis of stroke averaged 35.7 hours (Gabis et al., 2002). Several aspects have been posited to contribute to this delay: low overall incidence of pediatric stroke, which leads health care providers to underestimate the probability of stroke; heterogeneity of etiology and risk factors; heterogeneity and non-specificity of presentation symptoms; challenges with recognizing mild signs, particularly in infants; large number of differential diagnoses of more common disorders, such as migraine; and challenges with access to neuroimaging (Bonfert et al., 2018; Cárdenas et al., 2011; Roach et al., 2008).

Mortality and Sequelae

Stroke is among the top 10 causes of death in the pediatric population (Greenham et al., 2016). Older studies have suggested mortality rates up to 30% (Blom et al., 2003; Lanthier et al., 2000; Lynch & Han, 2005), but rates have declined over the past decades (Fullerton et al., 2002; Krishnamurthi et al., 2015; Mallick et al., 2010). Possible reasons include decline of risk factors, advances in diagnostics, new treatment options, and better intensive care (Kopyta et al., 2021). More recent studies have reported mortality rates around 4-5% (Blauwblomme et al., 2014; deVeber et al., 2017; Fox et al., 2012; Fullerton et al., 2007). Mortality rates vary considerably across studies, partly because death following stroke is often attributable to an underlying condition rather than the stroke itself.

Pediatric stroke is an important cause of childhood disability (Ferriero et al., 2019). Most survivors suffer long-term neurological deficits that can span a multitude of cognitive, motor, sensory, and visual impairments (Beslow et al., 2013; Blom et al., 2003; Cárdenas et al., 2011; deVeber et al., 2000, 2017; Fitzgerald et al., 2006; Greenham et al., 2016; Grunt et al., 2015; Lynch & Han, 2005; Mercuri et al., 2003; Roach et al., 2008). In regard to cognitive sequelae, pediatric stroke has been shown to hinder functioning across a wide range of neuropsychological domains, including language, executive functioning, attention, memory, visuospatial abilities, and processing speed (Allman & Scott, 2013; Bosenbark et al., 2018; Champigny et al., 2020; Cruz, 2001; Everts et al., 2008; Härtel et al., 2004; Jacomb et al., 2018; Max, 2004; Murphy et al., 2017; Peterson et al., 2019; Rivella & Viterbori, 2021; Westmacott et al., 2009, 2010). A key difference between children and adults is that pediatric stroke may result in a decreased ability to develop skills rather than a loss of acquired skills (Greenham et al., 2016). Neurocognitive outcome is contingent upon many factors and interactions between factors, and scientists have called for further research to elucidate predictors (Fuentes et al., 2016). In regard to motor impairments, these occur in 50% to 80% of children with stroke, with common conditions including hemiplegia and hemidystonia (Blom et al., 2003; de Schryver et al., 2000; deVeber et al., 2000; Ganesan et al., 2000; Tibussek et al., 2015). Sensory impairments, such as sensory processing disorder, are also common following stroke (Giudice et al., 2019). Visual impairments, such as visual field defects and reduced acuity, arise, too, but rates are lesser known (Luckman et al., 2020). Lastly, between 15% and 25% of youth are diagnosed with a seizure disorder following stroke (Beslow et al., 2013; Blom et al., 2003; deVeber et al., 2000; Murdaugh et al., 2018).

Pediatric stroke hampers emotional, behavioural, and psychosocial development (Anderson et al., 2014; Gomes et al., 2014; Gordon et al., 2015; Greenham, Anderson, Cooper, et al., 2017; Greenham, Anderson, Hearps, et al., 2017; Lo, Gordon, Hajek, Gomes, Greenham, Perkins, et al., 2014; O'Keeffe et al., 2012, 2017; Steinlin et al., 2004). Studies have documented increased rates of psychopathology, including attention-deficit/hyperactive disorder and learning disabilities (Champigny et al., 2020; Max et al., 2003; Williams et al., 2017, 2018) as well as anxiety, depression, and post-traumatic stress disorder (Badar et al., 2020; Lehman et al., 2020;

Max et al., 2002; Westmacott et al., 2018). Scientists have called for further study regarding psychological outcomes following pediatric stroke (Ferriero et al., 2019).

Conclusion

Despite awareness of devastating and long-term sequelae following pediatric stroke, research in this domain is lacking, underserving this medical population. My doctoral dissertation contains two clinical studies that seek to remedy these gaps in the scientific literature in order to improve clinical outcomes for families impacted by pediatric stroke. Study 1 uses a cross-sectional design to investigate possible predictors of neurocognitive outcome in pediatric stroke. Study 2 examines psychological adjustment following stroke in childhood using an inductive qualitative approach. Summary of results, clinical implications, limitations, and future directions are discussed in the last chapter.

Chapter 2: Aims and Hypotheses

Study 1

The overarching goal of this study was to examine the impact of potential predictors of neurocognitive outcomes on a series of neuropsychological measures in patients with a history of pediatric stroke. Predictors included: age at stroke; stroke type (i.e., hemorrhagic or ischemic); lesion size; lesion location; time since stroke; neurologic severity; seizures post-stroke; and socioeconomic status. Neurocognitive abilities assessed included: abstract reasoning, verbal reasoning, working memory, processing speed, learning ability, long-term memory, attention, visuomotor integration, and executive functioning.

Aim 1

Our first aim was to examine the impact of age at time of stroke on neurocognitive outcome. In line with developmental neuropsychology theory led by Maureen Dennis' (2000) work, the developmental stage of the brain at the time of injury influences neurocognitive outcome. However, research findings are conflicted regarding the shape and direction of that relationship.

The dominant position for many years was the plasticity hypothesis, which emphasizes the young brain's ability to reorganize itself (Abgottspon et al., 2022; Max et al., 2010). The plasticity hypothesis was based on the Kennard principle, which posits a negative linear relationship between age at time of injury and outcome (Dennis, 2010). The Kennard principle is a simplified interpretation (Fitch et al., 2013) of the research led by Dr. Margaret Kennard, a neurologist in the 20th century and one of the earliest scientists to defend the idea of neuroplasticity (Dennis, 2010). Over time, as associations were uncovered between younger age at stroke and worse cognitive outcomes, consensus shifted towards the vulnerability hypothesis, which focuses on the developing brain's vulnerability to injury (Everts et al., 2008; Jacomb et al., 2018; Max et al., 2010; Peterson et al., 2019; Studer et al., 2014; Westmacott et al., 2010). Recent studies now support the idea that both plasticity and vulnerability mediate neurocognitive outcome (Anderson et al., 2011).

In accordance with contemporary scientific literature, we hypothesized that (1) neurocognitive outcome in youth with perinatal stroke and childhood stroke would differ and (2) there would be a polynomial quadratic relationship between age at onset and neurocognitive outcome in youth with childhood stroke. Given the mixed findings in the literature, we did not have hypotheses regarding the concavity of the polynomial relationship (i.e., whether it would show a U shape or a reverse U shape) nor the age at which the inflection points would centre.

Aim 2

Our second aim was to investigate the role of stroke type in neurocognitive outcome. Despite accounting for about half of all pediatric strokes, hemorrhagic stroke has received considerably less attention in research than ischemic stroke (Fullerton et al., 2003; Murphy et al., 2017; Yvon et al., 2018). Scientists have called for more studies comparing stroke types (Boulouis et al., 2019; Fuentes et al., 2016). Given the lack of evidence available, we did not postulate hypotheses regarding neurocognitive differences between youth with ischemic and hemorrhagic stroke.

Aim 3

We aimed to replicate previous findings regarding the impact of lesion size on neurocognitive outcome following ischemic stroke, and to examine its impact in a hemorrhagic stroke context which has been less extensively studied. Lesion size relative to total brain volume has consistently been identified as a predictor, with larger lesions associated with worse neurocognitive outcome compared to small and medium lesions (Abgottspon et al., 2022; Bartha-Doering et al., 2021; Bosenbark et al., 2017; Everts et al., 2008; Hajek et al., 2014; Kornfeld et al., 2017; Long et al., 2011; Westmacott et al., 2010). Our hypotheses reflect these findings.

Aim 4

Our fourth aim was to elucidate whether lesion location has an impact on neurocognitive outcome. We chose to examine lesion location in three ways, in line with how it has been defined across studies.

The first grouping is laterality. Many recent pediatric studies have found no evidence of an effect of laterality on cognitive outcome (Abgottspon et al., 2022; Avila et al., 2010; Ballantyne et al., 2007; Bosenbark et al., 2017; Champigny et al., 2020; Everts et al., 2008; Jacomb et al., 2018; Long et al., 2011; Max, 2004; O'Keeffe et al., 2014; Peterson et al., 2019). In line with these results, we hypothesized that lesion laterality would not predict neurocognitive outcome.

We then chose to classify lesion location based on the structures impacted by the stroke (i.e., cortical, subcortical, combined), reflecting the categories used by many neuropsychological studies on stroke. Combined cortical-subcortical lesions have been found to be more detrimental than cortical- or subcortical-only lesions (Fuentes et al., 2016; Hajek et al., 2014; Lo et al., 2013; Long et al., 2011; Studer et al., 2014; Westmacott et al., 2010). We hypothesized that our findings would support what has been reported in previous studies.

Lastly, we aimed to investigate location by comparing infratentorial and supratentorial regions. Hemorrhage originating in the infratentorial region of the brain worsens outcome, as demonstrated in studies of adults with stroke (Hemphill et al., 2001, 2009). We hypothesized that youth with stroke in the infratentorial region would score significantly lower on neurocognitive measures compared to youth with stroke in the supratentorial region.

Aim 5

We aimed to examine the role of time since stroke on neurocognitive outcome. Some studies have suggested that the extent of cognitive deficits may not be apparent until years post injury and that some impairments emerge in school age (Anderson et al., 2011; Levine et al., 2005; van Buuren et al., 2013; Westmacott et al., 2009); others have found that cognitive impairments remain stable (Allman & Scott, 2013; Ballantyne et al., 2008; Jacomb et al., 2018; Kornfeld et al., 2017; Murphy et al., 2017; O'Keeffe et al., 2014; van Buuren et al., 2013); and others have noted improvements over time (Avila et al., 2010; Everts et al., 2008; Murphy et al., 2017). Given the mixed findings in the literature, we did not have a priori expectations regarding the associations between time since stroke and neurocognitive outcome.

Aim 6

We aimed to assess the role of neurologic severity on neurocognitive outcome. Neurologic severity has been associated with worse neurocognitive outcome following pediatric ischemic stroke (Hajek et al., 2014; Lo, Gordon, Hajek, Gomes, Greenham, Anderson, et al., 2014; Studer et al., 2014). To our knowledge, there are no published studies examining the relationship between neurologic severity and neurocognitive outcome following pediatric hemorrhagic stroke. We hypothesized that neurologic severity would predict neurocognitive outcome in both ischemic and hemorrhagic groups.

Aim 7

We aimed to evaluate the impact of seizures on neurocognitive outcome. Seizures following pediatric stroke have been associated with worse cognitive outcome (Avila et al., 2010; Ballantyne et al., 2007, 2008; Bosenbark et al., 2017; Fuentes et al., 2016; O'Keeffe et al., 2014; Studer et al., 2014; van Buuren et al., 2013; Vojcek et al., 2022). Youth with epilepsy have notable difficulties with executive functioning skills and are at increased risk for attention-deficit hyperactivity disorder (Bolk et al., 2022). We hypothesized that youth with seizures post-stroke would show worse neurocognitive outcome than their peers without seizures, especially on measures of executive functioning.

Aim 8

We aimed to explore associations between socioeconomic status (SES) and neurocognitive outcome following pediatric stroke. SES positively predicts neurological outcome in this population (Fullerton et al., 2015; Jordan et al., 2018). To date, only one research team has examined SES and neurocognitive outcome following pediatric stroke. In a sample of 18 youth with a history of unilateral arterial ischemic stroke, Bartha-Doering and colleagues (2021) found that SES was the strongest predictor of neurocognitive outcome, more than clinical stroke-related factors. These findings highlight the need to further investigate SES as a potential predictor, including for patients with bilateral lesions and hemorrhagic stroke; we aimed to contribute to the development of this field of study. We hypothesized that SES would positively influence neurocognitive outcome in our sample.

Overall, neurocognitive outcomes following pediatric stroke are a challenging area of study because they are contingent upon many factors and interactions and because a large sample size is required to analyze multiple predictors with appropriate statistical power. This first dissertation study examines eight possible predictors of neurocognitive outcome in a sample of 92 patients with a history of pediatric stroke.

Study 2

The overarching goal of the second study in this dissertation was to shed light on the processes involved in psychological adjustment to stroke through the use of qualitative health research. In the context of this study, adjustment is defined as the gradual process of adaptation that occurs as a person copes with sudden changes in their lives (Taylor et al., 2011).

An experiential qualitative paradigm was chosen, which is an exploratory, open-ended methodology that organizes data using an interpretive framework to express the experiences of participants according to their own interpretations (Clarke & Braun, 2013). In line with the data-driven nature of this type of qualitative analysis, there were no a priori hypotheses.

Aim 1

The primary aim of Study 2 was to explore the lived experiences of youth with stroke. Qualitative health research benefits clinical practitioners conceptually by providing a lens to gain insight into lived experience with a specific health condition (Jack & Phoenix, 2022). In the adult stroke literature, certain themes related to adjustment post-stroke have consistently appeared across qualitative studies, such as difficulties accepting a changed reality and disruptions in social relationships (Ford et al., 2021; Gulek-Bakirci, 2022; Large et al., 2020). The experience of living through a stroke has not yet been examined qualitatively from the perspective of affected youth, representing an important gap in the literature that this study sought to fill. We conceptualized our study with this goal in mind because understanding what patients go through on an individual level is key to practicing with compassion and effectiveness.

Qualitative health research has been increasingly recognized as a valuable methodology in health sciences and an important reason for this is that findings have direct clinical implications; they provide insight about patient priorities and have the potential to inform changes in clinical care and support (Jack & Phoenix, 2022). For example, in the case of the adult stroke literature, medical professionals commonly used the bereavement model as a framework through which to view stroke adjustment, and this contrasted with survivors' tendency to adjust to their reality in goal-oriented ways (Alaszewski et al., 2004; Scobbie et al., 2021). Qualitative health research shed light on the experiences of survivors, which gave clinicians the opportunity to align their attitudes with that of their patients and thus better support their rehabilitation (Alaszewski et al., 2004; Scobbie et al., 2021).

Two studies have used a qualitative health methodology to investigate the lived experiences and needs of families impacted by childhood stroke, both involving interviews with caregivers (McKevitt et al., 2019; Soufi et al., 2017). According to these studies, caregivers felt unprepared for their child's social, emotional, behavioural, and cognitive challenges, and the hidden burdens associated with long-term sequelae (McKevitt et al., 2019; Soufi et al., 2017). Because there may be differences in how parents and children experience stroke, it is important to hear from affected youth directly regarding adjustment and coping.

Aim 2

The second aim of this study was to identify positive outcomes following pediatric stroke. Positive psychological outcomes have been identified in survivors of acquired and traumatic brain injury (Gould & Ponsford, 2015; Grace et al., 2015; Hawley & Joseph, 2008; McGrath & Linley, 2009; Ownsworth & Fleming, 2011; Pais-Hrit et al., 2020; Powell et al., 2012); for example, a commonly reported positive outcome is "post-traumatic growth," defined as a positive change in self following a crisis (Tedeschi & Calhoun, 2004). An improved understanding of positive outcomes following pediatric stroke may help clinicians in facilitating their patients' adjustment and empowering them to cope with long-term sequelae.

In conclusion, psychological adjustment following pediatric stroke has not yet been examined from the perspective of affected youth. This study addresses this gap in the literature through the use of an inductive qualitative framework, with the participation of 14 patients with a history of childhood stroke.

Chapter 3: Predictors of Neurocognitive Outcome in Pediatric Ischemic and Hemorrhagic Stroke

Publication Status and Author Contributions

The following chapter is based on a manuscript which, as of August 2022, has been submitted for publication in a peer-reviewed scientific journal and is awaiting a decision from the editorial office. Currently, the reference for this manuscript is as follows:

Champigny, C.M., Feldman, S.J., Beribisky, N., Desrocher, M., Isaacs, T., Krishnan, P., Monette, G., Dlamini, N., Dirks, P., & Westmacott, R. (2022). Predictors of neurocognitive outcome in pediatric ischemic and hemorrhagic stroke. [Manuscript submitted for publication]. Department of Psychology, York University.

Claire Champigny, the first author, led research efforts spanning study conceptualization, application to the Research Ethics Boards of the Hospital for Sick Children and York University, participant recruitment and data collection, analysis and interpretation of data, and writing the manuscript for publication.

Abstract

Objective: This clinical study aimed to examine the impact of eight predictors of neurocognitive outcome following pediatric stroke (i.e., age at stroke, stroke type, lesion size, lesion location, time since stroke, neurologic severity, seizures, and socioeconomic status) on neurocognitive outcomes (i.e., abstract reasoning, verbal reasoning, working memory, processing speed, learning, long-term memory, attention, visuomotor integration, and executive functioning).

Method: This study used a cross-sectional design. Participants with pediatric stroke (n=92) were administered neuropsychological tests and questionnaires. Hospital records were accessed for medical history. Spline regressions, one-way analysis of variance, Welch's t-tests, and simple linear regressions examined associations between predictors and outcome measures.

Results: Large lesions, ischemic stroke, and lower SES were associated with worse neurocognitive outcomes compared to small-medium lesions, hemorrhagic stroke, and higher SES, across most neurocognitive domains. Graphs examining age at stroke showed U-shaped patterns suggesting worse outcome across most domains when stroke occurred at 5 to 10 years of age. Participants with seizures had more severe executive functioning impairments than participants without seizures. There was little to no evidence of associations between the other predictors and neurocognitive outcome. **Conclusions:** Lesion size, stroke type, age at stroke, and SES predict neurocognitive outcome following pediatric stroke. An improved understanding of predictors is especially valuable to clinicians who have pivotal responsibilities related to neuropsychological assessment, diagnosis, treatment, and referral for this population. Findings should inform clinical practice through enhanced appraisals of prognosis as well as the development of services and interventions aimed at fostering optimal development for youth with stroke.

Introduction

Neurocognitive deficits commonly occur following pediatric stroke and can impact many domains such as language, executive functioning, attention, memory, and processing speed (Bolk et al., 2022; Bosenbark et al., 2018; Murphy et al., 2017; Peterson et al., 2019; Rivella & Viterbori, 2021; Westmacott et al., 2010, 2018). These deficits hinder academic advancement (Champigny et al., 2020; Hawks et al., 2016; Li et al., 2022; Peterson et al., 2019; Yvon et al., 2018) as well as social-emotional development and mental health (Ledochowski et al., 2020; Max et al., 2002, 2003; O'Keeffe et al., 2017; Peterson et al., 2021; Williams et al., 2017). Despite awareness of these deleterious effects, neurocognitive outcome after pediatric stroke, especially hemorrhagic stroke, is understudied. The pediatric stroke population is remarkably heterogeneous, and neurocognitive outcomes are contingent upon multiple variables and interactions. Possible predictors of neurocognitive outcome in pediatric stroke that have been explored in the literature include: age at stroke; lesion location, laterality, and size; time since stroke; neurologic severity; and presence of seizures post-stroke (Fuentes et al., 2016). More recently, socioeconomic status (SES) has been identified as a predictor (Bartha-Doering et al., 2021). Lastly, it is likely that stroke type predicts outcome, despite a paucity of research comparing ischemic and hemorrhagic pediatric stroke (van Buuren et al., 2013; Yvon et al., 2018). More research is needed to disentangle the effects of these predictors on specific neurocognitive domains.

