

ENVIRONMENTAL, COGNITIVE, AND NEUROLOGICAL PREDICTORS OF MENTAL
HEALTH FOLLOWING PEDIATRIC STROKE: A MIXED METHODS FRAMEWORK

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Abstract

Pediatric stroke has been found to be an important source of acquired brain injury that can adversely impact cognition in children. However, less is known about predictors of mental health in this clinical population. The current project explored emotional, behavioural, and social outcomes in pediatric stroke and the personal and environmental factors that can influence psychological risk or resilience. The investigation of psychological outcomes was approached from quantitative (Study 1) and qualitative (Study 2) paradigms in order to attain both breadth and depth of understanding. *Study 1*: Thirty-one children between the ages of 8-18 years with a history of ischemic stroke and 34 demographically equivalent healthy controls participated. Information on participants' mood, anxiety, behaviour, and social factors relevant to mental health were collected via parent-report (Conners CBRS-CI) and child-report (RCADS and KIDSCREEN-52) standardized questionnaires. Children also underwent performance-based testing of cognitive abilities. A review of medical records provided information on stroke patients' neurological functioning, diagnostic/clinical history, and brain injury characteristics. All parents also completed inventories of parent mental health and family functioning. Statistical group comparisons revealed that the stroke group was significantly more likely to have physical disability, learning disability, poorer executive functioning, and emotion regulation concerns. Clinically elevated anxiety symptoms were present in 45.2% of stroke participants. In the stroke group, linear regression models revealed that higher internalizing symptoms were predicted by poorer executive functioning, learning and language problems, reduced fine-motor speed, bullying, reduced social support, perinatal/neonatal stroke, and greater time since stroke. Parent mental health was the strongest environmental predictor of childhood behaviour. Results highlight internalizing symptomatology risk in pediatric stroke and the converging roles of

neurological, cognitive, and social factors in determining psychological outcomes. *Study 2*: In-depth individual qualitative interviews were conducted with 14 children with stroke history who were recruited from Study 1. The semi-structured interviews aimed to capture the lived experience of pediatric stroke survivors and encompassed open-ended questions about stroke participants' daily life, memories, perceptions, and psychological experiences. Interviews were audio recorded, transcribed verbatim, and qualitatively analyzed using reflexive Thematic Analysis methodology. Coding, theme generation, and data visualization were completed using NVivo12 software. Prominent psychosocial themes encompassed shyness and social anxiety, test anxiety, hiding sadness, trouble with thinking, missing out, bullying, and isolation. Insight into adaptive coping mechanisms and personal values was present, as was emphasis on family closeness and the importance of supportive peers. Taken together, findings across studies illustrate the profound impact that pediatric stroke can have on children's emotional experiences, personal identity, self-efficacy, learning, behaviour, and psychosocial functioning. Focus should be given to the coordination of services to meet multiple, complex needs in pediatric stroke patients at heightened risk for poor mental health outcomes.

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Environmental, cognitive, and neurological predictors of mental health following pediatric stroke: A mixed methods framework

Stroke is a serious cause of neurological injury in pediatric populations and is becoming increasingly recognized as such by health professionals and the public alike (Kirton & deVeber, 2009; Westmacott et al., 2018). Despite the commonly held belief that increased plasticity protects the young brain against deficits associated with brain insult, there is now a substantial body of evidence to indicate that pediatric stroke is associated with long-term adverse outcomes across multiple neuropsychological domains of functioning. Consequences can encompass sensorimotor deficits, language delays, intellectual impairment, attention and executive dysfunction, academic underachievement, and behavioral problems (Felling et al., 2017; Fuentes et al., 2016). Ischemic stroke survival rates are far greater in children than in adult populations; however, neurological morbidity is present in more than half of pediatric stroke survivors (deVeber et al., 2017; Westmacott et al., 2018). Given the extensive clinical manifestations of pediatric stroke and associated implications for quality of life, it is of utmost importance to investigate psychological outcomes in this unique group of children in order to find pathways for optimizing resilience and mental health.