Scientists agree that the developmental stage of the brain at the time of stroke influences neurocognitive outcome, but results are inconsistent regarding the shape and direction of that relationship. The dominant position for many years was the plasticity hypothesis, which emphasizes the young brain's ability to reorganize itself (Abgottspon et al., 2022; Max et al., 2010). Consensus then shifted towards the vulnerability hypothesis, which focuses on the developing brain's vulnerability to injury (Everts et al., 2008; Jacomb et al., 2018; Max et al., 2010; Peterson et al., 2019; Studer et al., 2014; Westmacott et al., 2010). Recent studies support a revised theory that suggests both plasticity and vulnerability mediate neurocognitive outcome as they "represent extremes along a 'recovery continuum'" (Anderson et al., 2011, p. 2209). Some researchers have suggested a polynomial relationship in an inverted U shape, but the ages at which the U is centered vary (Allman & Scott, 2013; Everts et al., 2008). Other researchers have suggested the opposite shape – a U shape – though results depend on the cognitive domain in question (Abgottspon et al., 2022).

Lesion laterality does not appear to influence neurocognitive outcome following pediatric stroke (Abgottspon et al., 2022; Avila et al., 2010; Ballantyne et al., 2007; Bosenbark et al., 2017; Everts et al., 2008; Jacomb et al., 2018; Long et al., 2011; Max, 2004; O'Keeffe et al., 2014; Peterson et al., 2019). There may be one exception related to language; some researchers have indicated worse outcomes in verbal reasoning and expression following a left hemisphere stroke in childhood (de Montferrand et al., 2019; Lidzba et al., 2017), but others have been unable to replicate this finding (Bartha-Doering et al., 2019; Funnell & Pitchford, 2010).

Combined cortical-subcortical lesions are more detrimental for neurocognitive outcomes than cortical or subcortical lesions (Champigny et al., 2020; Fuentes et al., 2016; Hajek et al., 2014; Lo et al., 2013; Long et al., 2011; Studer et al., 2014; Westmacott et al., 2010). Parietal lobe involvement in perinatal hemorrhagic stroke was associated with worse cognitive impairments (Vojcek et al., 2022), but studies examining location in hemorrhagic stroke are lacking. Finally, some studies found no evidence that lesion location impacts neurocognitive outcome (Abgottspon et al., 2022; Bosenbark et al., 2017).

Lesion size has also been identified as a predictor, with larger lesions associated with worse neurocognitive outcome compared to small and medium lesions (Abgottspon et al., 2022; Bartha-Doering et al., 2021; Bosenbark et al., 2017; Everts et al., 2008; Hajek et al., 2014; Kornfeld et al., 2017; Long et al., 2011; Westmacott et al., 2010).

Neurologic severity following ischemic stroke, often measured with the Pediatric Stroke Outcome Measure (deVeber et al., 2000), is associated with worse neurocognitive outcome (Hajek et al., 2014; Lo, Gordon, Hajek, Gomes, Greenham, Anderson, et al., 2014; Studer et al., 2014). Beslow et al. (2014) developed the pediatric intracerebral hemorrhage score (pICH score), the first measure of neurologic severity for pediatric hemorrhage. To date, there are no publications examining the pICH score and neurocognitive outcome.

Mixed findings have been reported on time since stroke and neurocognitive outcome. Some have found that cognitive impairments remain stable (Allman & Scott, 2013; Ballantyne et al., 2008; Jacomb et al., 2018; Kornfeld et al., 2017; Murphy et al., 2017; O'Keeffe et al., 2014; van Buuren et al., 2013), while others have reported improvements (Avila et al., 2010; Everts et al., 2008; Murphy et al., 2017), and others have noted a decline over time or emergence of new deficits (Anderson et al., 2011; Levine et al., 2005; van Buuren et al., 2013; Westmacott et al., 2009, 2010).

Seizures commonly occur after pediatric stroke, especially perinatal stroke (Sundelin et al., 2021). Seizures following stroke have been associated with worse neurocognitive outcome (Avila et al., 2010; Ballantyne et al., 2007, 2008; Bosenbark et al., 2017; Fuentes et al., 2016; O'Keeffe et al., 2014; Studer et al., 2014; van Buuren et al., 2013; Vojcek et al., 2022).

SES, often measured using household income or maternal education, has been positively associated with cognitive development in pediatric studies (Ursache & Noble, 2016). It has also been found to impact neurological outcome following stroke (Fullerton et al., 2015; Jordan et al., 2018). A recent study by Bartha-Doering and colleagues (2021) examined SES and neurocognitive outcome following unilateral pediatric arterial ischemic stroke and found that SES was a stronger predictor than all other clinical factors, such as lesion size.

A dearth of studies have investigated neurocognitive outcomes following hemorrhagic stroke (Boulouis et al., 2019), which accounts for half of the pediatric cases (Singhal et al., 2013). One team found that ischemic stroke was associated with slightly worse neurocognitive impairments than hemorrhagic stroke, but differences were not statistically significant (Yvon et al., 2018). A second study reported that participants under the age of three with intraventricular hemorrhagic stroke had lower cognitive functioning than those with ischemic stroke (van Buuren et al., 2013).

This clinical study examines the impact of potential predictors: age at stroke, stroke type, lesion location, lesion size, time since stroke, neurologic severity, seizures post-stroke, and SES, on a series of distinct neurocognitive abilities: abstract reasoning, verbal reasoning, working memory, processing speed, attention, learning ability, long-term memory, visuomotor integration, and executive functioning, in patients with a history of pediatric stroke. Hypotheses were informed by scientific evidence for each predictor.

Methods

Participants

Families were contacted by random selection via medical record searches and upcoming clinical appointments at the Hospital for Sick Children in Toronto, Canada, between December 2020 and October 2021. Inclusion criteria consisted of: history of one or multiple strokes occurring before 18 years of age, 6 to 25 years of age at time of participation, at least 6 months post-stroke at time of participation, and fluency in English. A total of 92 patients participated.

Measures

Hospital records were accessed for medical history, including age at stroke, stroke type, and presence of seizures post-stroke. Lesion size and location were retrieved from medical records or the Canadian Pediatric Ischemic Stroke Registry (deVeber et al., 2017) or were coded by a neuroradiologist or neuropsychologist using neuroimaging records. Neurologic severity for youth with ischemic stroke was quantified using scores on the Pediatric Stroke Outcome Measure (PSOM; Kitchen et al., 2012). The PSOM scores were determined via neurological exam and included as part of the Canadian Pediatric Ischemic Stroke Registry (deVeber et al., 2017). The PSOM assesses neurological deficits across sensorimotor, language, and cognitive domains. It ranges from 0 to 10, with a higher score indicating more severe impairment. For youth with hemorrhagic stroke, neurologic severity was represented by the pediatric intracerebral hemorrhage score (pICH score), calculated by a neuroradiologist. The pICH score examines hemorrhage volume in proportion to total brain volume, infratentorial location, and presence of acute hydrocephalus and herniation. The score ranges from 0 to 5, with a higher score indicating more severe impairment. Lastly, household income represented SES, which caregivers reported on a 6-point scale.

Neurocognitive functioning was quantified using scores on standardized neuropsychological tests assessing verbal reasoning, abstract reasoning, working memory, processing speed, attention, learning, long-term memory, and visuomotor integration (Table 1). A standardized questionnaire provided an estimate of executive functioning. Scores were determined relative to age-appropriate norms.

Procedure

Each participant completed a series of neuropsychological tests while caregivers completed the executive functioning questionnaire. All measures were administered, scored, and interpreted by graduate students in clinical neuropsychology or as part of standard clinical care at SickKids. On test measures, a higher score indicates higher ability, whereas on the executive functioning questionnaire, a higher score indicates more severe impairments.

Statistical Analyses

Analyses were conducted using R (R Core Team, 2020) and SPSS (IBM Corp., 2021). Variables were examined to ensure that parametric assumptions were met. Levene's test of equality of variances assessed homogeneity of variance across groups. Tests of normality, Q-Q plots, and z-scores for skewness and kurtosis informed data distribution. Alpha was set at .05 and confidence intervals were set at 95%.

Table 1

Neurocognitive skills and associated measures for Study 1

Neurocognitive skill	Standardized measure
Verbal reasoning, abstract reasoning[a], working memory, processing speed	Wechsler Intelligence Scale for Children – Fifth Edition (Wechsler, 2014) (Wechsler, 2014) / Wechsler Adult Intelligence Scale – Fourth Edition (Wechsler, 2008)
Attention	Test of Everyday Attention for Children (Manly et al., 1998) / Test of Everyday Attention (Robertson et al., 1994)
Learning ability, long term memory	California Verbal Learning Test for Children (Delis et al., 1994) / California Verbal Learning Test – Third Edition (Delis et al., 2017)
Visuomotor integration	Beery-Buktenica Developmental Test of Visual-Motor Integration – Sixth Edition (Beery et al., 2010)
Executive functioning	Behavior Rating Inventory of Executive Function – Second Edition Parent Form (Gioia et al., 2015) / Behavior Rating Inventory of Executive Function – Adult Version Self Report Form (Roth et al., 2005)

[a]Abstract reasoning refers to the Perceptual Reasoning Index Score of the WAIS-IV and the Visual Spatial and Fluid Reasoning Index Scores of the WISC-V merged with equal weights.

A spline regression with one knot was conducted (Monette et al., 2019) to examine the impact of age at stroke and lesion size – the two determinants hypothesized to be the strongest predictors of neurocognitive outcome – further divided by stroke type. To the left of the knot are participants with perinatal stroke (i.e., prior to one month of age) and to the right of the knot are participants with childhood stroke (i.e., at one month and older), for which a polynomial trend was expected between age at stroke and neurocognitive outcome. An examination of model fit suggested that an interaction between stroke type and age at stroke to the left of the knot improved model fit, so it was added. Given the exploratory nature of this study and some sparse combinations of data in the hemorrhagic group, it is advised to use caution while interpreting results of the spline regressions. Spline models are coded in such a way where reference groups are specified, so coefficients refer to specific comparisons. For these reasons, instead of focusing on statistical significance, the emphasis is on general patterns and trends across the age span, stroke types, and lesion sizes.

A series of one-way analysis of variance (ANOVA) examined differences in neurocognitive outcomes across variables with three levels: lesion laterality (left, right, bilateral) and structures impacted (cortical, subcortical, combined). Partial eta squared (partial η^2) values were reported as measures of effect size, with suggested norms: small = 0.01, medium = 0.06, large = 0.14. A series of Welch's *t*-tests examined differences between dichotomous variables: lesion region (i.e., supratentorial, infratentorial) and seizure disorder post-stroke (i.e., presence, absence). Cohen's *d* were reported as measures of effect size. Given the exploratory nature of this study, suggested cut-off norms were used: small = 0.2, medium = 0.5, large = 0.8. A series of simple linear regressions investigated relationships between neurocognitive outcomes and continuous variables: neurologic severity, time since stroke, and SES.

Results

Participants were generally well distributed in terms of clinical and demographic characteristics (Table 2), except for unequal group sizes for hemorrhagic (23.9%) and ischemic (76.1%) stroke mechanisms.

Table 2

Clinical and demographic characteristics of participants in Study 1

Gender, n (%)	
Female	46 (50.0%)
Male	42 (45.7%)
Non-binary	1 (1.1%)
Two-Spirit	1 (1.1%)
Unsure	1 (1.1%)
Age at stroke, *M (SD)*	4.28 (5.17)
Stroke onset age group, n (%)	
Perinatal (< 1 month)	38 (41.3%)
Early childhood (1 month – 5 years)	23 (25.0%)
Late childhood (6 – 18 years)	31 (33.7%)
Time since stroke, in years, *M (SD)*	8.47 (5.25)
Type of stroke, n (%)	
Ischemic	70 (76.1%)
Hemorrhagic	22 (23.9%)
Lesion location, n (%)	
Laterality	
Left hemisphere	40 (43.5%)
Right hemisphere	28 (30.4%)
Bilateral	21 (22.8%)
N/A[a]	3 (3.3%)
Region	
Supratentorial	76 (82.6%)
Infratentorial	11 (12.0%)
Combined (supra- and infratentorial)	2 (2.2%)
Subdural	1 (1.1%)
Subarachnoid	1 (1.1%)
Intraventricular	1 (1.1%)
Structures	
Cortical	10 (10.9%)
Subcortical	27 (29.3%)
Combined cortical-subcortical	55 (59.8%)
Lesion size, n (%)	
Small-medium	62 (67.4%)
Large	27 (29.3%)
N/A[a]	3 (3.3%)
Presence of seizure disorder post-stroke, n (%)	22 (23.9%)

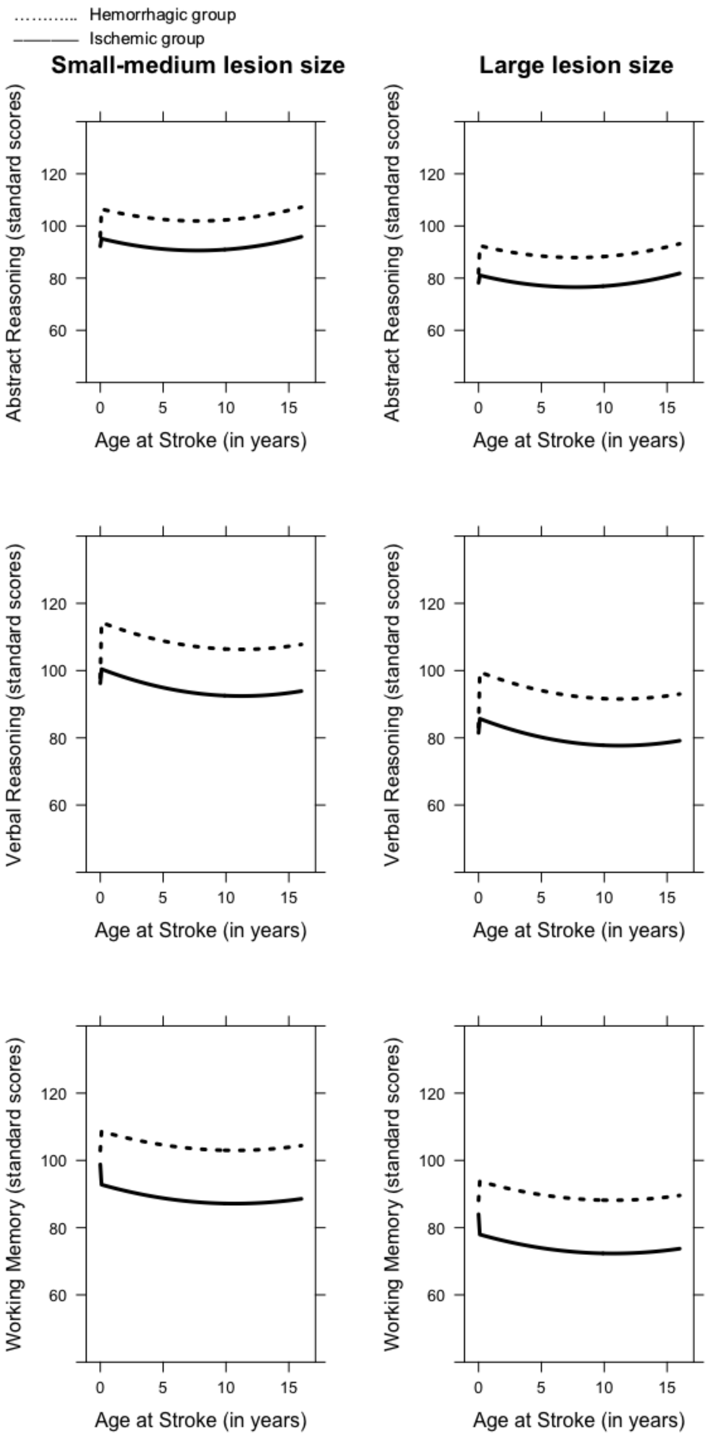
[a] Refers to the cases where lesions were subdural, subarachnoid, or intraventricular. It was deemed inappropriate to include these in the size, location, and laterality analyses.

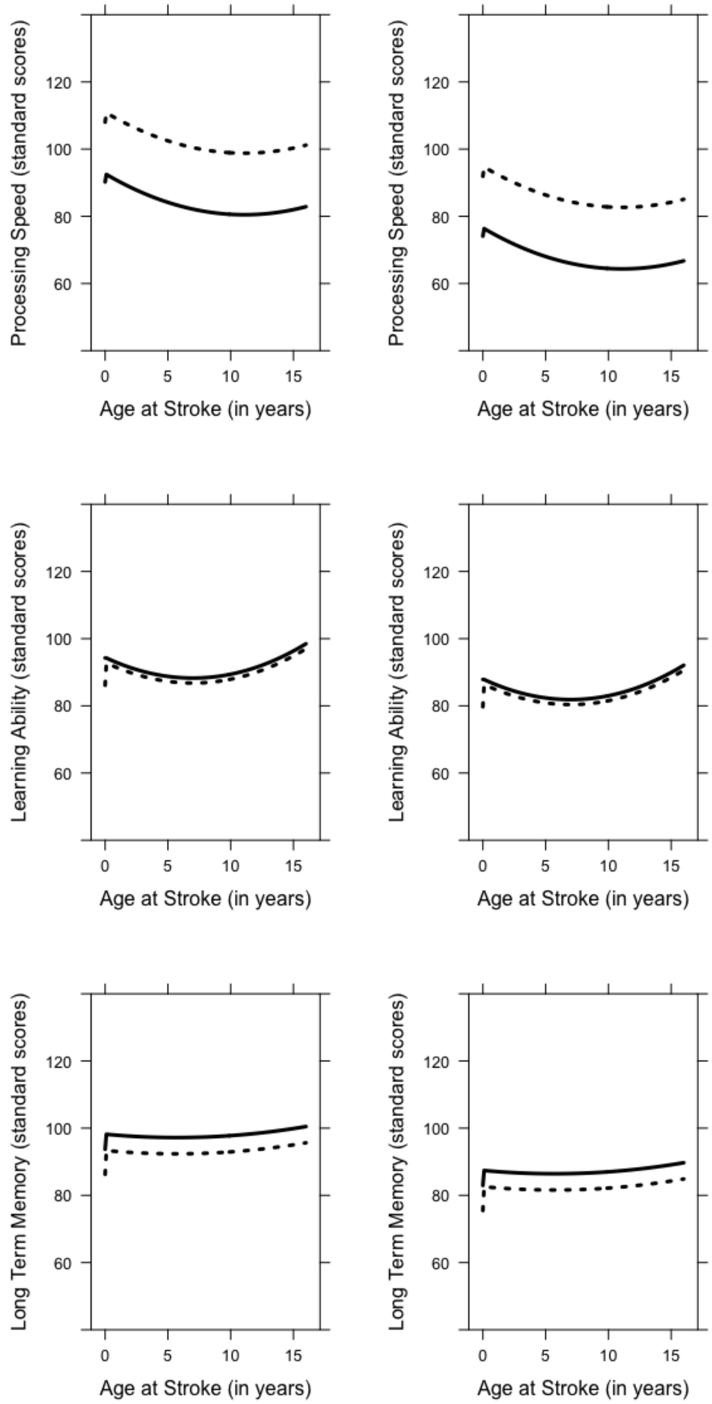
Graphs of the spline regressions give a visual representation of the patterns across domains (Figure 1). Results of the model fit are provided (Table 3). Participants with ischemic stroke scored lower than their same-aged peers with hemorrhagic stroke. This difference was largest for processing speed, working memory, and executive functioning, with mean differences of about 15 to 20 standard scores. Youth with ischemic stroke in childhood scored approximately 15 standard scores lower than their counterparts with hemorrhagic stroke on measures of verbal reasoning, but this difference does not appear in those with perinatal stroke.

Score differences between youth with perinatal versus childhood stroke were variable and challenging to compare given the linear nature of the perinatal group and the quadratic nature of the childhood group. On several measures, it appeared that hemorrhagic stroke had a different effect depending on whether the stroke occurred perinatally or in childhood. For instance, on average, youth with perinatal hemorrhagic stroke scored lower on abstract and verbal reasoning compared to the concave up inflection point of youth with hemorrhagic stroke in childhood; however, these differences were not seen in the ischemic group.

Figure 1

Spline regressions examining impact of age at stroke on neurocognitive outcomes in groups with small to medium lesions (left) and large lesions (right) in Study 1




Processing Speed (standard scores)
Learning Ability (standard scores)
Long Term Memory (standard scores)
120
100
80
60
0
5
10
15
Age at Stroke (in years)

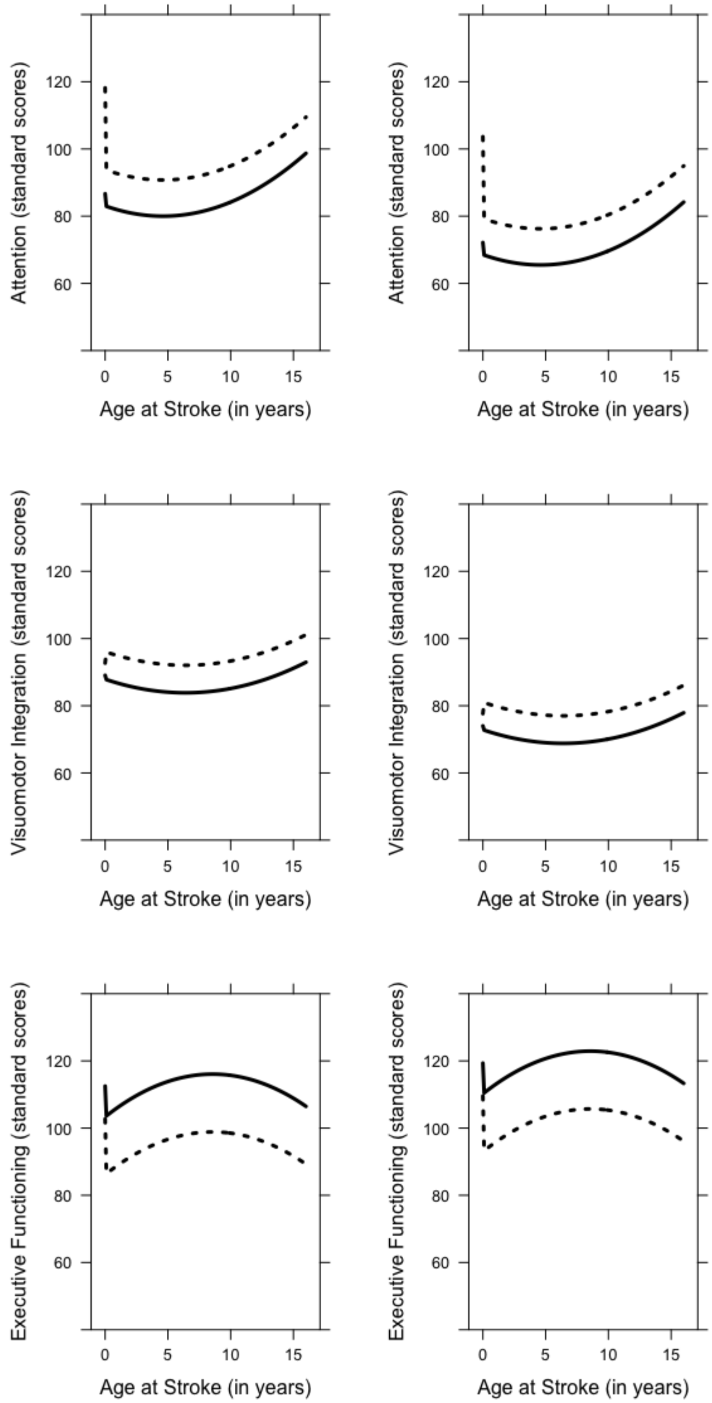

Attention (standard scores)
Visuomotor Integration (standard scores)
Executive Functioning (standard scores)
Age at Stroke (in years)
120
100
80
60
0
5
10
15

Table 3

Model fit for spline regression examining impact of stroke type, age at stroke, and lesion size on neurocognitive outcomes in Study 1

Neurocognitive outcome	Multiple R^2	*df*	*F*-value	*p*-value
Abstract reasoning	**0.21**	**6, 81**	**3.57**	**.003****
Verbal reasoning	**0.24**	**8, 80**	**3.14**	**.004****
Working memory	**0.20**	**6, 82**	**3.46**	**.004****
Processing speed	**0.23**	**6, 81**	**4.13**	**.001****
Attention	**0.26**	**6, 82**	**4.91**	**<.001*****
Learning ability	0.06	6, 80	0.80	.580
Long term memory	0.10	6, 80	1.55	.170
Visuomotor integration	**0.22**	**6, 78**	**3.67**	**.003****
Executive functioning	**0.18**	**6, 82**	**3.10**	**.009****

Note. df = degrees of freedom.

**p* < .05. ***p* < .01. ****p* < .001. Significant results are bolded.

Consistent with our hypothesis of a polynomial pattern in youth with childhood stroke, the U-shaped graphs suggest more severe cognitive impairments following stroke in middle childhood compared to stroke in early or late childhood. The dips in middle childhood are steep on measures of learning, attention, and executive functioning. Results on measures of abstract reasoning, learning, and visuomotor integration suggest that scores tend to dip to their lowest when stroke occurred between 5 to 10 years of age. Processing speed and working memory scores appear to dip slightly later, around age 10, and verbal reasoning scores dip even later, with the point of inflection somewhere between 10 to 15 years of age. On measures of verbal reasoning, processing speed, and long-term memory, graphs have a less pronounced dip before they curve up, suggesting a flatter trend of low scores for youth with early and middle childhood stroke, and an increase in scores for those with stroke in late childhood. In terms of the age at which scores tend to curve up, there is a clear increase around age 10 on measures of abstract reasoning, learning, visuomotor integration, and executive functioning. On the attention measure, the uptick appears sooner, around 6 years of age. The uptick is milder on measures of verbal reasoning, processing speed, working memory.

Across all measures, ages, and stroke types, youth with a large lesion scored lower than youth with small to medium lesions, with differences as high as about 15 standard scores as seen in youth with childhood stroke on measures of abstract reasoning, verbal reasoning, processing speed, working memory, and visuomotor integration.

There was no evidence of differences on any outcomes based on lesion laterality or region defined as supra- versus infratentorial (Table 4). In terms of structures impacted (i.e., cortical, subcortical, or combined), there was a significant difference between groups on abstract reasoning, with a large effect size (p = .002, partial η^2 = .14), and attention, with a medium effect size (p = .034, partial η^2 = .08). Given that error variances were equal across groups, post-hoc tests using Tukey's HSD procedure were chosen to examine differences across pairs. On abstract reasoning, participants with combined cortical-subcortical lesions (M = 86.77, SD = 17.02) scored lower than participants with cortical (M = 104.17, SD = 10.49; p = .010) and subcortical (M = 94.28, SD = 16.78; p = .021) lesions. On attention, participants with combined lesions (M = 80.80, SD = 18.97) scored lower than participants with cortical lesions (M = 97.00, SD = 21.11; p = .042).

Regarding neurologic severity, in the ischemic group, the PSOM predicted scores on measures of abstract reasoning (b = -7.37, p < .001), attention (b = -8.69, p < .001), and processing speed (b = -6.83, p = .011), while in the hemorrhagic group, the pICH score predicted scores on the visuomotor integration measure (b = -5.14, p = .041) (Table 5).

There was no evidence of a linear relationship between time since stroke and any neurocognitive outcome (Table 6).

Youth with seizures ($M = 123.59$, $SD = 17.12$) had more severe executive functioning impairments than their peers without seizures ($M = 106.70$, $SD = 15.81$), with a large effect size ($p < .001$, $d = 1.03$). There was no evidence of group differences on other measures (Table 7).

Household income positively predicted scores on abstract reasoning ($b = 3.61$, $p = .002$), verbal reasoning ($b = 4.11$, $p < .001$), working memory ($b = 3.73$, $p = .002$), processing speed ($b = 4.81$, $p < .001$), attention ($b = 4.30$, $p = .001$), visuomotor integration ($b = 3.14$, $p = .003$), and executive functioning impairments ($b = -3.39$, $p = .003$) (Table 8).

Table 4

Results of Welch's t-tests and ANOVAs examining impact of lesion location on neurocognitive outcomes in Study 1

Neurocognitive outcome	Lesion laterality: left, right, bilateral (ANOVA)				Lesion region: supratentorial, infratentorial (Welch's t-test)					Lesion structure: cortical, subcortical, combined (ANOVA)			
	df	*F*-value	*p*-value	partial η^2	*df*	*t*-value	*p*-value	MD	Cohen's *d*	*df*	*F*-value	*p*-value	partial η^2
Abstract reasoning	2	0.11	.895	.00	1, 12.91	1.51	.241	6.79	0.40	**2,81**	**6.78**	**.002****	**.14**
Verbal reasoning					1, 12.63	0.30	.596	3.14	0.18	2,81	2.21	.116	.05
Laterality [a]	2	1.32	.273	.03									
Age group [a]	1	0.38	.539	.01									
Interaction [a]	2	0.60	.552	.02									
Working memory	2	0.52	.598	.01	1, 12.51	0.08	.786	1.88	0.09	2,81	0.55	.577	.01
Processing speed	2	0.83	.921	.00	1, 12.44	0.37	.554	4.42	0.20	2,81	2.93	.059	.07
Attention	2	0.79	.456	.02	1, 13.64	0.19	.672	2.68	0.14	**2,81**	**3.52**	**.034***	**.08**
Learning ability	2	0.00	.996	.00	1, 12.01	0.00	.981	0.16	0.01	2,81	0.65	.526	.02
Long term memory	2	0.17	.844	.01	1, 14.39	0.26	.620	2.58	0.15	2,81	0.05	.950	.00
Visuomotor integration	2	0.02	.982	.00	1, 14.57	3.89	.068	9.00	0.60	2,81	1.80	.172	.04
Executive functioning	2	3.07	.052	.08	1, 11.94	0.52	.485	4.90	0.25	2,81	0.04	.959	.00

Note. *df* = degrees of freedom, partial η^2= partial eta squared, MD = mean difference.

[a] Results of the two-way ANOVA examining lesion laterality and verbal reasoning between age groups (0-5 years and 6-18 years).

**p* < .05. ***p* < .01. ****p* < .001. Significant results are bolded.

Table 5

Results of simple linear regressions examining impact of neurologic severity on neurocognitive outcomes in Study 1

Neuro-cognitive outcome	Neurologic severity in ischemic stroke group (pediatric stroke outcome measure, PSOM) (n=40)								Neurologic severity in hemorrhagic stroke group (pediatric intracerebral hemorrhage score, pICH score) (n=19)							
	R^2	*df*	*F*-value	*p*-value	*b*	SE	*t*-value	*p*-value	R^2	*df*	*F*-value	*p*-value	*b*	SE	*t*-value	*p*-value
Abstract reasoning	**0.26**	**1, 38**	**13.36**	**<.001*******	**-7.37**	**2.02**	**-3.66**	**<.001*******	0.07	1, 17	1.36	.260	-3.19	2.74	-1.16	.260
Verbal reasoning	0.05	1, 38	1.92	.174	-3.12	2.25	-1.39	.174	0.07	1, 17	1.23	.283	-3.00	2.71	-1.11	.283
Working memory	0.04	1, 38	1.75	.194	-3.43	2.59	-1.32	.194	0.19	1, 17	4.04	.061	-5.83	2.90	-2.01	.061
Processing speed	**0.16**	**1, 38**	**7.18**	**.011***	**-6.83**	**2.55**	**-2.68**	**.011***	0.18	1, 17	3.62	.074	-5.84	3.07	-1.90	.074
Attention	**0.26**	**1, 38**	**13.09**	**<.001*******	**-8.69**	**2.40**	**-3.62**	**<.001*******	0.24	1, 17	0.42	.524	-2.18	3.35	-0.16	.524
Learning ability	0.03	1, 37	1.30	.261	-2.68	2.35	-1.14	.261	0.04	1, 17	0.75	.398	-2.43	2.81	-0.21	.398
Long term memory	0.07	1, 37	2.85	.100	-3.92	2.32	-1.69	.100	0.01	1, 17	0.16	.699	-1.13	2.88	-0.39	.699
Visuomotor integration	0.00	1, 35	0.14	.709	-0.85	2.26	-0.38	.709	**0.22**	**1, 17**	**4.89**	**.041***	**-5.14**	**2.33**	**-2.21**	**.041***
Executive functioning	0.06	1, 38	2.23	.139	3.51	2.33	1.51	.139	.003	1, 17	0.05	.820	-0.67	2.91	-0.23	.820

Note. df = degrees of freedom, *b* = unstandardized coefficient, SE = standard error.

*p < .05. **p < .01. ***p < .001. Significant results are bolded.

Table 6

Results of simple linear regressions examining impact of time since stroke on neurocognitive outcomes in Study 1

Neurocognitive outcome	R^2	*df*	*F*-value	*p*-value	*b*	SE	*t*-value	*p*-value
Abstract reasoning	0.01	1, 89	0.76	.386	-0.30	0.35	-0.87	.386
Verbal reasoning	0.01	1, 90	0.78	.381	-0.30	0.34	-0.88	.381
Working memory	0.02	1, 90	1.75	.190	-0.51	0.39	-1.32	.190
Processing speed	0.02	1, 89	1.52	.221	-0.50	0.41	-1.23	.221
Attention	0.00	1, 90	0.08	.773	-0.12	-0.03	-0.29	.773
Learning ability	0.00	1, 88	0.02	.890	-0.05	0.35	-0.14	.890
Long term memory	0.00	1, 88	0.00	.958	0.02	0.36	0.05	.958
Visuomotor integration	0.00	1, 86	0.25	.617	-0.16	0.33	-0.50	.617
Executive functioning	0.04	1, 90	3.40	.069	0.64	0.35	1.84	.069

Note. df = degrees of freedom, *b* = unstandardized coefficient, SE = standard error.

**p* < .05. ***p* < .01. ****p* < .001. Significant results are bolded.

Table 7

Results of Welch's t-tests examining impact of seizures post-stroke on neurocognitive outcomes in Study 1

Neurocognitive outcome	*df*	*t*-value	*p*-value	MD	Cohen's *d*
Abstract reasoning	1, 40.05	1.19	.283	4.27	0.26
Verbal reasoning	1, 43.67	2.28	.138	5.53	0.35
Working memory	1, 34.05	0.03	.859	0.88	0.04
Processing speed	1, 39.12	2.04	.161	6.72	0.34
Attention	1, 31.12	0.59	.448	4.20	0.20
Learning ability	1, 32.02	0.00	.999	0.00	0.00
Long term memory	1, 29.88	0.23	.634	2.26	0.12
Visuomotor integration	1, 34.12	2.54	.121	6.22	0.40
Executive functioning	**1, 33.07**	**16.91**	**<.001*****	**16.89**	**1.03**

Note. df = degrees of freedom, MD = mean difference.

p < .05. **p* < .01. ***p* < .001. Significant results are bolded.

Table 8

Results of simple linear regressions examining impact of socioeconomic status on neurocognitive outcomes in Study 1

Neurocognitive outcome	R^2	*df*	*F*-value	*p*-value	*b*	SE	*t*-value	*p*-value
Abstract reasoning	**0.12**	**1, 79**	**10.79**	**.002****	**3.61**	**1.10**	**3.29**	**.002****
Verbal reasoning	**0.17**	**1, 80**	**16.06**	**<.001*****	**4.11**	**1.03**	**4.01**	**<.001*****
Working memory	**0.11**	**1, 80**	**10.03**	**.002****	**3.73**	**1.18**	**3.17**	**.002****
Processing speed	**0.15**	**1, 79**	**14.33**	**<.001*****	**4.81**	**1.27**	**3.79**	**<.001*****
Attention	**0.13**	**1, 80**	**11.65**	**.001*****	**4.30**	**1.26**	**3.41**	**.001*****
Learning ability	0.04	1, 79	3.36	.070	2.10	1.15	1.83	.070
Long term memory	0.00	1, 79	0.11	.739	0.39	1.16	0.33	.739
Visuomotor integration	**0.11**	**1, 76**	**9.67**	**.003****	**3.14**	**1.01**	**3.11**	**.003****
Executive functioning	**0.10**	**1, 80**	**9.21**	**.003****	**-3.39**	**1.12**	**-3.04**	**.003****

Note. df = degrees of freedom, *b* = unstandardized coefficient, SE = standard error.

**p* < .05. ***p* < .01. ****p* < .001. Significant results are bolded.

Discussion

Findings from the current study indicate that important predictors of neurocognitive outcome following pediatric stroke include lesion size, stroke type, SES, and age at stroke. Large lesions, ischemic stroke, and lower SES were associated with worse neurocognitive outcomes compared to small to medium lesions, hemorrhagic stroke, and higher SES, respectively. Data visualization of spline regressions indicated U-shaped patterns suggesting worse outcome across most neurocognitive domains when stroke occurred at approximately 5 to 10 years of age.

There was little to no evidence of associations between the other predictors and neurocognitive outcome. Participants with seizures had more severe executive functioning impairments, in line with the fact that these skills are dependent on interhemispheric interactions in the brain, which seizures tend to disrupt (Bolk et al., 2022). There were no differences on other measures between participants with and without seizures, which was surprising given that seizures impede cerebral reorganization (Ballantyne et al., 2007). Lesion location generally did not predict outcome, which is consistent with the current scientific consensus; the younger brain is less functionally specialized and has better potential for reorganization (Everts et al., 2008; Smitherman et al., 2016). In line with our hypotheses, there was no evidence of differences based on time since stroke. Lastly, neurologic severity predicted scores in the ischemic group on abstract reasoning, attention, and processing speed, and in the hemorrhagic group, on visuomotor integration.

Limitations

Due to the statistically small sample size, analyses may have been underpowered, and the number of significant associations may have been overestimated. Due to sparse data combinations in the hemorrhagic group, the spline regression was exploratory. Regarding seizures, existing patterns may have been missed due to sample heterogeneity; youth experiencing any number of seizures post-stroke, whether managed with medication or not, were placed in the seizure group. Next, neurologic severity was assessed with the PSOM for ischemic stroke and the pICH score for hemorrhagic stroke; although these tools are standard practice in their respective domains, they measure different components of a stroke. The PSOM consists of a neurological exam assessing sensorimotor, language, and cognitive functioning, while the pICH score is based on radiological findings such as hemorrhage volume and presence of hydrocephalus and herniation. As such, different constructs represented neurologic severity across both stroke types; results across these two groups cannot be reliably compared. Lastly, certain cognitive deficits may only become apparent at school age (Westmacott et al., 2009, 2010), but children younger than 6 years old were not included in our sample. Consequently, within the time since stroke analysis, we may have not uncovered the full extent of cognitive impairments that emerge later in development, such as those related to executive functioning.