Incidence of Pediatric Ischemic Stroke

Ischemic stroke is caused by severely reduced blood flow to the brain due to occlusion of cerebral arteries or veins. Tissue death occurs in affected brain regions, and the resulting lesion is referred to as an infarct (Cárdenas et al., 2011). Epidemiological studies have documented pediatric ischemic stroke risk to be greatest within the first two years of life, with perinatal stroke representing an exceptionally high proportion of cases (Dunbar & Kirton, 2019; Kirton et al., 2011). Perinatal ischemic stroke occurs between 20 weeks of gestation and 28 days following

birth, with reported incidence ranging from 1 in every 2500 to 3600 live births each year (Agrawal et al., 2009; Cárdenas et al., 2011; Dunbar & Kirton, 2019). More specifically, the term neonatal ischemic stroke is used when there is an acute stroke diagnosis, which is typically made due to the presence of focal seizures in newborns. Presumed perinatal ischemic stroke refers to suspected ischemic stroke that is presumed to have occurred during the perinatal time period. A diagnosis of presumed perinatal stroke is made retrospectively, with clinical signs often including emerging hemiparesis at 4 to 8 months of age (Felling et al., 2017; Kirton & deVeber, 2009). Childhood ischemic stroke is much less common; yearly incidence rates for youth aged one month to 18 years have been found to range from 0.6 – 13 cases per 100,000 children (Hartel et al., 2004; Kirton & Westmacott, 2007; Mackay & Steinlin, 2019). Nevertheless, these statistics are likely to be an underestimation given that our awareness of the commonality of pediatric stroke is complicated by high rates of delayed diagnosis and misdiagnosis, even when stroke presents acutely (Cárdenas et al., 2011).

Vascular Pathophysiology

Vascular disruption characterized by ischemia occurs when there is insufficient blood flow to a region of the brain, which deprives the brain tissue of essential nutrients like oxygen and glucose (Hart et al., 2018). Ischemia can occur in the arterial system (arterial ischemic stroke) or the venous system (cerebral venous sinus thrombosis; CVST) and may result from thrombotic or embolic mechanisms (Felling et al., 2017). In thrombosis, a blood clot locally develops on a blood vessel wall, causing the vessel to occlude. An embolus is another ischemic mechanism, whereby a mass of material (e.g., blood clot, tissue, cholesterol, or amniotic fluid) detaches from its point of origin and travels throughout the circulation to occlude a blood vessel downstream (Kirton & deVeber, 2009; Mackay & Steinlin, 2019).

The cerebral arteries are the site of the majority of pediatric ischemic strokes, with embolic etiology being most common. The major cerebral arteries consist of the anterior cerebral artery (ACA), the middle cerebral artery (MCA), and the posterior cerebral artery (PCA). Numerous branches arise from the ACA, MCA, and PCA, which travel into the subarachnoid space and over the surface of the brain through the sulci (Hart et al., 2018). These penetrating branches supply blood to the cortex, underlying white matter, and deep brain structures. Specifically, the vascular territory of the ACA covers the anterior medial surface of the brain, spanning from the frontal to the anterior parietal lobes, medially. Branches of the ACA supply several subcortical structures, including the head of the caudate, anterior putamen, globus pallidus, and internal capsule, as well as other deep structures (Blumenfeld, 2010). In contrast, lateral areas of the cortex are supplied by the MCA, which enters the Sylvian fissure and splits into inferior and superior divisions. The inferior MCA division supplies the superior temporal and inferior lateral parietal lobes, while the superior MCA division supplies the insula, lateral frontal lobe, and superior lateral parietal regions. Deep branches of the MCA also supply the caudate nucleus and portions of the internal capsule (Scremin, 2012). The vascular territory of the PCA encompasses the inferior and medial temporal lobes and the occipital cortex. The deep, penetrating arteries that arise from the PCA supply the thalamus (Blumenfeld, 2010).

The MCA is particularly vulnerable to arterial ischemic stroke. The predominance of MCA infarcts in both pediatric and adult populations has been attributed to the large territory covered by this cerebral artery, which includes the lateral frontal, temporal, and parietal lobes (Tsze & Valente, 2011). Furthermore, the deep penetrating arteries of the MCA, such as the lenticulostriate arteries, are vulnerable to embolic occlusion due to their narrow and small structure (Mackay & Steinlin, 2019). Occlusion of the lenticulostriate arteries can produce

infarction of the basal ganglia and internal capsule. Large MCA infarcts with cortical and subcortical involvement are often seen in neonatal strokes. Pediatric arterial ischemic stroke is more likely to occur in the left hemisphere due to anatomical differences in the left and right common carotid arteries (Cárdenas et al., 2011).

CVST strokes are caused by a sudden blockage of veins or major venous sinuses, resulting in impaired blood drainage from the brain. Across pediatric ischemic stroke cases, approximately 25% involve the venous system (Kirton & deVeber, 2009; Tsze & Valente, 2011). In CVST, the superficial venous system is more frequently involved. For instance, bilateral parasagittal infarcts are often secondary to sagittal sinus thrombosis. Deep venous thrombosis involving the internal cerebral veins, straight sinus, and/or the Vein of Galen can produce infarction of the deep white matter, basal ganglia, and/or thalamus. The pressure produced by blocked blood drainage can create subsequent hemorrhagic transformation (Cárdenas et al., 2011; Westmacott et al., 2018).