Clinical Implications

This study yielded clinically applicable findings that should be considered in the practice of medical professionals working with youth with stroke. An understanding of determinants of neurocognitive outcome helps clinicians to improve appraisals of prognosis, refer patients to support services tailored to their expected patterns of recovery, and communicate these expected patterns to families (Watson et al., 2022; Ylvisaker et al., 2005). Family-centered psychoeducation can help manage expectations, assist with adjustment, and facilitate transitions back to the home, school, and community (Koterba & Hoskinson, 2018). An enhanced understanding of neurocognitive outcomes can also inform the development of effective, targeted neurorehabilitation strategies to optimize cognitive recovery in this population. Lastly, the identification of SES as a predictor of neurocognitive outcome highlights the importance of a patient's environment in recovery. It is recommended that clinicians assess and understand the impact of patient circumstances in their practice. High-quality clinical care requires a thorough understanding of the multiple layers of a child's environment as well as consideration of non-clinical factors (e.g., SES, culture) that can influence stroke recovery.

Future Directions

Future research should examine other possible predictors of neurocognitive outcome that remain unexplored. For example, it has been postulated that lesion location plays a role via broader functional networks rather than direct structure-function relationships, or via changes in interhemispheric resting-state connectivity (Kornfeld et al., 2017). Future research should also continue to examine stroke type and SES and elucidate how these factors might play a role in outcome. Investigations of nonlinear relationships between age at stroke and neurocognitive outcome are also warranted. Lastly, multisite collaborations would provide larger sample sizes and allow teams to build models with better statistical power and more predictors, and better ascertain interactions between predictors.

Conclusions

There is a paucity of research on neurocognitive outcomes following pediatric stroke, especially the hemorrhagic type. The current study contributed to the scientific literature by identifying lesion size, stroke type, age at stroke, and SES as predictors. Enhancing understanding of neurocognitive outcomes following pediatric stroke is a first step towards improving appraisals of prognosis and developing targeted rehabilitation strategies to optimize recovery for this underserved population.

Chapter 4: A Qualitative Examination of Psychological Adjustment Following Stroke in Childhood and Adolescence

Publication Status and Author Contributions

The following chapter is based on a manuscript which, as of August 2022, has been submitted for publication in a peer-reviewed scientific journal and is awaiting a decision from the editorial office. Currently, the reference for this manuscript is as follows:

Champigny, C.M., Feldman, S.J., Westmacott, R., Wojtowicz, M., Aurin, C., Dlamini, N., Dirks, P., & Desrocher, M. (2022). ‘My stroke is part of my identity’: A qualitative examination of psychological adjustment following pediatric stroke. [Manuscript submitted for publication]. Department of Psychology, York University.

Claire Champigny, the first author, led research efforts spanning study conceptualization, application to the Research Ethics Boards of the Hospital for Sick Children and York University, participant recruitment and data collection, analysis and interpretation of data, and writing the manuscript for publication.

Abstract

Aim: This qualitative study seeks to examine psychological adjustment following stroke in adolescence from the perspective of affected youth. **Method:** Fourteen participants ages 13 to 25 with a history of ischemic or hemorrhagic stroke in adolescence participated in one-on-one semi-structured interviews at the Hospital for Sick Children in Toronto, Canada. Interviews were audio-recorded and transcribed verbatim. Two independent coders conducted an inductive thematic analysis. **Results:** Five themes were identified as representative of adjustment after stroke: 1) Processing the Story, 2) Loss and Challenges, 3) I've Changed, 4) Keys to Recovery, and 5) Adjustment and Acceptance. **Interpretation:** This study provides medical professionals with a personal, patient-driven lens through which to better understand the challenges of adjusting to life following pediatric stroke. Findings highlight the need to provide mental health support to patients to assist them in processing their stroke and adapting to long-lasting sequelae.

Introduction

Pediatric stroke is an important cause of acquired brain injury in youth (Ferriero et al., 2019). Contrary to popular belief, youth do not recover from stroke better than adults do; mortality rates and functional outcomes are similar (Goeggel Simonetti et al., 2015). Most youth with stroke experience long-term neurological deficits (Beslow et al., 2010; deVeber et al., 2000; Ferriero et al., 2019; Mallick et al., 2016). Motor and physical impairments are especially common, affecting 50-80% of survivors (Cooper et al., 2017; deVeber et al., 2000). Neurocognitive deficits frequently occur and can impact a range of domains such as processing speed, working memory, and executive functioning (Murphy et al., 2017; O'Keeffe et al., 2014; Peterson et al., 2019; Rivella & Viterbori, 2021; Westmacott et al., 2018), contributing to lower academic achievement (Champigny et al., 2020; Deotto et al., 2019). Pediatric stroke also adversely impacts social, emotional, and behavioural functioning (Anderson et al., 2014; O'Keeffe et al., 2017), and is associated with increased rates of psychopathology such as attention-deficit hyperactivity disorder (Max et al., 2003; Williams et al., 2017) as well as anxiety, depression, and post-traumatic stress disorder (Lehman et al., 2020; Max et al., 2002; Westmacott et al., 2018).

Qualitative health research has been increasingly recognized as a valuable methodology in neurology, aiming to shed light on patients' lived experiences including trajectories associated with recovery and rehabilitation (Jack & Phoenix, 2022). Qualitative evidence can benefit healthcare practitioners conceptually by giving insight into "what it is 'like' to live, play, learn with, or receive care for a specific condition" (Jack & Phoenix, 2022, p. 832). To guide practitioners in supporting their patients, scientists have indicated the need to hear from affected youth directly regarding adjustment following stroke (McKevitt et al., 2019; Soufi et al., 2017).

Methods

Participants

Patients at the Hospital for Sick Children (Toronto, Canada) who met inclusion criteria were contacted between January and June 2021. Patients were identified either by random selection following a systematic search of medical records, or they had an upcoming appointment for a neuropsychological assessment as part of standard of care. Inclusion criteria consisted of stroke occurring in adolescence (i.e., approximately ages 10 to 18), age at the time of interview between 13 and 25 years (i.e., old enough to reflect on past experiences), at least 6 months post-stroke, and proficiency in English. Exclusion criteria included unstable medical condition and a diagnosis of moderate to severe intellectual disability.

The study was approved by the Research Ethics Board of The Hospital for Sick Children (#1000070780).

Procedure and Materials

Author C.C. wrote the interview script, informed by the scientific literature and clinical experience. A survivor of pediatric stroke consulted and provided feedback on the script.

Once informed written consent was obtained, participants took part in a semi-structured interview with C.C. at the Hospital for Sick Children or through Zoom for Healthcare (*Zoom for Healthcare*, 2016). Interviews were audio-recorded and lasted approximately 45 minutes. Open-ended questions queried stroke recovery and adjustment. After fourteen interviews, data saturation was met (i.e., no new codes appeared and clear patterns had emerged) and recruitment ended. Interviews were transcribed verbatim and reviewed for accuracy.

Participants or caregivers completed a Demographics & History Questionnaire querying demographic information as well as medical, developmental, and family history.

Data Analysis

Authors C.C. and S.F. conducted a thematic analysis closely following the steps outlined by Clarke and Braun (2013) for a methodically rigorous, data-driven, inductive approach. They reviewed transcripts for familiarisation with the data, then created a living codebook that was continually revised in line with emerging patterns in the data, using the software ATLAS.ti (Friese, 2021). C.C. and S.F. coded the interviews independently and met weekly to compare codes, consistently achieving high interrater agreement; discrepancies were minor and resolved through discussion. C.C. grouped codes into broader subthemes and generated and defined overarching themes. Results were reviewed with S.F., R.W., and M.D. to ensure consensus. Self-reflection on a priori expectations assisted in reducing personal bias during the processes of coding and identifying themes.

Results

Clinical information was collected from medical records and the Demographics and History Questionnaire (Table 9). Participants were 13 to 25 years old (M_{age}=17 years). Age at stroke onset ranged from 9 to 16 years (M_{age}=12 years).

Following thematic analysis, five overarching themes were identified as representative of adjustment following stroke. Anonymized quotations illustrate themes and subthemes.

Table 9

Clinical characteristics of the sample in Study 2

Age at time of interview, in years, M (SD)	17 years 5 months (3 years 8 months)
Age at time of stroke, in years, M (SD)	12 years 0 months (2 years 0 months)
Time since stroke, in years, M (SD)	5 years 5 months (4 years 6 months)
Stroke type, n	
Ischemic	7
Hemorrhagic	7
Stroke etiology[a], n	
Aneurysm	2
Arteriovenous malformation	7
Moya Moya disease	1
Sickle cell disease	1
None/unknown	4
Psychiatric comorbidities, n (%)	
Attention-deficit/hyperactivity disorder	1
Anxiety disorder	2
Autism spectrum disorder	1
Depressive disorder	3
Intellectual disability	1
Learning disorder	2
Obsessive-compulsive disorder	1
Post-traumatic stress disorder	1
Sleep disorder	1
None	6
Prefer not to say	2
Symptoms at onset, n (%)	
Headache, migraine	7
Lethargy, sudden fatigue	6
Loss of consciousness, coma	6
Motor difficulties	8
Nausea, vertigo	8
Speech difficulties	6
Sensory difficulties	6
Vomiting	7
Other[b]	7
No symptoms	0

[a]Numbers add up to 15 because one participant reported two etiologies. [b]In the blank space provided next to 'Other,' participants/parents wrote the following responses: loss of vision (n=2), earache (n=1), dizziness (n=1), seizure (n=1), while sedated at the hospital (n=1), wouldn't wake up from sleep (n=1).

Theme 1: Processing the Story

Participants struggled to process the acute stroke event, and this processing was described as a necessary step to begin adjusting to life after stroke. Three subthemes encompass their experience.

Something's wrong. Most participants vividly remembered when they realized something serious was happening. Confusion and fear were prominent emotions. Several participants underestimated symptom severity until pain became unbearable or unexpected symptoms appeared (e.g., loss of motor function). Some participants also felt extreme tiredness. Symptoms experienced during stroke onset are presented in Table 9.

> I remember screaming really, really loud … I kept turning right and left to find a way so that the pain would stop. (age 15)
>
> It felt like a really, really bad sting of pain. … And then I tried to move but the right [side] of my body was not moving at all. … And then my speech got slurred, and that's when I felt like, I really panicked. … That's when I knew something was really wrong. (age 21)
>
> I started feeling violently ill, and I thought I was dreaming. ... It felt like it was the most tired I've ever felt in my life. … I kept dropping the water bottle in my left hand and I was so confused at what was happening. It was scaring me. (age 17)
>
> It feels like my soul's been knocked out. (age 14)

Piecing together what happened. Most participants described varying degrees of memory loss surrounding the event and confusion after waking up in a hospital. They attempted to piece together what had happened by trying to recall the event, asking people who were present about it, and processing information from their hospital care team.

> [I was] really confused, 'cause obviously I didn't really know why I was in the hospital and then I was hooked up to all these tubes and stuff. (age 16)

> I didn't really know how to take it in or how to understand what happened to me. … Mostly my mom told when it happened … later on, throughout life. Like, "oh this happened, and this happened," so I was kind of putting in the pieces and stuff. (age 24)

Feeling and sharing the story. Participants described feelings of surrealness when processing the stroke event. Most participants felt that these emotions attenuated as they became habituated to recounting their story to others. Some felt frustrated as they had outstanding questions even years later. Most participants chose to share their story with friends and family, most often because they felt that stroke is an important part of their identity or because it felt good to talk about it. Some participants shared their story with broader audiences to raise awareness about pediatric stroke. A small number of participants preferred to keep their stories private.

> It's like a surreal experience that takes a long time to really hit you. (age 15)

> Sometimes Mom will say a story and I won't even remember it and that really frustrates me. 'Cause it's like, that was me, that happened to me, and I can't even remember it. (age 16)

> I like to bring awareness to it and tell people my story because I like people to know what happened to me. 'Cause I feel like that's a very important thing in my life. (age 17)

> There's obviously emotions attached to it, but it was much harder the first time telling somebody than now because, I don't know, I've said it quite a few times. (age 14)

Theme 2: Loss and Challenges

Participants expressed several losses and challenges impacting their day-to-day and plans for the future. Five subthemes were identified.

Letting go. Participants had to let go of hobbies, activities, and plans for the future that were no longer feasible due to neurocognitive and motor sequelae.

> I was a huge reader, I loved reading. … But now it's a struggle. … It's really exhausting. (age 15)

> Before my stroke, I was an athlete. I did everything. … So, it was really, really hard to get, to understand that I couldn't do those things anymore. (age 25)

> I used to do a lot of art and drawing before my stroke. … Now I'm left-handed and now suddenly I have to switch over. I learned how to draw and everything, but it didn't feel the same. (age 21)

> Eyesight has been affected, which has affected things that were really important to me, like getting my driver's licence … So that was a big thing for me … One of the things that kinda hit me the most, that I wouldn't be able to get that. (age 15)

Challenges with day-to-day. Participants struggled with day-to-day tasks that used to require little effort. They emphasized the patience needed to cope with these challenges.

> …Little challenges, that was new to me. Trying to learn how to hold a pen or hold an object with my right hand. (age 24)

> [I have] to rely a lot on my parents and family members and friends to have to get me places 'cause I can't get anywhere by myself. (age 15)

Feeling left behind. Participants' statements reflected a common experience of feeling left behind, overwhelmed, and slower than their peers, especially regarding academics. Many felt unable to keep up with their classes due to their neurocognitive deficits, and this was compounded by having missed classes during their inpatient stay. Some participants also described feeling socially isolated because they had spent formative time as inpatients or could not participate in social events due to motor impairments.

> I feel like I'm just always playing catch up. … I really just feel like I'm behind. (age 18)
>
> At school it's like the kids are like the rabbit, they're like, okay, they're going faster and faster, and I felt like the turtle going... You know? (age 24)
>
> I missed out a lot … Like I couldn't make as many friends. (age 15)

What could have been. Participants identified a tendency to contemplate an alternate reality in which they had not suffered a stroke. They mourned their ideas of what they felt could have been their life.

> I had a vision of myself in the future, kind of working on my own, independent. But now I can't even do simple things by myself. (age 18)
>
> I have this habit of looking back, like what if I didn't have my stroke. … I would've continued swimming. … I would've become a lifeguard or instructor. (age 15)
>
> If I didn't have a stroke and my hand was functioning normal, then I would've gone into [the] baking industry. (age 21)
>
> If I didn't have this, would I be further from where I am right now? (age 24)

Worries about the future. Many participants shared worries and anxiety about their future due to impaired abilities and decreased independence.

> I think I'm not ready yet to be on my own. And I do worry about that sometimes, what that would look like. … The fear of what the future will look like. (age 18)
>
> I might not be able to get some job because of my disability. They could say, "oh, this job is focused on memory, and if you have memory loss, I don't think we can hire you." (age 13)

> Maybe because of the stroke, my marks in school goes down a bit, so that I can't go to the university that I wanna go. (age 16)

Theme 3: I've Changed

Nearly all participants described changes in their emotions, behaviour, and self-confidence. Two subthemes illustrate these changes in self-perception.

Anxiety, anger, and sadness. Newfound worry and anxiety, anger and frustration, and sadness and overwhelm were commonly endorsed. Some participants described these changes as significant concerns, while others felt they were minor but noticeable.

> I'll be doing something, and the stroke will, like I'll be reminded of it – like my right hand for example, I'll be reminded of it – and then I'll get really angry and like, why me, why did it have to happen to me? (age 16)

> There was definitely a part of me that was mad about it. … I think it's where the depression also came. I was mad at myself. (age 24)

> I felt anxious all the time. I was always scared of another stroke happening. (age 21)

Self-consciousness. A common experience was increased self-consciousness regarding motor impairments. Several participants noticed a shift in their behaviour as they became uncharacteristically quiet.

> I was talkative but now I'm like, shy and anonymous. Because I don't wanna say something like, weird. (age 16)

> My right arm … it kind of just looks like it's like there, like I can't even use it … I'm so worried about people looking at that. (age 16)

> People in the hallway were like, "Oh what happened to you? Why do you limp? Why do you walk like that?" … I wanted to live a normal life, like not have to worry about

> putting all the AFO [ankle foot orthosis] … or taking a special needs bus to school. (age 21)

Theme 4: Keys to Recovery

Recovery looked different from one person to the next, but support and hard work were consistently reported as crucial components for success. Three subthemes summarize the common experiences.

A strong support system. Family and friends were valuable sources of support. Teachers and principals played important roles in transitioning back to school. Some participants brought up fond memories of hospital staff who had made a lasting impact through their kindness. Three youth reported that faith or faith leaders contributed to their recovery.

> If I was by myself doing it, there's no way I would find that strength, but to see everyone cheering me on, on the sidelines, I was like, "okay I can do this, I can get through this." (age 16)

> [The school and rehab team] had a whole afternoon meeting about transition and like, what I needed and everything. … I felt safe. (age 25)

> My classmates were really, really understanding and caring, like I remember they used to compliment my hand splints [laughs]. (age 21)

Determination and hard work. Nearly all participants reported that recovery involved intensive rehabilitation on a daily basis even years after stroke. The importance of determination, hard work, and a positive attitude were discussed.

> I knew I needed to gain strength in my right hand, so I just kept writing with my right hand. … I was like, "okay, just do everything with your right hand." (age 24)

> I'm using the elliptical every day, so I'm working out just to get my strength back. Still not there, but I've improved. (age 18)

Finding your community. Some participants met peers who had undergone a similar medical experience (e.g., acquired brain injury, neurological condition); for them, finding a community that made them feel understood played an important role in their emotional adjustment to stroke. Communities described included adaptive sports teams and support groups.

> I have a lot of friends from ParaSport now, who I wouldn't have met otherwise. … A lot of the advocacy, like self-advocacy I got, or I have now, stems from watching my teammates or someone in the community go through it. (age 25)

> We had a teen lounge. … Just being able to, after therapy, go there and complain about brain injuries and stuff that affected us, I mean, that made a world of a difference. … To have those friends that understood what I was going through. (age 15)

Theme 5: Adjustment and Acceptance

Participants expressed how they had adjusted to their new reality and accepted their stroke. They identified feelings of strength, resilience, and gratitude. Four subthemes reflect their insights.

Adapting, one step at a time. Participants found an array of strategies to compensate for and adapt to motor and cognitive impairments, with practice, patience, and determination.

> Learning how to adapt to do everything with one hand … [is] the hardest thing … like to put on my socks, zip up my coat and stuff. I still haven't learned how to tie my shoes yet. (age 17)

> It took me years to figure out how to put my hair up in a ponytail. (age 25)

> I have to go my own pace and try to understand it slowly, step by step. So, it’s just kind of, go slow and take your time on the basic things. (age 24)

Gratitude. Many participants described feeling grateful that they had survived their stroke and contemplated how the consequences could have been worse.

> I feel like it’s made me a better person ‘cause I am more thankful for little things. … I try to make the most of my life with how it is.’ (age 17)
>
> I know it sounds weird, but after everything, I feel much more appreciative … I’m alive! There’s a huge chance, toss of a coin, that I couldn’t have been, right? (age 15)

Resilience. For most participants, their experience unearthed a resilience they did not know they had. Some also felt the stroke had increased their pain tolerance.

> If I can go through that, then I can go through anything. (age 21)
>
> It did make me stronger for sure. … [If] I have to get a needle for any reason or blood tests or anything, I remember how I’ve been literally through any worse pain. (age 15)
>
> It changed me in a positive way because I overcame it and that’s a really big accomplishment. I survived it. (age 14)

This is me. Stroke changed many aspects of participants’ life and body. They described how they came to terms with who they are today.

> There’s no before and after. It’s just me. (age 25)
>
> It was weird at first, but then I just kind of accepted this is a part of my body now. (age 13)
>
> My stroke is part of my identity. Obviously, every day I’m trying to get better and better, but I don’t hide from it. I'm okay, yeah. I had a stroke, this is who I am today. (age 21)

Advice for Peers with Stroke

Participants were asked what advice they would have for a peer newly diagnosed with stroke. Their responses were organized into categories: 1) Work hard and stay motivated, 2) Expect changes, 3) Surround yourself with supportive people, 4) Do things you enjoy, and 5) Take it day by day. A selection of quotes was compiled (Table 10).

Table 10.

Advice from participants in Study 2 to youth recently diagnosed with stroke

Work hard and stay motivated

‘Say yes to every single thing the therapists are telling you to do. … They know how to help you.’
‘Stay strong and motivated.’
‘Push yourself to the limit and do the best you can. And yes, sometimes it’s going to be hard, and yes you could fail at some things, but it’s natural because you can’t succeed unless you fail once in a while.’
‘I would say that even if it’s hard or it gets boring, to do the physio … because with each time you do it, it will get easier.’

Expect changes

‘You’re gonna face some difficulties and not be able to do things other kids can do, but that’s okay … You’re you and you don't have to be like everyone else.’
‘It might change your health, and sports, if you play any sports, or like any physical stuff, it might change. Also, your emotions might change more too.’
‘You're gonna come out a new person and you're gonna be stronger. … You won’t be the person you were before, and that’s not a bad thing.’

Surround yourself with supportive people

‘If you have the right, good support system, everyone cheering you on, like you’ll be able to push through.’
‘Make sure that there’s a lot of people around you that love you.’
‘Find [your] own community … find someone to go through it together.’
‘Find someone you can talk to, who will really care about you. ... And if it’s not a person in your life, you can go to a psychiatrist or a psychologist who will actually care for you … If you feel overwhelmed, you know, talk to someone about it, don’t just take it on as a burden.’
‘Make sure to tell people who need to know, like the school or something like that, because they can help. Because if they don't know, they can’t do anything.’

Do things you enjoy

‘Find new things to enjoy. I've played sitting volleyball … and then I started golf. So just, you gotta find new things to love and keep yourself entertained.’
‘Just try to make sure you still do everything that you enjoyed doing before your stroke to make it a little more normalized.’
‘Comedy can be a really big relief. … I watch funny stuff. That really, really helps me.’

Take it day by day

‘Don’t worry so much about the future, just worry about the moment.’
‘Have patience. It might seem really, really frustrating at times, but if you have patience and try different things, it will … work out.’
‘Take a day off … You need that mental break. Your emotional recovery is really important, as much as your physical recovery. … You’ll have moments where you’ll have pitfalls and you’ll feel really emotional as to what happened.’
‘Just take your time. It takes time to recover. … You’ll feel slow, but you’ll eventually get there.’

Discussion

This qualitative study investigated adjustment following stroke in adolescence from the perspective of affected youth. Many topics brought up by participants were consistent with concerns indicated in the literature. For instance, a common concern was the negative impact of motor impairments on day-to-day life, social participation, and self-confidence. Past studies have indicated that motor impairments limit the activities youth can participate in and hinder self-confidence (Greenham et al., 2016; O'Keeffe et al., 2017). Youth also reported worries about future independent activities of daily living, which has been identified as a significant challenge in a study examining functional outcome in adults with childhood stroke (Hurvitz et al., 2004). Youth reported self-consciousness and some social anxiety, consistent with findings from a systematic review on psychosocial outcome which indicated that youth with childhood stroke tend to have poorer social adjustment, reduced social participation, and difficulties with peer relationships (O'Keeffe et al., 2017). Youth struggled academically due to difficulties with attention, processing speed, reading, and having missed school time. Similarly, research has shown that most youth with stroke require extra help at school and rates of learning disability are high (Champigny et al., 2020; Everts et al., 2008; O'Keeffe et al., 2017; Williams et al., 2017). In terms of emotional outcome, participants noted symptoms of anxiety and depression, in line with studies on mood disorders following pediatric stroke (Greenham et al., 2015; Lehman et al., 2020; Max et al., 2002) and qualitative studies interviewing families of youth with stroke (McKevitt et al., 2019; Soufi et al., 2017). This study identified positive outcomes and shone light on changes in self-perception, which had not been examined in this population yet. Newfound resilience and gratitude were consistent outcomes that emerged within this sample.

Limitations

This study has three key limitations. Firstly, it is possible that the virtual nature of some interviews limited rapport and disclosure compared to in-person interviews. Secondly, the interviewer was involved in the neuropsychological assessment of two participants, which may have biased their disclosure. To reduce this possibility, she explained during informed consent that discussions in the interview, as well as study participation or decline thereof, would not impact clinical care. Thirdly, qualitative research uses small sample sizes which may affect the generalizability of results. Although the experiences of these participants do not represent the experiences of all youth with stroke, we believe that the patterns and themes that emerged within the interviews illustrate common threads in the lived experiences of this population.

Clinical Implications

Findings have important implications for clinical practice. Many youths struggled with the psychological toll that the stroke onset and long-term recovery took on them, underlining a need to expand the resources offered to families upon discharge and follow-up. We recommend that tertiary care centres discuss the potential psychological repercussions of stroke with families, regularly assess risk at follow-up appointments, and refer for mental health services pre-emptively. In addition, many youth felt like their peers could not understand their experience, and a few had benefitted from meeting others with similar medical experiences. It is recommended that support groups be offered as part of clinical care to connect families impacted by stroke.

Future Directions

Future research should build on the burgeoning literature examining predictors of psychological adjustment following stroke as this line of research can help determine which youth are most at risk for psychopathology. Furthermore, investigation of therapy modalities is key to provide effective support for this population. In line with participant reflections regarding the relief found in meeting others who went through similar experiences, it is our recommendation that researchers consider developing group therapy programs for this population. Lastly, the literature on stroke in adulthood suggests that resilience plays an important role in prognosis and adjustment (Liu et al., 2019). Investigating predictors and correlates of resilience in the pediatric stroke population is warranted to inform the development of psychological support services for affected youth.

Conclusions

This is the first study to examine the lived experience of youth with pediatric stroke from their own perspective. The qualitative design gave participants the space to discuss topics of their choosing. These conversations provided researchers with a unique and personal lens through which to learn about living with pediatric stroke. Participants shared insights regarding the burden of the stroke onset and sequelae, changes in self-perception, coping strategies, and adjustment post-stroke. Some topics converged with those from other studies on outcome after pediatric stroke, such as worries about academics and symptoms of anxiety, while other topics were novel, such as concerns about the future, feelings of resilience and gratitude, and shifts in components of identity. Findings highlight the need to provide mental health support to patients and to assist them in understanding and processing their stroke. As a first step, it is our hope that printouts of the advice given by our participants will be shared clinically to help youth with stroke anticipate what to expect for their recovery, learn strategies to cope with sequelae, feel less alone in their experience, and draw on their resilience to adjust to their new reality.

Chapter 5: General Discussion

Pediatric stroke is an important cause of acquired brain injury (ABI) in infants and children (Fuentes et al., 2016), and long-term neurological sequelae present in up to 80% of survivors (Beslow et al., 2010; Roach et al., 2008). Given the onset of disability in childhood, pediatric stroke carries significant emotional burdens to families and economic costs to society (Tsze & Valente, 2011). Complex neurocognitive impairments are common and can impact a wide range of neuropsychological domains, in turn hindering emotional and behavioural regulation, psychosocial functioning, academic advancement, quality of life, and mental health (Champigny et al., 2020; Gomes et al., 2014; Hajek et al., 2014; Max et al., 2002; O'Keeffe et al., 2014, 2017; Rivella & Viterbori, 2021). Despite awareness of its devastating consequences, pediatric stroke, especially hemorrhagic stroke, remains understudied. An improved understanding of predictors of neurocognitive outcome is warranted to identify children most at risk for worse cognitive outcome and to guide clinical interventions tailored to expected recovery patterns. An investigation of the psychological consequences of pediatric stroke, including processes involved in adjustment to life post stroke and coping with sequelae, is essential to begin developing resources and services that will support patients' mental health.

Overview of Studies

Using a mixed methods approach, my doctoral research comprised two clinical studies aiming to (1) clarify the role of factors identified in the scientific literature as possible predictors of neurocognitive outcome, and (2) shed light on the lived experiences of survivors of childhood stroke, with a focus on psychological adjustment post injury. Both studies were developed and conducted at the Hospital for Sick Children in Toronto, Canada.

Study 1 examined eight factors identified in the literature as possible predictors of neurocognitive outcome following pediatric stroke: age at stroke, stroke type, lesion size, lesion location, time since stroke, neurologic severity, seizures post-stroke, and socioeconomic status. Neurocognitive abilities were assessed in 92 patients with stroke and included abstract reasoning, verbal reasoning, working memory, processing speed, learning ability, long-term memory, attention, visuomotor integration, and executive functioning. Statistical analyses included spline regressions, one-way analysis of variance, Welch's t-tests, and simple linear regressions, to examine associations between predictors and outcome measures.

Study 2 involved one-on-one interviews with 14 adolescents and young adults with a history of stroke in childhood. Interviews were semi-structured, which means there was a set of pre-defined topics and questions as well as freedom to explore answers in greater depth and ask follow-up questions (Queirós et al., 2017). Topics spanned the stroke onset, rehabilitation and coping with sequelae, and adjustment to life post stroke. Transcribed interviews were analysed using inductive thematic analysis, a qualitative methodology that uses an interpretive framework to express the experiences of participants according to their own perspectives (Clarke & Braun, 2013).

Summary of Results

Results from Study 1 identified lesion size, stroke type, age at stroke, and SES as predictors of neurocognitive outcome following pediatric stroke. Large lesions were associated with worse neurocognitive outcomes compared to small to medium lesions across cognitive domains. Exploratory spline regressions suggested that ischemic stroke was associated with worse neurocognitive outcomes than hemorrhagic stroke. Based on patterns shown in graphs, age at stroke appeared to have an impact on outcome depending on the neurocognitive domain and stroke type, with U-shaped trends suggesting worse outcome across most domains when stroke occurred at approximately 5 to 10 years of age. SES positively predicted outcomes across most neurocognitive domains. Participants with seizures had more severe executive functioning impairments than youth without seizures. Youth with combined cortical-subcortical lesions scored lower on abstract reasoning than youth with cortical and youth with subcortical lesions, and lower on attention than youth with cortical lesions. Neurologic severity predicted scores on abstract reasoning, attention, processing speed, and visuomotor integration, depending on stroke type. There was no evidence of differences on outcome measures based on time since stroke, lesion laterality, or lesion region defined as supra- versus infratentorial.

Study 2 investigated adjustment following childhood stroke from the point of view of affected youth. The use of an inductive qualitative methodology provided an avenue through which participants' personal experiences, interpretations, and ideas were prioritized. Participants shared insights regarding the painful and confusing stroke onset, the burden of short- and long-term sequelae, and the strategies they devised to adjust to their new reality. Matters important to them revolved around difficulties keeping up with school, loss of hobbies and abilities, worries about a less independent future, and shifts in behaviour due to self-consciousness. Participants discussed a wide array of sources of support and personal characteristics that helped in their recovery, rehabilitation, and acceptance of their stroke. Lastly, they shared insightful advice for hypothetical peers newly diagnosed with stroke. Findings underscored a need for mental health support for survivors of stroke. Many youth felt alone in their experience and struggled with the burdens of sequelae. Most were open to support groups that would allow them to meet others with similar neurological histories.

The two studies in this dissertation complement each other because neurocognitive impairments and adjustment to life following stroke are closely interrelated. Study 1 examined predictors of neurocognitive outcome across a range of neuropsychological domains, while Study 2 provided a deeper personal lens through which to view the day-to-day impact of neurocognitive impairments, among other sequelae, on post-stroke adjustment. Adjustment entails coping with stroke sequelae and establishing good social-emotional well-being. Neurocognitive deficits can hinder social-emotional functioning (Lo, Gordon, Hajek, Gomes, Greenham, Perkins, et al., 2014) by causing difficulties with communication, academic advancement, and emotion and behaviour regulation (Champigny et al., 2020; Denham et al., 2007; Deotto et al., 2019; Gordon et al., 2002; Steinlin et al., 2004). In Study 2, participants reported many challenges that were influenced by impairments in cognitive functioning, such as feeling overwhelmed in class, worrying about securing employment in the future, and difficulty communicating in social situations. Youth with stroke may also experience social difficulties such as decreased social acceptance (Everts et al., 2008), changes in peer relationships (O'Keeffe et al., 2012), reduced social participation (Anderson et al., 2014), and social isolation (Bakopoulou & Dockrell, 2016; Mukherjee et al., 2006), all of which can be exacerbated by cognitive deficits. Studies have found that social support may promote cognitive resilience, supporting the notion that the relationship between social and cognitive functioning is reciprocal (Glymour et al., 2008). Furthermore, neurocognitive deficits may place youth at increased risk for mood and anxiety disorders (Max et al., 2002). Symptoms of depression may arise due to loss of cognitive abilities while symptoms of anxiety may reflect worries about the future in light of cognitive limitations (Mukherjee et al., 2006). The relationship between neurocognitive deficits and social-emotional well-being is bidirectional and dynamic; for instance, depression is associated with decreased processing speed and executive function, and symptoms of anxiety (e.g., rumination) may impair working memory and attention (Knight & Baune, 2018; Mukherjee et al., 2006). Using a mixed methods approach to the conduct of this research allowed for understanding more about children with ischemic and hemorrhagic stroke with standardized measures that are used in clinical practice combined with a follow up on lived experiences. The conclusions drawn from each study have an impact on clinical practice and future research.

Clinical Implications

This dissertation yielded clinically applicable findings that should be considered in the practice of medical professionals working with youth with stroke. Treating children with stroke requires competencies and knowledge specific to the heterogeneous and transitional nature of this population, which necessitates a solid grasp of scientific advances in the field (Popernack et al., 2015). The current dissertation contributes to the literature by providing novel insights that can inform clinical practice.

Results from both studies underscore the importance of considering a patient's environment to optimize assessment and treatment. Study 1 identified SES as a key predictor of neurocognitive outcome. Extending this finding, it is recommended that clinicians assess and understand the impact of patient circumstances in their practice. For instance, SES may influence accessibility to treatments and services based on the family's financial means and geographic location. Study 2 underlined the value of strong support systems, especially families, in adjusting to life after stroke. An important responsibility of clinicians includes communicating expected patterns of recovery to families (Watson et al., 2022; Ylvisaker et al., 2005), as families are in a unique position to support rehabilitation following brain injury through scaffolding and emotional support (Watson et al., 2022; Ylvisaker et al., 2005) and caregivers can provide warmth, encouragement, and advocacy for their children (Deotto, 2022; LeBlond et al., 2021; Wade et al., 2011). Family-centered psychoeducation can help manage expectations, assist with adjustment, and facilitate transitions back to the home, school, and community (Koterba & Hoskinson, 2018). High-quality clinical care requires a thorough understanding of the multiple layers of a child's environment; in this way, diagnostic formulation is more accurate and referral to support services can be tailored to the needs of each family. Overall, a holistic approach using a biopsychosocial framework is needed to effectively consider non-clinical factors (e.g., environment, culture) that can influence stroke recovery.

Study 2 underlined unmet needs regarding mental health support following stroke. Participants discussed symptoms of anxiety and depression as well as low self-esteem, social isolation, and feeling misunderstood. It is recommended that clinicians discuss the potential psychological repercussions of stroke with families, regularly assess risk for mental health concerns, and refer to appropriate services and resources when applicable. To date, there are no published studies examining psychotherapeutic interventions for youth with stroke to guide clinical recommendations; however, a few studies have shown promising results for pediatric ABI populations (Ross et al., 2011). Moreover, in line with participant reflections regarding the rarity of peer support groups and the relief found in meeting others who went through similar experiences, it is our recommendation that tertiary care centres offer support groups to connect families impacted by stroke.

Lastly, Study 2 also showcased the insightfulness and self-awareness of youth with stroke regarding their needs. Findings should encourage clinicians to interview youth and not just caregivers to gain a more comprehensive idea of recovery and associated challenges. In fact, pediatric mental health research has shown trends towards the inclusion of children's perspectives on their own well-being, recognizing them as "competent interpreters of their everyday worlds" (Mason & Danby, 2011, p. 186). Listening to youth with stroke and appreciating their point of view is essential in establishing trust and rapport and can inform diagnoses and referral for additional services.

Limitations and Future Directions

This dissertation has limitations that should be addressed in future work, beginning with self-selection bias. A common drawback in research that limits the generalizability of findings, self-selection bias likely influenced which families chose to participate in our studies. Study 1 required neuropsychological testing lasting several hours, in-person, at the Hospital for Sick Children. Some families may have declined to participate due to lack of time, difficulties with commuting to the hospital, childcare requirements for siblings, and caregivers needing to request time off work or children missing school. Study 2 provided more flexibility because the interview was less time-consuming and could be conducted virtually (*Zoom for Healthcare*, 2016), which was especially useful for participants living remotely. Nonetheless, it is possible that youth who agreed to being interviewed differed from youth who declined. To minimize self-selection bias, we offered families flexible time slots to participate (e.g., week-ends and evenings), overlap between clinical appointments at the hospital and the research session, a virtual option for interviews, and compensation for their time (i.e., gift cards, volunteer hours certificates, and individualized summary reports of testing results).

Generalizability of findings and validity of results are often a concern in research. The sample in Study 1 (n=92) was larger than seen in most neuropsychological studies on pediatric stroke, which frequently include 20 to 40 participants due to the rarity of this neurological population. The decision to have few exclusion criteria was made in order to increase the number of eligible participants and ensure the representativeness of our sample within the heterogenous pediatric stroke population. Despite these efforts, our sample size was statistically small, which signifies that analyses may have been underpowered and the number of significant associations may have been overestimated. With transparency, many analyses were presented as exploratory, with a focus on providing preliminary data illustrating trends and patterns of interest. Large-scale studies are needed to replicate our results and assess generalizability of findings. Multi-centre collaborations would be beneficial in providing larger sample sizes so that models can include more predictors with enough statistical power. Study 2 also has challenges with replication and generalizability of findings. Due to the nature of semi-structured interviews as a discussion between the researcher and the participant, each transcript is unique, which renders the study impossible to replicate and the validity of findings difficult to confirm in a larger population (Queirós et al., 2017).

A limitation of Study 2 pertains to the analytic procedure inevitably involving interpretation on the part of the researchers, whose expectations and personal biases influence both the interview and the analysis (Braun & Clarke, 2006). It would be a "naive realist view of qualitative research" to assume that researchers can be passive vehicles that simply give a voice to participants (Braun & Clarke, 2006, p. 80). Actions were undertaken to minimize the impact of personal interpretation. First, two coders analyzed the data independently and discrepancies were discussed; by consistently examining interrater reliability, the possibility that a participant's words were interpreted differently than intended was reduced. Second, both researchers reflected on and monitored their personal biases and expectations when coding the data and generating themes.

Though Study 1 emphasized mostly clinical factors, individual variability in outcome following pediatric stroke may be modulated by non-clinical factors, as supported by our findings regarding SES. A relatively novel line of research has begun exploring environmental factors that can influence outcome following pediatric brain injury, such as the home environment and family functioning (Anderson et al., 2014; Deotto, 2022; Greenham et al., 2015; Semrud-Clikeman, 2010). This research aligns with the concept of reserve; the support available within the child, family, school, and community contributes to neurobehavioural outcome following an insult to the central nervous system (Dennis, 2000). Further research investigating non-clinical predictors of neurocognitive outcome in pediatric stroke would complement current research efforts that focus on clinical factors.