Etiological Mechanisms

Stroke pathophysiology is relatively similar across the lifespan; however, pediatric stroke is unique with respect to etiological mechanisms. The presence of congenital or acquired heart disease appears to be a primary risk factor, with the heart being the most common source of cerebral emboli in children (Numis & Fox, 2014). Non-atherosclerotic arteriopathies have also been implicated and account for half of all arterial ischemic strokes in the pediatric population (Cárdenas et al., 2011). Small vessel disease increases the likelihood of thrombi or emboli occluding the narrowed vessels, while blood disorders, such as sickle cell disease, increase the risk of blood clots developing within the vascular system (deVeber et al., 2017). Cerebral artery dissection is a flap like tear on the inner lining of an artery, and accounts for a subset of ischemic

strokes in children (Blumenfeld, 2010; Riel-Romero et al., 2009). The flap-like tear allows for blood to enter the arterial wall and form a clot, which impedes flow. Dissection is often associated with trauma, which is much more likely to impact the vertebral artery due to its susceptibility to injury. Accordingly, when dissections occur in youth, they are more likely to be associated with stroke to the PCA (Riel-Romero et al., 2009). Occlusion of the anterior circulation in children is associated with Moyamoya, an arteriopathy characterized by progressive stenosis and narrowing of the proximal ACA and proximal MCA, leading to occlusion and infarcts within the territories fed by these arteries (Felling et al., 2017; Riel-Romero et al., 2009).

Head and neck infections (such as sinusitis, otitis, and meningitis) also commonly co-occur with pediatric stroke and have been associated with emboli and infarcts via the inflammatory immune response (Cárdenas et al., 2011; Mackay & Steinlin, 2019). For reasons that are not well understood, all types of childhood stroke seem to have a significant male predominance. African-American children also have higher stroke risk, even after accounting for sickle cell disease (Cárdenas et al., 2011; Hart et al., 2018).

Distinct etiological mechanisms separate perinatal ischemic stroke, and causes tend to be multifactorial. The hypercoagulable nature of pregnancy and the complex interaction of maternal and fetal circulations places the fetus and newborn infant at increased risk of stroke (Felling et al., 2017). Higher incidence of ischemic strokes in the perinatal time period has been associated with placental blood clots entering the fetal circulation (Dunbar & Kirton, 2019; Hart et al., 2018). Doppler ultrasound imaging has been used to document the common vascular pathway taken by emboli arising from the degenerating placenta around the time of birth (Coker et al., 1988). The amniotic embolus travels from the umbilical cord veins to the aortic arch, where

turbulent flows from the ductus tend to direct its passage into the left common carotid artery. The embolus then travels into the left internal carotid and continues until it reaches and occludes the left MCA or its penetrating branches (Coker et al., 1988; Hart et al., 2018). Instrumental delivery or emergency caesarean section also increases the risk of perinatal stroke. Maternal risk factors encompass preeclampsia, gestational diabetes, placental abnormalities, autoimmune disease, advanced maternal age, low amniotic fluid, urinary tract infection, twin gestation, and prolonged second stage of labour (Felling et al., 2017; Hart et al., 2018).

Psychosocial Consequences of Pediatric Acquired Brain Injury

Despite knowledge concerning the seriousness and prevalence of pediatric stroke, there is limited awareness of the immediate and long-term effects on children's social-emotional functioning and psychological adjustment. To date, the majority of research within this area has focused on neurological, intellectual, and motor outcomes, and it has been indicated that up to 66% of children diagnosed with stroke will develop neurological deficits or will present with subsequent seizure disorders, cognitive, or developmental problems (Tsze & Valente, 2011). Long-term impact of childhood stroke in emerging adulthood has also been documented. Although the majority of young adults will be independent in employment, driving, and relationships, cognitive disabilities and abnormal functional outcomes often persist, with documented mild and moderate/severe neurological deficits in 42% of 23% of young adults, respectively (Elbers et al., 2014). Functional status at 1-year poststroke strongly predicts long-term outcome (Elbers et al., 2014; Greenham et al., 2016). Given the potential for pervasive changes in various aspects of daily life, a comprehensive understanding of the psychological experiences and perceptions of pediatric stroke patients is essential, as it will facilitate opportunity for timely interventions that can improve coping and adaptive outcome.