Following ABI, adjustment challenges may emerge and translate to mental health difficulties, with adolescent females particularly at risk (Hendry et al., 2020). In line with findings from Study 2, research has shown that ABI can impede self-esteem and beliefs about competency (Ownsworth, 2014; Pastore et al., 2015), and that elevated symptoms of anxiety and depression are common following stroke (Deotto, 2022; Lehman et al., 2020; Max et al., 2002; Westmacott et al., 2018). Mental health concerns can be directly due to the brain injury; for instance, they may arise from damage to fronto-limbic structures that control emotion and behaviour regulation (Watson et al., 2022). As discussed in Study 2 and in line with the current literature, they may also appear due to frustrations related to new limitations and impairments, long hospital stays and treatments, changing relationships, and academic difficulties (Jorge et al., 2004; Ownsworth et al., 2011; Pastore et al., 2014; Üstün et al., 2003; Watson et al., 2022). Future studies should build on the burgeoning literature examining predictors of psychological adjustment following stroke as this line of research can help determine which youth are most at risk for psychiatric concerns.

Knowledge of predictors of neurocognitive outcome is particularly useful if clinicians can refer patients to evidence-based neurorehabilitation services. Neurorehabilitation involves restoring cognitive function, teaching compensatory strategies, and adapting environments to increase functional independence (Watson et al., 2022). Regrettably, a limited number of studies have investigated cognitive neurorehabilitation following ABI, and those that have, have seldom followed the gold standard design of randomized controlled trials and blind outcome measures (Laatsch et al., 2007). This line of research has expanded in recent years (Haskins, 2012; Locascio & Slomine, 2018; Ross et al., 2011; Wade et al., 2010, 2014), but further work is needed to establish efficacy of neurorehabilitation programs for youth with ABI.

Conclusion

The overarching goal of this dissertation was to contribute to the advancement of research in developmental neuropsychology and to produce novel and clinically applicable findings regarding outcomes in pediatric stroke. An improved understanding of predictors of neurocognitive outcome and adjustment following stroke is especially valuable to clinicians who have pivotal roles related to assessment, diagnosis, treatment, and referral. Findings from this dissertation should inform clinical practice as well as the development of services and interventions aimed at fostering optimal development for youth with stroke.

References

Abgottspon, S., Thaqi, Q., Steiner, L., Slavova, N., Grunt, S., Steinlin, M., & Everts, R. (2022). Effect of age at pediatric stroke on long-term cognitive outcome. *Neurology*, *98*(7), E721–E729. https://doi.org/10.1212/WNL.0000000000013207

Agrawal, N., Johnston, S. C., Wu, Y. W., Sidney, S., & Fullerton, H. J. (2009). Imaging data reveal a higher pediatric stroke incidence than prior U.S. estimates. *Stroke*, *40*(11), 3415. https://doi.org/10.1161/STROKEAHA.109.564633

Alaszewski, A., Alaszewski, H., & Potter, J. (2004). The bereavement model, stroke and rehabilitation: A critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation*, *26*(18), 1067–1078. https://doi.org/10.1080/09638280410001703521

Allman, C., & Scott, R. B. (2013). Neuropsychological sequelae following pediatric stroke: a nonlinear model of age at lesion effects. *Child Neuropsychology*, *19*(1), 97–107. https://doi.org/10.1080/09297049.2011.639756

Amlie-Lefond, C., Bernard, T. J., Sebire, G., Friedman, N. R., Heyer, G. L., Lerner, N. B., Deveber, G., & Fullerton, H. J. (2009). Predictors of cerebral arteriopathy in children with arterial ischemic stroke: Results of the International Pediatric Stroke Study. *Circulation*, *119*(10), 1417–1423. https://doi.org/10.1161/CIRCULATIONAHA.108.806307

Anderson, V., Gomes, A., Greenham, M., Hearps, S., Gordon, A., Rinehart, N., Gonzalez, L., Yeates, K. O., Hajek, C. A., Lo, W., & Mackay, M. (2014). Social competence following pediatric stroke: Contributions of brain insult and family environment. *Social Neuroscience*, *9*(5), 471–483. https://doi.org/10.1080/17470919.2014.932308

Anderson, V., Spencer-Smith, M., & Wood, A. (2011). Do children really recover better? Neurobehavioural plasticity after early brain insult. *Brain*, *134*(Pt 8), 2197–2221. https://doi.org/10.1093/brain/awr103

Avila, L., Riesgo, R., Pedroso, F., Goldani, M., Danesi, M., Ranzan, J., & Sleifer, P. (2010). Language and focal brain lesion in childhood. *Journal of Child Neurology*, *25*(7), 829–833. https://doi.org/10.1177/0883073809350724

Badar, S. A., Radhakrishnan, R., & Golomb, M. R. (2020). The impact of pediatric basal ganglia stroke on mental health in children: Report of 2 cases. *Child Neurology Open*, *7*, 2329048X2097924. https://doi.org/10.1177/2329048X20979248

Bakopoulou, I., & Dockrell, J. E. (2016). The role of social cognition and prosocial behaviour in relation to the socio-emotional functioning of primary aged children with specific language impairment. *Research in Developmental Disabilities*, *49–50*(Complete), 354–370. https://doi.org/10.1016/j.ridd.2015.12.013

Ballantyne, A. O., Spilkin, A. M., Hesselink, J., & Trauner, D. A. (2008). Plasticity in the developing brain: Intellectual, language and academic functions in children with ischaemic perinatal stroke. *Brain*, *131*(11), 2975–2985. https://doi.org/10.1093/brain/awn176

Ballantyne, A. O., Spilkin, A. M., & Trauner, D. A. (2007). Language outcome after perinatal stroke: Does side matter? *Child Neuropsychology*, *13*(6), 494–509. https://doi.org/10.1080/09297040601114878

Bartha-Doering, L., Gleiss, A., Knaus, S., Schmook, M. T., & Seidl, R. (2021). Influence of socioeconomic status on cognitive outcome after childhood arterial ischemic stroke. *Developmental Medicine and Child Neurology*, *63*(4), 465–471. https://doi.org/10.1111/DMCN.14779

Bartha-Doering, L., Novak, A., Kollndorfer, K., Schuler, A. L., Kasprian, G., Langs, G., Schwartz, E., Fischmeister, F. P. S., Prayer, D., & Seidl, R. (2019). Atypical language representation is unfavorable for language abilities following childhood stroke. *European Journal of Paediatric Neurology*, *23*(1), 102–116. https://doi.org/10.1016/J.EJPN.2018.09.007

Beery, K. E., Buktenica, N. A., & Beery, N. A. (2010). *Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery VMI-6)*. Pearson.

Beslow, L. A., Abend, N. S., Gindville, M. C., Bastian, R. A., Licht, D. J., Smith, S. E., Hillis, A. E., Ichord, R. N., & Jordan, L. C. (2013). Pediatric intracerebral hemorrhage: Acute symptomatic seizures and epilepsy. *JAMA Neurology*, *70*(4), 448. https://doi.org/10.1001/JAMANEUROL.2013.1033

Beslow, L. A., Ichord, R. N., Gindville, M. C., Kleinman, J. T., Engelmann, K., Bastian, R. A., Licht, D. J., Smith, S. E., Hillis, A. E., & Jordan, L. C. (2014). Pediatric intracerebral hemorrhage score: A simple grading scale for intracerebral hemorrhage in children. *Stroke*, *45*(1), 66–70. https://doi.org/10.1161/STROKEAHA.113.003448

Beslow, L. A., & Jordan, L. C. (2010). Pediatric Stroke: The Importance of Cerebral Arteriopathy and Vascular Malformations. *Child's Nervous System*, *26*(10), 1263–1273. https://doi.org/10.1007/s00381-010-1208-9

Beslow, L. A., Licht, D. J., Smith, S. E., Storm, P. B., Heuer, G. G., Zimmerman, R. A., Feiler, A. M., Kasner, S. E., Ichord, R. N., & Jordan, L. C. (2010). Predictors of outcome in childhood intracerebral hemorrhage: A prospective consecutive cohort study. *Stroke*, *41*(2), 313–318. https://doi.org/10.1161/STROKEAHA.109.568071

Blauwblomme, T., Bourgeois, M., Meyer, P., Puget, S., di Rocco, F., Boddaert, N., Zerah, M., Brunelle, F., Sainte-Rose, C., & Naggara, O. (2014). Long-term outcome of 106 consecutive pediatric ruptured brain arteriovenous malformations after combined treatment. *Stroke*, *45*(6), 1664–1671. https://doi.org/10.1161/STROKEAHA.113.004292

Blom, I., de Schryver, E. L. L. M., Kappelle, L. J., Rinkel, G. J. E., Jennekens-Schinkel, A., & Peters, A. C. B. (2003). Prognosis of haemorrhagic stroke in childhood: A long-term follow-up study. *Developmental Medicine and Child Neurology*, *45*(4), 233–239.

Bolk, J., Simatou, E., Söderling, J., Thorell, L. B., Persson, M., & Sundelin, H. (2022). Association of perinatal and childhood ischemic stroke with attention-deficit/hyperactivity disorder. *JAMA Network Open*, E228884. https://doi.org/10.1001/jamanetworkopen.2022.8884

Bonfert, M. v., Badura, K., Gerstl, J., Borggraefe, I., Heinen, F., Schroeder, S., Olivieri, M., Weinberger, R., Landgraf, M. N., Vill, K., Tacke, M., Berweck, S., Reiter, K., Hoffmann, F., Nicolai, T., & Gerstl, L. (2018). Childhood stroke: Awareness, interest, and knowledge among the pediatric community. *Frontiers in Pediatrics*, *6*, 182. https://doi.org/10.3389/FPED.2018.00182/FULL

Bosenbark, D. D., Krivitzky, L., Ichord, R., Jastrzab, L., & Billinghurst, L. (2018). Attention and executive functioning profiles in children following perinatal arterial ischemic stroke. *Child Neuropsychology*, *24*(1), 106–123. https://doi.org/10.1080/09297049.2016.1225708

Bosenbark, D. D., Krivitzky, L., Ichord, R., Vossough, A., Bhatia, A., Jastrzab, L. E., & Billinghurst, L. (2017). Clinical Predictors of Attention and Executive Functioning Outcomes in Children After Perinatal Arterial Ischemic Stroke. *Pediatric Neurology*, *69*, 79–86. https://doi.org/10.1016/J.PEDIATRNEUROL.2017.01.014

Boulouis, G., Blauwblomme, T., Hak, J. F., Benichi, S., Kirton, A., Meyer, P., Chevignard, M., Tournier-Lasserve, E., MacKay, M. T., Chabrier, S., Cordonnier, C., Kossorotoff, M., & Naggara, O. (2019). Nontraumatic pediatric intracerebral hemorrhage. *Stroke*, *50*(12), 3654–3661. https://doi.org/10.1161/STROKEAHA.119.025783

Braun, K. P. J., Kappelle, L. J., Kirkham, F. J., & DeVeber, G. (2006). Diagnostic pitfalls in paediatric ischaemic stroke. *Developmental Medicine and Child Neurology*, *48*(12), 985–990. https://doi.org/10.1017/S0012162206002167

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Cárdenas, J. F., Rho, J. M., & Kirton, A. (2011). Pediatric stroke. *Child's Nervous System*, *27*(9), 1375–1390. https://doi.org/10.1007/s00381-010-1366-9

Champigny, C. M., Deotto, A., Westmacott, R., Dlamini, N., & Desrocher, M. (2020). Academic outcome in pediatric ischemic stroke. *Child Neuropsychology*, *26*(6), 817–833. https://doi.org/10.1080/09297049.2020.1712346

Clarke, V., & Braun, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. Sage.

Cooper, A. N., Anderson, V., Hearps, S., Greenham, M., Ditchfield, M., Coleman, L., Hunt, R. W., MacKay, M. T., Monagle, P., & Gordon, A. L. (2017). Trajectories of motor recovery in the first year after pediatric arterial ischemic stroke. *Pediatrics*, *140*(2), 20163870. https://doi.org/10.1542/PEDS.2016-3870/38655

Cruz, E. B. (2001). Stroke in children. *Loss, Grief & Care*, *9*(1–2), 45–60. https://doi.org/10.1300/J132v09n01_05 de Montferrand, C., Vassel-Hitier, J., Yvon-Chaou, E., Câmara-Costa, H., Dellatolas, G., & Chevignard, M. (2019). Language and cognitive outcomes after childhood stroke: Theoretical implications for hemispheric specialization. *Cortex*, *120*, 509–523. https://doi.org/10.1016/J.CORTEX.2019.07.020

de Schryver, E. L. L. M., Kappelle, L. J., Jennekens-Schinkel, A., & Peters, A. C. B. (2000). Prognosis of ischemic stroke in childhood: A long-term follow-up study. *Developmental Medicine & Child Neurology*, *42*(5), 313–318. https://doi.org/10.1017/S0012162200000554

Delis, D. C., Kramer, J. H., Kaplan, E., & Ober, B. A. (1994). *California Verbal Learning Test for Children (CVLT-C)*. Pearson.

Delis, D. C., Kramer, J. H., Kaplan, E., & Ober, B. A. (2017). *California Verbal Learning Test, Third Edition (CVLT-3)*. Pearson.

Denham, S. A., Bassett, H. H., & Wyatt, T. (2007). The Socialization of Emotional Competence. In J. E. Grusec & P. D. Hastings (Eds.), *Handbook of socialization: Theory and research* (pp. 614–637). Guilford Press. http://psycnet.apa.org/psycinfo/2006-23344-024

Dennis, M. (2000). Developmental plasticity in children: The role of biological risk, development, time, and reserve. *Journal of Communication Disorders*, *33*(4), 321–332. https://doi.org/10.1016/S0021-9924(00)00028-9

Dennis, M. (2010). Margaret Kennard (1899–1975): Not a ‘principle’ of brain plasticity but a founding mother of developmental neuropsychology. *Cortex*, *46*(8), 1043–1059. https://doi.org/10.1016/j.cortex.2009.10.008

Deotto, A. (2022). *Environment, cognitive, and neurological predictors of mental health following pediatric stroke: A mixed methods framework* [Doctor of Philosophy]. York University.

Deotto, A., Westmacott, R., Fuentes, A., deVeber, G., & Desrocher, M. (2019). Does stroke impair academic achievement in children? The role of metacognition in math and spelling outcomes following pediatric stroke. *Journal of Clinical and Experimental Neuropsychology*, *41*(3), 257–269. https://doi.org/10.1080/13803395.2018.1533528

deVeber, G. A., Kirton, A., Booth, F. A., Yager, J. Y., Wirrell, E. C., Wood, E., Shevell, M., Surmava, A. M., McCusker, P., Massicotte, M. P., MacGregor, D., MacDonald, E. A., Meaney, B., Levin, S., Lemieux, B. G., Jardine, L., Humphreys, P., David, M., Chan, A. K. C., … Bjornson, B. H. (2017). Epidemiology and outcomes of arterial ischemic stroke in children: The Canadian Pediatric Ischemic Stroke Registry. *Pediatric Neurology*, *69*, 58–70. https://doi.org/10.1016/J.PEDIATRNEUROL.2017.01.016

deVeber, G. A., MacGregor, D., Curtis, R., & Mayank, S. (2000). Neurologic outcome in survivors of childhood arterial ischemic stroke and sinovenous thrombosis. *Journal of Child Neurology*, *15*(5), 316–324. https://doi.org/10.1177/088307380001500508

Earley, C. J., Kittner, S. J., Feeser, B. R., Gardner, J., Epstein, A., Wozniak, M. A., Wityk, R., Stern, B. J., Price, T. R., Macko, R. F., Johnson, C., Sloan, M. A., & Buchholz, D. (1998). Stroke in children and sickle-cell disease: Baltimore-Washington Cooperative Young Stroke Study. *Neurology*, *51*(1), 169–176. https://doi.org/10.1212/WNL.51.1.169

Everts, R., Pavlovic, J., Kaufmann, F., Uhlenberg, B., Seidel, U., Nedeltchev, K., Perrig, W., & Steinlin, M. (2008). Cognitive functioning, behavior, and quality of life after stroke in childhood. *Child Neuropsychology*, *14*(4), 323–338. https://doi.org/10.1080/09297040701792383

Ferriero, D. M., Fullerton, H. J., Bernard, T. J., Billinghurst, L., Daniels, S. R., Debaun, M. R., Deveber, G., Ichord, R. N., Jordan, L. C., Massicotte, P., Meldau, J., Roach, E. S., & Smith,

E. R. (2019). Management of stroke in neonates and children: A scientific statement from the American Heart Association/American Stroke Association. *Stroke*, *50*(3), E51–E96. https://doi.org/10.1161/STR.0000000000000183

Fitch, R. H., Alexander, M. L., & Threlkeld, S. W. (2013). Early neural disruption and auditory processing outcomes in rodent models: Implications for developmental language disability. *Frontiers in Systems Neuroscience*, *7*(OCT). https://doi.org/10.3389/FNSYS.2013.00058

Fitzgerald, K. C., Williams, L. S., Garg, B. P., Carvalho, K. S., & Golomb, M. R. (2006). Cerebral sinovenous thrombosis in the neonate. *Archives of Neurology*, *63*(3), 405–409. https://doi.org/10.1001/ARCHNEUR.63.3.405

Ford, A., Douglas, J., & Ohalloran, R. (2021). The experience of close personal relationships after stroke: Scoping review and thematic analysis of qualitative literature. *Brain Impairment*. https://doi.org/10.1017/BRIMP.2021.12

Fox, C. K., Johnston, S. C., Sidney, S., & Fullerton, H. J. (2012). High critical care usage due to pediatric stroke: Results of a population-based study. *Neurology*, *79*(5), 420. https://doi.org/10.1212/WNL.0B013E3182616FD7

Friese, S. (2021). *ATLAS.ti* (22.0.0.214). ATLAS.ti Scientific Software Development GmbH.

Fuentes, A., Deotto, A., Desrocher, M., DeVeber, G., & Westmacott, R. (2016). Determinants of cognitive outcomes of perinatal and childhood stroke: A review. *Child Neuropsychology*, *22*(1), 1–38. https://doi.org/10.1080/09297049.2014.969694

Fullerton, H. J., Chetkovich, D. M., Wu, Y. W., Smith, W. S., & Johnston, S. C. (2002). Deaths from stroke in US children, 1979 to 1998. *Neurology*, *59*(1), 34–39. https://doi.org/10.1212/WNL.59.1.34

Fullerton, H. J., Hills, N. K., Elkind, M. S. V., Dowling, M. M., Wintermark, M., Glaser, C. A., Tan, M., Rivkin, M. J., Titomanlio, L., James Barkovich, A., & DeVeber, G. A. (2015). Infection, vaccination, and childhood arterial ischemic stroke: Results of the VIPS study. *Neurology*, *85*(17), 1459–1466. https://doi.org/10.1212/WNL.0000000000002065

Fullerton, H. J., Wu, Y. W., Sidney, S., & Johnston, S. C. (2007). Recurrent hemorrhagic stroke in children: a population-based cohort study. *Stroke*, *38*(10), 2658–2662. https://doi.org/10.1161/STROKEAHA.107.481895

Funnell, E., & Pitchford, N. J. (2010). Reading disorders and weak Verbal IQ following left hemisphere stroke in children: no evidence of compensation. *Cortex*, *46*(10), 1248–1258. https://doi.org/10.1016/J.CORTEX.2010.06.013

Gabis, L. v, Yangala, R., & Lenn, N. J. (2002). Time lag to diagnosis of stroke in children. *Pediatrics*, *110*(5), 924–928. https://doi.org/10.1542/peds.110.5.924

Ganesan, V., Hogan, A., Shack, N., Gordon, A., Isaacs, E., & Kirkham, F. J. (2000). Outcome after ischaemic stroke in childhood. *Developmental Medicine & Child Neurology*, *42*(7), 455–461. https://doi.org/10.1017/S0012162200000852

Ganesan, V., Prengler, M., McShane, M. A., Wade, A. M., & Kirkham, F. J. (2003). Investigation of risk factors in children with arterial ischemic stroke. *Annals of Neurology*, *53*(2), 167–173. https://doi.org/10.1002/ana.10423

Giang, K. W., Mandalenakis, Z., Dellborg, M., Lappas, G., Eriksson, P., Hansson, P. O., & Rosengren, A. (2018). Long-term risk of hemorrhagic stroke in young patients with congenital heart disease. *Stroke*, *49*(5), 1155–1162. https://doi.org/10.1161/STROKEAHA.117.020032

Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2015). *Behavior Rating Inventory of Executive Function – Second Edition (BRIEF-2)*. Psychological Assessment Resources.

Giudice, C., Rogers, E. E., Johnson, B. C., Glass, H. C., & Shapiro, K. A. (2019). Neuroanatomical correlates of sensory deficits in children with neonatal arterial ischemic stroke. *Developmental Medicine and Child Neurology*, *61*(6), 667–671. https://doi.org/10.1111/DMCN.14101

Glymour, M. M., Weuve, J., Fay, M. E., Glass, T., & Berkman, L. F. (2008). Social ties and cognitive recovery after stroke: Does social integration promote cognitive resilience? *Neuroepidemiology*, *31*(1), 10–20. https://doi.org/10.1159/000136646

Goeggel Simonetti, B., Cavelti, A., Arnold, M., Bigi, S., Regényi, M., Mattle, H. P., Gralla, J., Fluss, J., Weber, P., Hackenberg, A., Steinlin, M., & Fischer, U. (2015). Long-term outcome after arterial ischemic stroke in children and young adults. *Neurology*, *84*(19), 1941–1947. https://doi.org/10.1212/WNL.0000000000001555

Golomb, M. R., MacGregor, D. L., Domi, T., Armstrong, D. C., McCrindle, B. W., Mayank, S., & Deveber, G. A. (2001). Presumed pre- or perinatal arterial ischemic stroke: Risk factors and outcomes. *Annals of Neurology*, *50*(2), 163–168. https://doi.org/10.1002/ANA.1078

Gomes, A., Rinehart, N., Greenham, M., & Anderson, V. (2014). A critical review of psychosocial outcomes following childhood stroke (1995-2012). *Developmental Neuropsychology*, *39*(1), 9–24. https://doi.org/10.1080/87565641.2013.827197

Gordon, A. L., Anderson, V., Ditchfield, M., Coleman, L., Mackay, M. T., Greenham, M., Hunt, R. W., & Monagle, P. (2015). Factors associated with six-month outcome of pediatric stroke. *Journal of Stroke*, *10*(7), 1068–1073. https://doi.org/10.1111/ijs.12489

Gordon, A. L., Ganesan, V., Towell, A., & Kirkham, F. J. (2002). Functional outcome following stroke in children. *Journal of Child Neurology*, *17*(6), 429–434. https://doi.org/10.1177/088307380201700606

Gould, K. R., & Ponsford, J. L. (2015). A longitudinal examination of positive changes in quality-of-life after traumatic brain injury. *Brain Injury*, *29*(3), 283–290. https://doi.org/10.3109/02699052.2014.974671

Grace, J. J., Kinsella, E. L., Muldoon, O. T., & Fortune, D. G. (2015). Post-traumatic growth following acquired brain injury: A systematic review and meta-analysis. *Frontiers in Psychology*, *6*. https://doi.org/10.3389/FPSYG.2015.01162

Greenham, M., Anderson, V., Cooper, A., Hearps, S., Ditchfield, M., Coleman, L., Hunt, R. W., Mackay, M. T., Monagle, P., & Gordon, A. L. (2017). Early predictors of psychosocial functioning 5 years after paediatric stroke. *Developmental Medicine and Child Neurology*, *59*(10), 1034–1041. https://doi.org/10.1111/DMCN.13519

Greenham, M., Anderson, V., Hearps, S., Ditchfield, M., Coleman, L., Mackay, M. T., Monagle, P., & Gordon, A. L. (2017). Psychosocial function in the first year after childhood stroke. *Developmental Medicine and Child Neurology*, *59*(10), 1027–1033. https://doi.org/10.1111/DMCN.13387

Greenham, M., Gordon, A., Anderson, V., & Mackay, M. T. (2016). Outcome in childhood stroke. *Stroke*, *47*(4), 1159–1164. https://doi.org/10.1161/STROKEAHA.115.011622

Greenham, M., Hearps, S., Gomes, A., Rinehart, N., Gonzalez, L., Gordon, A., Mackay, M., Lo, W., Yeates, K., & Anderson, V. (2015). Environmental contributions to social and mental health outcomes following pediatric stroke. *Developmental Neuropsychology*, *40*(6), 348–362. https://doi.org/10.1080/87565641.2015.1095191

Grunt, S., Mazenauer, L., Buerki, S. E., Boltshauser, E., Mori, A. C., Datta, A. N., Fluss, J., Mercati, D., Keller, E., Maier, O., Poloni, C., Ramelli, G. P., Schmitt-Mechelke, T., & Steinlin, M. (2015). Incidence and outcomes of symptomatic neonatal arterial ischemic stroke. *Pediatrics*, *135*(5), e1220–e1228. https://doi.org/10.1542/PEDS.2014-1520

Guédon, A., Blauwblomme, T., Boulouis, G., Jousset, C., Meyer, P., Kossorotoff, M., Bourgeois, M., Puget, S., Zerah, M., Oppenheim, C., Meder, J. F., Boddaert, N., Brunelle, F., Sainte-Rose, C., & Naggara, O. (2018). Predictors of outcome in patients with pediatric intracerebral hemorrhage: Development and validation of a modified score. *Radiology*, *286*(2), 651–658. https://doi.org/10.1148/RADIOL.2017170152

Gulek-Bakirci, B. G. (2022). *Oscillating between gratitude and fear: Lived experience of aneurysmal subarachnoid hemorrhage survivors and health related quality of life*. Washington State University.

Günther, G., Junker, R., Sträter, R., Schobess, R., Kurnik, K., Kosch, A., & Nowak-Göttl, U. (2000). Symptomatic ischemic stroke in full-term neonates: Role of acquired and genetic prothrombotic risk factors. *Stroke*, *31*(10), 2437–2441. https://doi.org/10.1161/01.STR.31.10.2437

Hajek, C. A., Yeates, K. O., Anderson, V., Mackay, M., Greenham, M., Gomes, A., & Lo, W. (2014). Cognitive outcomes following arterial ischemic stroke in infants and children. *Journal of Child Neurology*, *29*(7), 887–894. https://doi.org/10.1177/0883073813491828

Härtel, C., Schilling, S., Sperner, J., & Thyen, U. (2004). The clinical outcomes of neonatal and childhood stroke: Review of the literature and implications for future research. *European Journal of Neurology*, *11*(7), 431–438. https://doi.org/10.1111/J.1468-1331.2004.00861.X

Haskins, E. C. (2012). *Cognitive Rehabilitation Manual: Translating Evidence-Based Recommendations into Practice* (L. E. Trexler, K. Cicerone, K. Dams-O'Connor, R. Eberle, D. Langenbahn, & A. Shapiro-Rosenbaum, Eds.). American Congress of Rehabilitation Medicine.

Hawks, C., Jordan, L. C., Gindville, M., Ichord, R. N., Licht, D. J., & Beslow, L. A. (2016). Educational placement after pediatric intracerebral hemorrhage. *Pediatric Neurology*, *61*, 46–50. https://doi.org/10.1016/j.pediatrneurol.2016.05.004

Hawley, C. A., & Joseph, S. (2008). Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury*, *22*(5), 427–435. https://doi.org/10.1080/02699050802064607

Hemphill, J. C., Bonovich, D. C., Besmertis, L., Manley, G. T., & Johnston, S. C. (2001). The ICH score: A simple, reliable grading scale for intracerebral hemorrhage. *Stroke*, *32*(4), 891–896. https://doi.org/10.1161/01.STR.32.4.891

Hemphill, J. C., Farrant, M., & Neill, T. A. (2009). Prospective validation of the ICH Score for 12-month functional outcome. *Neurology*, *73*(14), 1088–1094. https://doi.org/10.1212/WNL.0B013E3181B8B332

Hendry, K., Ownsworth, T., Waters, A. M., Jackson, M., & Lloyd, O. (2020). Investigation of children and adolescents' mood and self-concept after acquired brain injury. *Child Neuropsychology*, *26*(8), 1005–1025. https://doi.org/10.1080/09297049.2020.1750577

Hurvitz, E. A., Warschausky, S., Berg, M., & Tsai, S. (2004). Long-term functional outcome of pediatric stroke survivors. *Topics in Stroke Rehabilitation*, *11*(2), 51–59. https://doi.org/10.1310/CL09-U2QA-9M5A-ANG2

IBM Corp. (2021). *IBM SPSS Statistics* (28.0.1.0(142)). IBM Corp.

Jack, S. M., & Phoenix, M. (2022). Qualitative health research in the fields of developmental medicine and child neurology. *Developmental Medicine and Child Neurology*, *64*(7), 830–839. https://doi.org/10.1111/DMCN.15182

Jacomb, I., Porter, M., Brunsdon, R., Mandalis, A., & Parry, L. (2018). Cognitive outcomes of pediatric stroke. *Child Neuropsychology*, *24*(3), 287–303. https://doi.org/10.1080/09297049.2016.1265102

Jordan, L. C., Hills, N. K., Fox, C. K., Ichord, R. N., Pergami, P., Deveber, G. A., Fullerton, H. J., & Lo, W. (2018). Socioeconomic determinants of outcome after childhood arterial ischemic stroke. *Neurology*, *91*(6), e509–e516. https://doi.org/10.1212/WNL.0000000000005946

Jorge, R. E., Robinson, R. G., Moser, D., Tateno, A., Crespo-Facorro, B., & Arndt, S. (2004). Major depression following traumatic brain injury. *Archives of General Psychiatry*, *61*(1), 42–50. https://doi.org/10.1001/ARCHPSYC.61.1.42

Kim, S. K., Cho, B. K., Phi, J. H., Lee, J. Y., Chae, J. H., Kim, K. J., Hwang, Y. S., Kim, I. O., Lee, D. S., Lee, J., & Wang, K. C. (2010). Pediatric moyamoya disease: An analysis of 410 consecutive cases. *Annals of Neurology*, *68*(1), 92–101. https://doi.org/10.1002/ANA.21981

Kirton, A., DeVeber, G., Pontigon, A. M., Macgregor, D., & Shroff, M. (2008). Presumed perinatal ischemic stroke: Vascular classification predicts outcomes. *Annals of Neurology*, *63*(4), 436–443. https://doi.org/10.1002/ANA.21334

Kirton, A., Shroff, M., Pontigon, A. M., & DeVeber, G. (2010). Risk factors and presentations of periventricular venous infarction vs arterial presumed perinatal ischemic stroke. *Archives of Neurology*, *67*(7), 842–848. https://doi.org/10.1001/ARCHNEUROL.2010.140

Kitchen, L., Westmacott, R., Friefeld, S. J., MacGregor, D., Curtis, R., Allen, A., Yau, I., Askalan, R., Moharir, M., Domi, T., & deVeber, G. (2012). The Pediatric Stroke Outcome Measure: A validation and reliability study. *Stroke*, *43*(6), 1602–1608. https://doi.org/10.1161/STROKEAHA.111.639583

Knight, M. J., & Baune, B. T. (2018). Cognitive dysfunction in major depressive disorder. *Current Opinion in Psychiatry*, *31*(1), 26–31. https://doi.org/10.1097/YCO.0000000000000378

Kopyta, I., Cebula, A., & Sarecka-Hujar, B. (2021). Early deaths after arterial ischemic stroke in pediatric patients: Incidence and risk factors. *Children*, *8*(6). https://doi.org/10.3390/CHILDREN8060471

Kornfeld, S., Yuan, R., Biswal, B. B., Grunt, S., Kamal, S., Delgado Rodríguez, J. A., Regényi, M., Wiest, R., Weisstanner, C., Kiefer, C., Steinlin, M., & Everts, R. (2017). Resting-state connectivity and executive functions after pediatric arterial ischemic stroke. *NeuroImage. Clinical*, *17*, 359–367. https://doi.org/10.1016/J.NICL.2017.10.016

Koterba, C. H., & Hoskinson, K. R. (2018). Memory interventions. In G. Locasio & B. S. Slomine (Eds.), *Cognitive rehabilitation for pediatric neurological disorders*. Cambridge University Press.

Krishnamurthi, R. v., Deveber, G., Feigin, V. L., Barker-Collo, S., Fullerton, H., Mackay, M. T., O'Callahan, F., Lindsay, M. P., Kolk, A., Lo, W., Shah, P., Linds, A., Jones, K., Parmar, P., Taylor, S., Norrving, B., Mensah, G. A., Moran, A. E., Naghavi, M., … Roth, G. A. (2015). Stroke prevalence, mortality and disability-adjusted life years in children and youth aged 0-19 years: Data from the Global and Regional Burden of Stroke 2013. *Neuroepidemiology*, *45*(3), 177–189. https://doi.org/10.1159/000441087

Laatsch, L., Harrington, D., Hotz, G., Marcantuono, J., Mozzoni, M. P., Walsh, V., & Hersey, K. P. (2007). An evidence-based review of cognitive and behavioral rehabilitation treatment studies in children with acquired brain injury. *Journal of Head Trauma Rehabilitation*, *22*(4), 248–256. https://doi.org/10.1097/01.HTR.0000281841.92720.0A

Lanthier, S., Carmant, L., David, M., Larbrisseau, A., & de Veber, G. (2000). Stroke in children: The coexistence of multiple risk factors predicts poor outcome. *Neurology*, *54*(2), 371–378. https://doi.org/10.1212/WNL.54.2.371

Large, R., Samuel, V., & Morris, R. (2020). A changed reality: Experience of an acceptance and commitment therapy (ACT) group after stroke. *Neuropsychological Rehabilitation*, *30*(8), 1477–1496. https://doi.org/10.1080/09602011.2019.1589531

LeBlond, E., Smith-Paine, J., Narad, M., Wade, S. L., Gardis, M., Naresh, M., Makoroff, K., & Rhine, T. (2021). Understanding the relationship between family functioning and health-related quality of life in very young children with moderate-to-severe TBI. *The Clinical Neuropsychologist*, *35*(5), 868–884. https://doi.org/10.1080/13854046.2021.1881163

Ledochowski, J., Desrocher, M., Williams, T., Dlamini, N., & Westmacott, R. (2020). Mental health outcomes in children with acquired dystonia after basal ganglia stroke and associations with cognitive and motor outcomes. *Child Neuropsychology*, *26*(5), 691–710. https://doi.org/10.1080/09297049.2020.1721453

Lee, J., Croen, L. A., Backstrand, K. H., Yoshida, C. K., Henning, L. H., Lindan, C., Ferriero, D. M., Fullerton, H. J., Barkovich, A. J., & Wu, Y. W. (2005). Maternal and infant characteristics associated with perinatal arterial stroke in the infant. *JAMA*, *293*(6), 723–729. https://doi.org/10.1001/JAMA.293.6.723

Lehman, L. L., Maletsky, K., Beaute, J., Rakesh, K., Kapur, K., Rivkin, M. J., & Mrakotsky, C. (2020). Prevalence of symptoms of anxiety, depression, and post-traumatic stress disorder in parents and children following pediatric stroke. *Journal of Child Neurology*, *35*(7), 472–479. https://doi.org/10.1177/0883073820909617

Levine, S. C., Kraus, R., Alexander, E., Suriyakham, L. W., & Huttenlocher, P. R. (2005). IQ decline following early unilateral brain injury: A longitudinal study. *Brain and Cognition*, *59*(2), 114–123. https://doi.org/10.1016/j.bandc.2005.05.008

Li, E., Smithson, L., Khan, M., Kirton, A., Pei, J., Andersen, J., Yager, J. Y., Brooks, B. L., & Rasmussen, C. (2022). Effects of perinatal stroke on executive functioning and mathematics performance in children. *Journal of Child Neurology*, *37*(2), 133–140. https://doi.org/10.1177/08830738211063683

Lidzba, K., Küpper, H., Kluger, G., & Staudt, M. (2017). The time window for successful right-hemispheric language reorganization in children. *European Journal of Paediatric Neurology*, *21*(5), 715–721. https://doi.org/10.1016/J.EJPN.2017.06.001

Liu, J., Wang, D., Lei, C., Xiong, Y., Yuan, R., Hao, Z., Tao, W., & Liu, M. (2015). Etiology, clinical characteristics and prognosis of spontaneous intracerebral hemorrhage in children: A prospective cohort study in China. *Journal of the Neurological Sciences*, *358*(1–2), 367–370. https://doi.org/10.1016/J.JNS.2015.09.366

Liu, Z., Zhou, X., Zhang, W., & Zhou, L. (2019). Factors associated with quality of life early after ischemic stroke: The role of resilience. *Topics in Stroke Rehabilitation*, *26*(5), 335–341. https://doi.org/10.1080/10749357.2019.1600285

Lo, W. D., Gordon, A., Hajek, C., Gomes, A., Greenham, M., Perkins, E., Zumberge, N., Anderson, V., Yeates, K. O., & Mackay, M. T. (2014). Social competence following neonatal and childhood stroke. *International Journal of Stroke*, *9*(8), 1037–1044. https://doi.org/10.1111/ijs.12222

Lo, W. D., Gordon, A. L., Hajek, C., Gomes, A., Greenham, M., Anderson, V., Yeates, K. O., & Mackay, M. T. (2014). Pediatric stroke outcome measure: Predictor of multiple impairments in childhood stroke. *Journal of Child Neurology*, *29*(11), 1524–1530. https://doi.org/10.1177/0883073813503186

Lo, W. D., Hajek, C., Pappa, C., Wang, W., & Zumberge, N. (2013). Outcomes in children with hemorrhagic stroke. *JAMA Neurology*, *70*(1), 66–71. https://doi.org/10.1001/jamaneurol.2013.577

Lo, W. D., Lee, J. E., Rusin, J., Perkins, E., & Roach, E. S. (2008). Intracranial hemorrhage in children: An evolving spectrum. *Archives of Neurology*, *65*(12), 1629–1633. https://doi.org/10.1001/ARCHNEUROL.2008.502

Locascio, G., & Slomine, B. (2018). Cognitive Rehabilitation for Pediatric Neurological Disorders. In G. Locascio & B. S. Slomine (Eds.), *Cognitive Rehabilitation for Pediatric Neurological Disorders*. Cambridge University Press. https://doi.org/10.1017/9781316855683

Long, B., Spencer-Smith, M. M., Jacobs, R., Mackay, M., Leventer, R., Barnes, C., & Anderson, V. (2011). Executive function following child stroke: The impact of lesion location. *Journal of Child Neurology*, *26*(3), 279–287. https://doi.org/10.1177/0883073810380049

Luckman, J., Chokron, S., Michowiz, S., Belenky, E., Toledano, H., Zahavi, A., & Goldenberg-Cohen, N. (2020). The need to look for visual deficit after stroke in children. *Frontiers in Neurology*, *11*, 617. https://doi.org/10.3389/FNEUR.2020.00617/BIBTEX

Lynch, J. K., & Han, C. J. (2005). Pediatric stroke: What do we know and what do we need to know? *Seminars in Neurology*, *25*(4), 410–423. https://doi.org/10.1055/S-2005-923535

Mackay, M. T., Wiznitzer, M., Benedict, S. L., Lee, K. J., Deveber, G. A., Ganesan, V., & Group, I. P. S. S. (2011). Arterial ischemic stroke risk factors: the International Pediatric Stroke Study. *Annals of Neurology*, *69*(1), 130–140. https://doi.org/10.1002/ana.22224

Mallick, A. A., Ganesan, V., Kirkham, F. J., Fallon, P., Hedderly, T., McShane, T., Parker, A. P., Wassmer, E., Wraige, E., Amin, S., Edwards, H. B., Cortina-Borja, M., & O'Callaghan, F. J. (2016). Outcome and recurrence 1 year after pediatric arterial ischemic stroke in a population-based cohort. *Annals of Neurology*, *79*(5), 784–793. https://doi.org/10.1002/ANA.24626

Mallick, A. A., Ganesan, V., & O'Callaghan, F. J. K. (2010). Mortality from childhood stroke in England and Wales, 1921-2000. *Archives of Disease in Childhood*, *95*(1), 12–19. https://doi.org/10.1136/ADC.2008.156109

Manly, T., Robertson, I. H., Anderson, V. A., & Nimmo-Smith, I. (1998). *Test of Everyday Attention for Children (TEA-Ch)*. Pearson.