Evidence from the broader childhood literature suggests that young individuals living with disabilities or neurological conditions are at considerably greater risk for emotional and behavioral adjustment problems and lower quality of life, in comparison to children without disabilities (Edwards et al., 2003; Hendry et al., 2020). Given the small quantity of literature concerning psychosocial outcomes in pediatric stroke, professionals have relied on research that has been conducted in other acquired brain injury populations in order to gain insight into the impact of brain injury on behavioural and emotional development. For instance, studies on children and youth with traumatic brain injury (TBI) have indicated heightened risk for psychiatric symptoms and disorders (Hendry et al., 2020; Li & Liu, 2013; O'Connor et al., 2012; Schachar et al., 2015).

Globally, TBI is a common cause of disability in children and occurs when the head is violently struck, jolted, or penetrated, resulting in physical damage to the brain (Yeates & Brooks, 2017). Pre-existing psychopathology and psychosocial adversity increase the likelihood of sustaining TBI, especially when children are struggling with aggression, hyperactivity, and poor attention (Schachar et al., 2015). However, children with mild to severe TBI are at risk for the appearance of a novel psychiatric disorder that was not present before the injury (Max et al., 2012). In comparison to orthopedic injury samples, rates of new psychiatric disorders are up to three times more common among children who have sustained brain trauma (Max, 2014; Max et al., 2015). Prevalence rates for post-injury behavioural problems have been found to vary from 10% to 50% and encompass difficulties with anxiety, low mood, personality change, attention, and aggression (Hendry et al., 2020; Li & Liu, 2013). Emotional dysregulation and disinhibition syndromes are common (Roebuck-Spencer et al., 2018). These problems can appear shortly after the injury or emerge several years later. Behavioural impairments that do not resolve within the

first year following injury often stabilize or can even worsen over time, and, if left untreated, may persist into adulthood (Catroppa et al., 2017; Chapman et al., 2010). Demographic and injury-related factors associated with internalizing symptoms and poor self-concept following pediatric TBI include lower functional status and adolescent age range (ages 13–16 years), with a particularly significant effect for adolescent females (Hendry et al., 2020).

Despite the fact that TBI is a well-studied cause of pediatric brain injury, physical symptoms and cognitive disorders continue to take precedence in research studies and represent the most recognized clinical manifestations (Babikian & Asarnow, 2009; V. M. Johnson & Donders, 2018). Assessment of psychosocial sequelae from acquired brain injury of varying etiologies continues to be a challenge for researchers, especially since impact on the developing brain must be considered. The neurobehavioural changes that follow brain injury are broad, and it is unclear to what degree symptoms are directly related to injury of important brain structures versus the associated stress of the injury and disruption to daily tasks and responsibilities (Roebuck-Spencer et al., 2018). Additional relevant factors include injury timing, pre-injury status, insult severity, sex/biological factors, and environment (Greenham, 2010). Despite these complexities, an increased focus on mental health following acquired brain injury is warranted given that psychosocial and behavioral issues are often reported to be the most concerning problems by parents and teachers due to their adverse impact on daily adaptive functioning, learning, and quality of life (Li & Liu, 2013).

While the pediatric TBI literature provides a working model for understanding the potential developmental impact of brain injury, findings cannot be considered analogous to outcomes in pediatric stroke due to the unique pathophysiology and clinical manifestations associated with the disease (Westmacott et al., 2018). In contrast to the diffuse axonal injury

sometimes seen in TBI, pediatric stroke can present with increased specificity of lesion location on neuroimaging. Additionally, TBI factors, such as pre-injury neurological status or post-injury life adjustment, are not as relevant in the context of perinatal stroke, which represents a large proportion of pediatric stroke cases. Only a handful of studies have investigated psychosocial functioning in pediatric stroke, and even fewer have examined the relevant factors contributing to mental health outcomes in this group. Overall, the existing research suggests that childhood stroke survivors are at increased risk of psychiatric disorders and emotional problems when compared against typically developing children or clinical controls (e.g., children without stroke who have a chronic illness). Elevated rates of internalizing problems, such as social anxiety and generalized anxiety, have been reported (Greenham et al., 2015; Max et al., 2002; O’Keeffe et al., 2017) as well as significantly higher levels of externalizing behaviours (Steinlin et al., 2004) and attention deficit hyperactivity disorder (Everts et al., 2008; Williams et al., 2017, 2018). The limited research body also suggests that children and youth have a heightened risk for social problems post-stroke, including reduced social participation and peer acceptance (Anderson et al., 2014; Greenham et al., 2015; O’Keeffe et al., 2012). Social cognitive difficulties have been documented, including lower performance on theory of mind tasks (Lo et al., 2020). In summary, mental health and social findings indicate elevated risk for systemic psychosocial difficulties and an associated reduction in factors related to quality of life, such as autonomy, self-esteem, and feelings of well-being (Everts et al., 2008; Neuner et al., 2011).

Project Objectives

The overarching goal of the current project was to examine social, emotional, and behavioural outcomes amongst children and youth with a history of stroke, with a focus on mood, anxiety, peer relationships, and social competence. The investigation of mental health

outcomes was approached from both quantitative (Study 1) and qualitative (Study 2) paradigms in order to attain breadth (e.g., population trends and generalizability of findings) and depth (e.g., detailed descriptions of personal experiences and perceptions) of understanding. More specifically, a convergent parallel mixed methods design was adopted such that quantitative and qualitative data were collected concurrently and each dataset was analyzed separately. Datasets were subsequently merged by comparing findings across Study 1 and Study 2 during interpretation (general discussion). A convergent parallel design gives equal value to quantitative and qualitative paradigms for understanding the research problem and allows corroboration of results from different methods (Edmonds & Kennedy, 2017). Taken together, this project aimed to utilize a comprehensive and multifactorial method in the investigation of post-stroke psychosocial outcomes in order to expand upon the current literature and examine previously unexplored relationships.

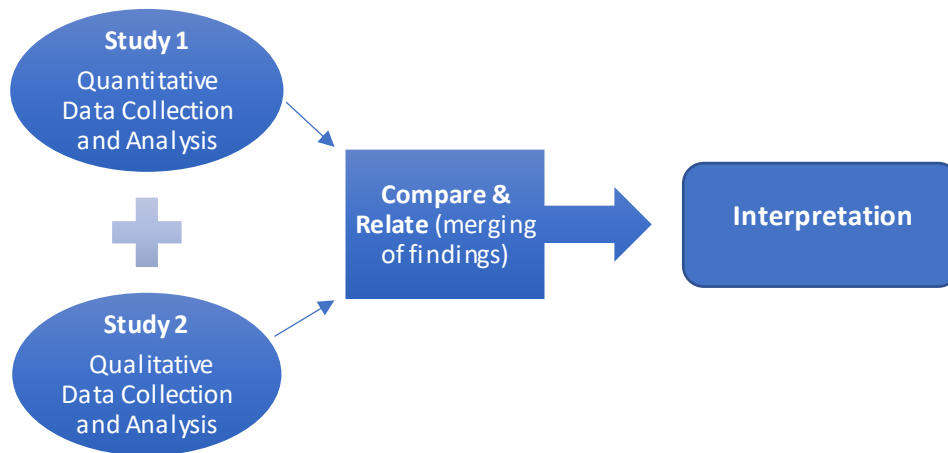


Figure 1. Diagram representing the convergent parallel mixed methods design utilized within the current project.

STUDY 1:

A Quantitative Investigation of Mental Health in Pediatric Stroke and Associated Neurological, Cognitive, and Environmental Factors

The examination of neurological, cognitive, and environmental predictors of mental health in pediatric stroke is essential to uncovering pathways towards psychological risk and resilience in this vulnerable childhood population. The unearthing of relevant risk factors reflects an important first step in identifying childhood stroke patients who may be more likely to manifest mental health symptomatology. Clinically, the quantitative conceptualization of variable relationships in this area may be instrumental in directing preventative efforts and coordinating therapeutic interventions as it relates to psychological wellbeing. Developmental neuropsychology theory and previous quantitative literature in acquired pediatric brain injury have provided insights into early presenting factors that represent essential areas for consideration that were encapsulated by the present study.

The Relevance of Neurological Status and Cognitive Functioning

A variety of factors have been implicated in the relationship between an adverse neurologic event and pediatric psychopathology. Notably, developmental neuropsychology theories suggests that there are both direct and indirect effects of brain injury on childhood functioning, with outcome being influenced by biological insult (i.e., lesion size and location), current abilities (i.e., skill acquisition, mastery, maintenance, and decline), and the developmental stage of the child (e.g., age at assessment, age at and time since brain insult) (Dennis, 2000). For instance, stroke may directly impact emotion centers of the brain, resulting in poor emotion regulation, response inhibition, and impaired social cognition. Psychosocial

problems could also presumably result from neurological difficulties (e.g., hemiparesis) and poor post-stroke cognitive and adaptive functioning via impact on quality of life.