Mason, J., & Danby, S. (2011). Children as experts in their lives: Child inclusive research. *Child Indicators Research*, *4*(2), 185–189. https://doi.org/10.1007/S12187-011-9108-4

Max, J. E. (2004). Effect of side of lesion on neuropsychological performance in childhood stroke. *Journal of the International Neuropsychological Society*, *10*(5), 698–708. https://doi.org/10.1017/S1355617704105092

Max, J. E., Bruce, M., Keatley, E., & Delis, D. (2010). Pediatric stroke: Plasticity, vulnerability, and age of lesion onset. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *22*(1), 30–39. https://doi.org/10.1176/jnp.2010.22.1.30

Max, J. E., Mathews, K., Lansing, A. E., Robertson, B. A. M., Fox, P. T., Lancaster, J. L., Manes, F. F., & Smith, J. (2002). Psychiatric disorders after childhood stroke. *Journal of the American Academy of Child & Adolescent Psychiatry*, *41*(5), 555–562. https://doi.org/10.1097/00004583-200205000-00013

Max, J. E., Mathews, K., Manes, F. F., Robertson, B. A. M., Fox, P. T., Lancaster, J. L., Lansing, A. E., Schatz, A., & Collings, N. (2003). Attention deficit hyperactivity disorder and neurocognitive correlates after childhood stroke. *Journal of the International Neuropsychological Society*, *9*(6), 815–829. https://doi.org/10.1017/S1355617703960012

McGrath, J. C., & Linley, P. A. (2009). Post-traumatic growth in acquired brain injury: A preliminary small scale study. *Brain Injury*, *20*(7), 767–773. https://doi.org/10.1080/02699050600664566

McKevitt, C., Topor, M., Panton, A., Mallick, A. A., Ganesan, V., Wraige, E., & Gordon, A. (2019). Seeking normality: Parents' experiences of childhood stroke. *Child: Care, Health and Development*, *45*(1), 89–95. https://doi.org/10.1111/cch.12622

Mercuri, E., Anker, S., Guzzetta, A., Barnett, A., Haataja, L., Rutherford, M., Cowan, F., Dubowitz, L., Braddick, O., & Atkinson, J. (2003). Neonatal cerebral infarction and visual function at school age. *Archives of Disease in Childhood Fetal and Neonatal Edition*, *88*(6), F487. https://doi.org/10.1136/FN.88.6.F487

Monette, G., Fox, J., Friendly, M., Krause, H., & Zhu, F. (2019). *spida2: Collection of tools developed for the Summer Programme in Data Analysis 2000-2012.* (R package version 0.2.1.).

Mukherjee, D., Levin, R. L., & Heller, W. (2006). The cognitive, emotional, and social sequelae of stroke: Psychological and ethical concerns in post-stroke adaptation. *Topics in Stroke Rehabilitation*, *13*(4), 26–35. https://doi.org/10.1310/TSR1304-26

Murdaugh, D., Morris, S., & O'Toole, K. (2018). Tracking of neurocognitive outcomes over time in children with perinatal stroke and associated complex medical conditions: A case series. *Neurocase*, *24*(4), 195–203. https://doi.org/10.1080/13554794.2018.1525410

Murphy, L. K., Compas, B. E., Gindville, M. C., Reeslund, K. L., & Jordan, L. C. (2017). Cognitive functioning over 2 years after intracerebral hemorrhage in school-aged children. *Developmental Medicine and Child Neurology*, *59*(11), 1146–1151. https://doi.org/10.1111/DMCN.13547

Nelson, K. B., & Lynch, J. K. (2004). Stroke in newborn infants. *The Lancet. Neurology*, *3*(3), 150–158. https://doi.org/10.1016/S1474-4422(04)00679-9

O'Keeffe, F., Ganesan, V., King, J., & Murphy, T. (2012). Quality-of-life and psychosocial outcome following childhood arterial ischaemic stroke. *Brain Injury*, *26*(9), 1072–1083. https://doi.org/10.3109/02699052.2012.661117

O'Keeffe, F., Liégeois, F., Eve, M., Ganesan, V., King, J., & Murphy, T. (2014). Neuropsychological and neurobehavioral outcome following childhood arterial ischemic stroke: Attention deficits, emotional dysregulation, and executive dysfunction. *Child Neuropsychology*, *20*(5), 557–582. https://doi.org/10.1080/09297049.2013.832740

O'Keeffe, F., Stark, D., Murphy, O., Ganesan, V., King, J., & Murphy, T. (2017). Psychosocial outcome and quality of life following childhood stroke: A systematic review. *Developmental Neurorehabilitation*, *20*(7), 428–442. https://doi.org/10.1080/17518423.2017.1282052

Ownsworth, T. (2014). Self-identity after brain injury. In *Self-Identity after Brain Injury*. Psychology Press. https://doi.org/10.4324/9781315819549

Ownsworth, T., & Fleming, J. (2011). Growth through loss after brain injury. *Brain Impairment*, *12*(2), 79–81. https://doi.org/10.1375/BRIM.12.2.79

Ownsworth, T., Fleming, J., Haines, T., Cornwell, P., Kendall, M., Nalder, E., & Gordon, C. (2011). Development of depressive symptoms during early community reintegration after traumatic brain injury. *Journal of the International Neuropsychological Society*, *17*(1), 112–119. https://doi.org/10.1017/S1355617710001311

Pais-Hrit, C., Wong, D., Gould, K. R., & Ponsford, J. (2020). Behavioural and functional correlates of post-traumatic growth following traumatic brain injury. *Neuropsychological Rehabilitation*, *30*(7), 1205–1223. https://doi.org/10.1080/09602011.2019.1569536

Pastore, V., Colombo, K., Maestroni, D., Galbiati, S., Villa, F., Recla, M., Locatelli, F., & Strazzer, S. (2015). Psychological problems, self-esteem and body dissatisfaction in a sample of adolescents with brain lesions: A comparison with a control group. *Brain Injury*, *29*(7–8), 937–945. https://doi.org/10.3109/02699052.2015.1008045

Pastore, V., Galbiati, S., Villa, F., Colombo, K., Recla, M., Adduci, A., Avantaggiato, P., Bardoni, A., & Strazzer, S. (2014). Psychological and adjustment problems due to acquired brain lesions in pediatric patients: A comparison of vascular, infectious, and other origins. *Journal of Child Neurology*, *29*(12), 1664–1671. https://doi.org/10.1177/0883073813513329

Peterson, R. K., Williams, T., Dlamini, N., & Westmacott, R. (2021). Parent experiences and developmental outcomes following neonatal stroke. *Clinical Neuropsychologist*, *35*(5), 973–987. https://doi.org/10.1080/13854046.2020.1815855

Peterson, R. K., Williams, T. S., McDonald, K. P., Dlamini, N., & Westmacott, R. (2019). Cognitive and Academic Outcomes Following Childhood Cortical Stroke. *Journal of Child Neurology*, *34*(14), 897–906. https://doi.org/10.1177/0883073819866609

Popernack, M. L., Gray, N., & Reuter-Rice, K. (2015). Moderate-to-severe traumatic brain injury in children: Complications and rehabilitation strategies. *Journal of Pediatric Health Care*, *29*(3), e7. https://doi.org/10.1016/J.PEDHC.2014.09.003

Powell, T., Gilson, R., & Collin, C. (2012). TBI 13 years on: Factors associated with post-traumatic growth. *Disability and Rehabilitation*, *34*(17), 1461–1467. https://doi.org/10.3109/09638288.2011.644384

Queirós, A., Faria, D., & Almeida, F. (2017). Strengths and limitations of qualitative and quantitative research methods. *European Journal of Education Studies*, *3*(9), 369–386. https://doi.org/10.5281/ZENODO.887089

R Core Team. (2020). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing.

Rivella, C., & Viterbori, P. (2021). Executive function following pediatric stroke: A systematic review. *Child Neuropsychology*, *27*(2), 209–231. https://doi.org/10.1080/09297049.2020.1820472

Roach, E. S., Golomb, M. R., Adams, R., Biller, J., Daniels, S., deVeber, G., Ferriero, D., Jones, B. v, Kirkham, F. J., Scott, R. M., & Smith, E. R. (2008). Management of stroke in infants and children: A scientific statement from a Special Writing Group of the American Heart Association Stroke Council and the Council on Cardiovascular Disease in the Young. *Stroke*, *39*(9), 2644–2691. https://doi.org/10.1161/STROKEAHA.108.189696

Robertson, I. H., Ward, T., Ridgeway, V., & Nimmo-Smith, I. (1994). *Test of Everyday Attention (TEA)*. Thomas Valley Test Company.

Rodan, L., McCrindle, B. W., Manlhiot, C., MacGregor, D. L., Askalan, R., Moharir, M., & Deveber, G. (2012). Stroke recurrence in children with congenital heart disease. *Annals of Neurology*, *72*(1), 103–111. https://doi.org/10.1002/ANA.23574

Ross, K. A., Dorris, L., & Mcmillan, T. (2011). A systematic review of psychological interventions to alleviate cognitive and psychosocial problems in children with acquired brain injury. *Developmental Medicine and Child Neurology*, *53*(8), 692–701. https://doi.org/10.1111/J.1469-8749.2011.03976.X

Roth, R. M., Isquith, P. K., & Gioia, G. A. (2005). *Behavior Rating Inventory of Executive Function – Adult Version (BRIEF-A)*. Psychological Assessment Resources.

Scobbie, L., Brady, M. C., Duncan, E. A. S., & Wyke, S. (2021). Goal attainment, adjustment and disengagement in the first year after stroke: A qualitative study. *Neuropsychological Rehabilitation*, *31*(5), 691–709. https://doi.org/10.1080/09602011.2020.1724803

Semrud-Clikeman, M. (2010). Pediatric traumatic brain injury: Rehabilitation and transition to home and school. *Applied Neuropsychology*, *17*(2), 116–122. https://doi.org/10.1080/09084281003708985

Singhal, N. S., Hills, N. K., Sidney, S., & Fullerton, H. J. (2013). Role of trauma and infection in childhood hemorrhagic stroke due to vascular lesions. *Neurology*, *81*(6), 581–584. https://doi.org/10.1212/WNL.0b013e31829e6f5f

Smitherman, E., Hernandez, A., Stavinoha, P. L., Huang, R., Kernie, S. G., Diaz-Arrastia, R., & Miles, D. K. (2016). Predicting outcome after pediatric traumatic brain injury by early magnetic resonance imaging lesion location and volume. *Journal of Neurotrauma*, *33*(1), 35–48. https://doi.org/10.1089/neu.2014.3801

Soufi, S., Chabrier, S., Bertoletti, L., Laporte, S., & Darteyre, S. (2017). Lived experience of having a child with stroke: A qualitative study. *European Journal of Paediatric Neurology*, *21*(3), 542–548. https://doi.org/10.1016/j.ejpn.2017.01.007

Steinlin, M., Roellin, K., & Schroth, G. (2004). Long-term follow-up after stroke in childhood. *European Journal of Pediatrics*, *163*(4–5), 245–250. https://doi.org/10.1007/s00431-003-1357-x

Studer, M., Boltshauser, E., Capone Mori, A., Datta, A., Fluss, J., Mercati, D., Hackenberg, A., Keller, E., Maier, O., Marcoz, J.-P., Ramelli, G.-P., Poloni, C., Schmid, R., Schmitt-Mechelke, T., Wehrli, E., Heinks, T., & Steinlin, M. (2014). Factors affecting cognitive outcome in early pediatric stroke. *Neurology*, *82*(9), 784–792. https://doi.org/10.1212/WNL.0000000000000162

Sundelin, H. E. K., Tomson, T., Zelano, J., Soderling, J., Bang, P., & Ludvigsson, J. F. (2021). Pediatric ischemic stroke and epilepsy: A nationwide cohort study. *Stroke*, *52*(11), 3532–3540. https://doi.org/10.1161/STROKEAHA.121.034796

Taylor, G. H., Todman, J., & Broomfield, N. M. (2011). Post-stroke emotional adjustment: A modified social cognitive transition model. *Neuropsychological Rehabilitation*, *21*(6), 808–824. https://doi.org/http://dx.doi.org/10.1080/09602011.2011.598403

Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence on JSTOR. *Psychological Inquiry*, *15*(1), 1–18.

Tibussek, D., Mayatepek, E., Klee, D., & Koy, A. (2015). Post stroke hemi-dystonia in children: A neglected area of research. *Molecular and Cellular Pediatrics*, *2*(1). https://doi.org/10.1186/S40348-015-0026-2

Tsze, D. S., & Valente, J. H. (2011). Pediatric stroke: A review. *Emergency Medicine International*, *2011*, 734506. https://doi.org/https://doi.10.1155/2011/734506

Ursache, A., & Noble, K. G. (2016). Neurocognitive development in socioeconomic context: Multiple mechanisms and implications for measuring socioeconomic status. *Psychophysiology*, *53*(1), 71. https://doi.org/10.1111/PSYP.12547

Üstün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The International Classification of Functioning, Disability and Health: A new tool for understanding disability and health. *Disability and Rehabilitation*, *25*(11–12), 565–571. https://doi.org/10.1080/0963828031000137063

van Buuren, L. M., van der Aa, N. E., Dekker, H. C., Vermeulen, R. J., van Nieuwenhuizen, O., van Schooneveld, M. M. J., & de Vries, L. S. (2013). Cognitive outcome in childhood after unilateral perinatal brain injury. *Developmental Medicine and Child Neurology*, *55*(10), 934–940. https://doi.org/10.1111/DMCN.12187

Vojcek, E., Gráf, R., László, A. M., Gyebnar, G., & Seri, I. (2022). Long-term neurodevelopmental outcome of neonates born at term with perinatal haemorrhagic stroke: A population-based study. *Developmental Medicine and Child Neurology*. https://doi.org/10.1111/DMCN.15149

Wade, S. L., Cassedy, A., Walz, N. C., Taylor, H. G., Stancin, T., & Yeates, K. O. (2011). The relationship of parental warm responsiveness and negativity to emerging behavior problems following traumatic brain injury in young children. *Developmental Psychology*, *47*(1), 133. https://doi.org/10.1037/A0021028

Wade, S. L., Stancin, T., Kirkwood, M., Brown, T. M., McMullen, K. M., & Gerry Taylor, H. (2014). Counselor-assisted problem solving (CAPS) improves behavioral outcomes in older adolescents with complicated mild to severe TBI. *The Journal of Head Trauma Rehabilitation*, *29*(3), 198–207. https://doi.org/10.1097/HTR.0B013E31828F9FE8

Wade, S. L., Walz, N. C., Carey, J., Williams, K. M., Cass, J., Herren, L., Mark, E., & Yeates, K. O. (2010). A randomized trial of teen online problem solving for improving executive function deficits following pediatric traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, *25*(6), 409–415. https://doi.org/10.1097/HTR.0B013E3181FB900D

Watson, W. D., Lahey, S., Baum, K. T., Hamner, T., Koterba, C. H., Alvarez, G., Chan, J. B., Davis, K. C., DiVirgilio, E. K., Howarth, R. A., Jones, K., Kramer, M., Tlustos, S. J., Zafiris, C. M., & Slomine, B. S. (2022). The role of the neuropsychologist across the stages of recovery from acquired brain injury: A summary from the pediatric rehabilitation neuropsychology collaborative. *Child Neuropsychology*, 1–22. https://doi.org/10.1080/09297049.2022.2086691

Wechsler, D. (2008). *Wechsler Adult Intelligence Scale – Fourth Edition*. Pearson.

Wechsler, D. (2014). *Wechsler Intelligence Scale for Children - Fifth Edition*. Pearson.

Westmacott, R., Askalan, R., Macgregor, D., Anderson, P., & Deveber, G. (2010). Cognitive outcome following unilateral arterial ischaemic stroke in childhood: Effects of age at stroke and lesion location. *Developmental Medicine and Child Neurology*, *52*(4), 386–393. https://doi.org/10.1111/j.1469-8749.2009.03403.x

Westmacott, R., MacGregor, D., Askalan, R., & deVeber, G. (2009). Late emergence of cognitive deficits after unilateral neonatal stroke. *Stroke*, *40*(6), 2012–2019. https://doi.org/10.1161/STROKEAHA.108.533976

Westmacott, R., McDonald, K. P., Roberts, S. D., deVeber, G., MacGregor, D., Moharir, M., Dlamini, N., & Williams, T. S. (2018). Predictors of cognitive and academic outcome following childhood subcortical stroke. *Developmental Neuropsychology*, *43*(8), 708–728. https://doi.org/10.1080/87565641.2018.1522538

Williams, T. S., McDonald, K. P., Roberts, S. D., Dlamini, N., deVeber, G., & Westmacott, R. (2017). Prevalence and predictors of learning and psychological diagnoses following pediatric arterial ischemic stroke. *Developmental Neuropsychology*, *42*(5), 309–322. https://doi.org/10.1080/87565641.2017.1353093

Williams, T. S., Roberts, S. D., Coppens, A. M., Crosbie, J., Dlamini, N., & Westmacott, R. (2018). Secondary attention-deficit/hyperactivity disorder following perinatal and childhood stroke: impact on cognitive and academic outcomes. *Child Neuropsychology*, *24*(6), 763–783. https://doi.org/10.1080/09297049.2017.1333091

Ylvisaker, M., Adelson, P. D., Braga, L. W., Burnett, S. M., Glang, A., Feeney, T., Moore, W., Rumney, P., & Todis, B. (2005). Rehabilitation and ongoing support after pediatric TBI: Twenty years of progress. *The Journal of Head Trauma Rehabilitation*, *20*(1), 95–109. https://doi.org/10.1097/00001199-200501000-00009

Yock-Corrales, A., MacKay, M. T., Mosley, I., Maixner, W., & Babl, F. E. (2011). Acute childhood arterial ischemic and hemorrhagic stroke in the emergency department. *Annals of Emergency Medicine*, *58*(2), 156–163. https://doi.org/10.1016/J.ANNEMERGMED.2010.10.013

Yvon, E., Lamotte, D., Tiberghien, A., Godard, I., Mardaye, A., Laurent-Vannier, A., Agostini, M. de, & Chevignard, M. (2018). Long-term motor, functional, and academic outcome following childhood ischemic and hemorrhagic stroke: A large rehabilitation center-based retrospective study. *Developmental Neurorehabilitation*, *21*(2), 83–90. https://doi.org/10.1080/17518423.2016.1247923

Zoom for Healthcare. (2016). Zoom Video Communications Inc.