The Pediatric Stroke Outcome Measure (PSOM) is an assessment tool that was developed in Ontario, Canada to measure neurological impairment in children and youth with stroke (deVeber et al., 2000). Administered by neurologists, the PSOM quantifies neurological functioning in five different areas: right sensorimotor, left sensorimotor, language production, language comprehension, and cognitive/behavioural. Scores in each domain are summed to form a PSOM total score ranging from 0 (no deficit) to 10 (maximum deficit). Research that has utilized the PSOM to assess the impact of pediatric stroke on quality of life found poorer social and emotional outcomes in children with moderate/severe neurological deficits compared with patients that were normal/mildly affected (Neuner et al., 2011). A subsequent study noted that pediatric stroke patients with more severe neurological deficits on the PSOM had impairments in a range of adaptive behaviors, social adjustment, and social participation. Poorer social adjustment significantly correlated with greater deficit in the cognitive/behavioural domain of neurological functioning on the PSOM (Lo et al., 2014). Furthermore, childhood basal ganglia stroke patients diagnosed with dystonia through neurological PSOM assessment were found to have greater levels of anxiety and depression symptoms relative to children with similar patterns of stroke, but no dystonia diagnosis. In addition to poorer motor and mental health outcomes, this group of dystonia patients were also found to have greater cognitive difficulties (Ledochowski et al., 2020).

It is well-established that pediatric stroke is associated with reduced performance in children's executive functioning (i.e., goal directed behaviours like cognitive flexibility and working memory), attention control, verbal fluency, problem solving, processing speed, and

academic achievement (Allman & Scott, 2013; Champigny et al., 2020; Fuentes et al., 2016; Roberts et al., 2019; Westmacott et al., 2009, 2018; Williams et al., 2017). Studies suggest that cognitive problems following childhood acquired brain injury are associated with increased risk of mental health problems, including anxiety and depression (Li & Liu, 2013; O’Keeffe et al., 2017). This may be especially true for cognitive skills and domains that are heavily recruited for daily functioning and academics, such as verbal fluency, verbal reasoning, and executive functions. Many children with stroke history require rehabilitation therapy (e.g., physical and speech therapies), assistance with tasks of daily living, and educational supports (Yvon et al., 2018). There is evidence to suggest that pediatric stroke survivors with lower functional abilities, low school achievement, school activity limitations, and greater requirement for caregiver assistance are more likely to struggle with community participation, self-esteem, and a reduced sense of emotional wellbeing (Anderson et al., 2014; Blom et al., 2007; Christerson & Strömberg, 2010; Ganesan et al., 2000). Taken together, it appears likely that learning, cognitive, and physical disabilities can reduce social and academic participation and lead to poor mental health (O’Keeffe et al., 2012, 2017).

There have been inconsistent findings regarding the brain injury factors that are significantly associated with psychosocial outcome or quality of life following childhood stroke (Anderson et al., 2014; Everts et al., 2008; O’Keeffe et al., 2017). Mixed findings are likely due to methodological limitations, with issues including small and heterogeneous samples, lack of control groups, and measurement difficulties (O’Keeffe et al., 2017). Uncertainty has especially surrounded the relevance of lesion-related variables, such as infarct size and location within the brain. Previous research on acquired pediatric brain injury has generally suggested that lesion severity is more predictive of functional outcome when compared to the small and inconsistent

effects associated with lesion location (Ganesan et al., 1999; Studer et al., 2014; Westmacott et al., 2009, 2010). For instance, stroke involving large infarctions affecting both cortical and subcortical territories is associated with more impairing, immediate, and stable cognitive deficits in children due to neural network disruption (Levine et al., 2005). In contrast, the reduced functional specialization of the developing, immature brain makes precise brain-behaviour relationships difficult to ascertain (Everts et al., 2008).

Although some studies have related larger stroke infarctions to difficulties surrounding emotional control and wellbeing (Ghotra et al., 2015; Lo et al., 2014), several other studies have cited a general lack of association between lesion variables and social-emotional outcomes (Anderson et al., 2014; Everts et al., 2008; Ganesan et al., 2000). Although the latter findings may seem surprising, research on early focal brain insult commonly cites lack of association between lesion characteristics and social-emotional functioning (Gordon et al., 2002; Greenham, 2010). Authors have indicated that within the context of multiple prominent, non-injury related variables (e.g., environmental factors), lesion characteristics may not be as relevant to mental health, especially as time post-stroke increases (Anderson et al., 2014). As suggested above, lesion characteristics may be contributing to psychosocial functioning through mediating factors, such as the negative impact of large lesions on cognitive functional status, motor functioning, and quality of life (Lo et al., 2014).

Developmental Factors: Age at Stroke and Time Since Stroke

In applying developmental neuropsychology theory (Dennis, 2000) to pediatric stroke outcomes, it would seem that patients' response to biological and environmental risk factors would also be determined by the child's current developmental stage, age at stroke, and time since stroke. Indeed, studies have confirmed the relevance of time and developmental factors on

intellectual outcomes in pediatric stroke (Allman & Scott, 2013; Westmacott et al., 2009). Identification of the path towards social-emotional risk and resilience in this population is likely complex and multifactorial. With regard to age-at-stroke effects, children with perinatal-onset stroke have demonstrated a trend for better social participation, peer interactions, and self-esteem than individuals with childhood onset stroke (Anderson et al., 2014; Cnossen et al., 2010; Ganesan et al., 1999), and this finding held true even when perinatal-onset patients had larger lesions (Anderson et al., 2014). It is unclear if this age-at-stroke finding is due to neurobiological causes (e.g., adaptive experience-dependent neuronal plasticity associated with the young brain) and/or the direct psychological effects of stroke in older children (i.e., less time to adjust to one's deficits). For instance, individuals who have experienced a stroke in childhood will have memories of pre-stroke normative functioning, which may create a heightened awareness of current difficulties and produce feelings of sadness, despair, and anxiety. Similarly, parents of childhood stroke patients may also have to adapt to new neurological difficulties and problems in their child, and may be more likely to conceptualize the stroke event in terms of loss. Qualitative interviews on parents' experiences following childhood acquired brain injury revealed a common theme encompassing "grieving for the child I knew" (Roscigno & Swanson, 2011). In comparison, perinatal stroke likely becomes part of a child's perceived identity from early development. Research suggests that a caregiver's response to their child's brain injury influences behavioural outcomes in the patient. Greater externalizing and internalizing childhood problems are associated with poor parent coping (Kinsella et al., 1999; Raj et al., 2013), which may be more prevalent in families of childhood stroke patients when compared to perinatal patients. However, poor parent coping may also result from greater childhood internalizing and

externalizing problems, and it is also important to recognize the potential for bidirectional relationships and interactions between these factors.

While few studies have specifically examined the role of time-since-stroke in psychosocial outcomes, research has commonly shown that the adverse cognitive impact of pediatric brain injury can become more salient over time, leading to larger gaps in developmental trajectories, relative to healthy peers (Fuentes et al., 2016; Roberts et al., 2019; Westmacott et al., 2009). Older children and adolescents with stroke have been found to have increased difficulties regarding their peer related well-being, such as difficulty making friends and connecting with same-age peers (Neuner et al., 2011). When examining general quality of life, several researchers have found insignificant effects for age at testing (Friefeld et al., 2004; Ganesan et al., 2000; Gordon et al., 2002; Hurvitz et al., 2004). However, several of these findings may have been conflated with age-at-stroke given mixed samples and statistical methods. Further investigation of age-at-testing and time-since stroke effects are needed in order to untangle the impact of these important temporal and developmental factors.

Parent, Family, and Environmental Factors

Environmental factors, such as family environment, socioeconomic status, and parent mental health, have also been linked to childhood wellbeing in both typically developing children and in survivors of childhood brain insult (Anderson et al., 2006; Evans, 2004; Repetti et al., 2002), and may represent an important component of *reserve* (Dennis, 2000). Reserve is a developmental concept that reflects the brain's ability to cope with pathological changes (Donders & Kim, 2019). In the context of pediatric brain injury, reserve may include the impact of a favorable childhood environment on the strengthening of neuronal resilience as it applies to both cognitive and emotional functioning (Donders & Kim, 2019; Fay et al., 2010; Schoentgen et

al., 2020). Parenting plays a prominent role in how children and youth develop their ability to regulate emotions, and a tripartite model has been established for explaining causal mechanisms (Morris et al., 2007). Specifically, it is believed that parenting can contribute to self-regulation and psychological resilience in children through: children's observation of parents' emotion regulation, emotion-related parenting practices, and the emotional climate of the family (Morris et al., 2007, 2017). The tripartite model places parents and the family in a central position for establishing healthy coping. By modeling adaptive emotion regulation strategies and maintaining positive parenting (e.g., warmth, support, structure, and appropriate rules) and healthy family functioning, children are able to establish the foundations of emotion and behaviour regulation (Morris et al., 2017; Rutherford et al., 2015). The family emotional climate is reflected in the parent-child attachment relationship, sibling relationships, and emotionality within the home. When the relationship between a parent and child is secure, it often helps the child to feel supported and safe to express emotions, which is a precondition for the developing the ability to independently regulate emotional states (Crandall et al., 2015; Morris et al., 2017). Collectively, it is evident that parent mental health and level of family conflict/functioning are important variables to consider when investigating mental health outcomes in children.

To date, the pediatric acquired brain injury literature has focused on the role of insult severity in neurobehavioural outcomes. However, it appears that brain pathology may not be as central to the prediction of social-emotional wellbeing in children when compared to the saliency of family functioning and other environmental factors. Quality of the home environment, such as parental responsiveness, acceptance of the child, and level of family conflict, has been found to be predictive of long-term classroom behaviour in pediatric moderate and severe TBI (Durber et al., 2017). When investigating the contributions of environment, stroke pathology, and neurological

outcome to social outcomes following pediatric stroke, Anderson and colleagues (2014) found that family functioning was the strongest predictor of social adjustment, while lesion volume and location were not connected to social outcome.

Other researchers have also taken an interest in applying a more comprehensive, environmentally-focused approach to child and youth assessment. For instance, Greenham and colleagues (2015) found that post-stroke family environment (e.g., degree of conflict and disruption within the family unit), poor parent mental health, and lower parent education predicted internalizing problems and social dysfunction in pediatric stroke survivors. Results highlighted the importance of interventions that target the family support system (Anderson et al., 2014; Greenham et al., 2015). Family functioning was also found to be a significant predictor of psychosocial outcomes and self-esteem in a study on quality-of-life following childhood arterial ischemic stroke (O’Keeffe et al., 2012). However, a contradictory finding was reported by another study (Max et al., 2002), which cited a lack of significant relationship between pediatric stroke mental health outcomes and family functioning; instead, neurological symptom severity, parental psychiatric history, and intellectual and adaptive deficits were identified as prominent factors. Divergent findings amongst studies emphasize the need for more research in this area in order to uncover the nuances and relevance of central biological and environmental factors in their prediction of mental health.

School and social experiences may also be relevant to pediatric stroke patients’ mental health. Lack of published literature on this topic is surprising given that school comprises a central area of life experience amongst youth; a substantial amount of time is spent within the school environment and considerable value is given to school grades and social approval amongst classmates. Difficulties within these domains would presumably lead to distress and

low self-confidence amongst pediatric stroke patients, who may compare themselves to their typically developing classmates. The pediatric stroke literature on academic achievement has identified that this group is at risk of learning difficulties, with reports of low scores in reading, writing, and math (Allman & Scott, 2013; Champigny et al., 2020; Deotto et al., 2019; Funnell & Pitchford, 2010). In typically developing children, researchers have found several complex patterns of association between poor academic performance, peer victimization, and internalizing and externalizing symptoms (Vaillancourt et al., 2013). These findings underscore the importance of examining the role of social support, bullying, school environment, and academic achievement in the lives of children with stroke. In summary, there appear to be a variety of personal, family, and school-based variables that need to be taken into consideration when examining risk factors and sources of resilience in the psychosocial outcomes of patients with pediatric stroke.

Empirically, we were interested in determining the relevant neurological, cognitive, and environmental factors which may contribute to psychosocial functioning. Several variables were quantitatively investigated for their predictive value, including cognitive functioning, neurological status, stroke lesion characteristics, developmental factors, family functioning, parent mental health, socioeconomic status, school environment, and peer support. With regard to cognition, study measures focused on the assessment of intelligence, processing speed, cognitive flexibility, working memory, visual attention, response inhibition, verbal fluency, and academic achievement. Each of these cognitive skills constitutes a central neuropsychological domain that could potentially impact emotional and psychological wellbeing. In the interest of taking a developmentally-oriented theoretical approach, we also examined the effects of age-at-

stroke and time-since-stroke on social-emotional outcomes. The impact of lesion severity was also investigated.

Hypotheses

The following were the hypotheses and predictions for Study 1:

- 1) Relative to age-matched controls, it was expected that children and youth with a history of stroke would have significantly higher ratings on measures of psychopathology, indicating greater problems. In particular, higher incidence of social anxiety and low mood were expected as well as lower self-esteem.
- 2) Relative to age-matched controls, it was expected that children and youth with a history of stroke would have a significantly higher number of social problems, including lower rates of peer acceptance and social support.
- 3) Amongst neurological status variables, it was expected that physical disability in stroke patients would be related to poorer scores in social acceptance, physical well-being, and self-perception.
- 4) With regard to cognition, it was expected that stroke participants would have significantly lower scores (i.e., poorer performance) on measures of intellectual reasoning, executive functioning, and academic skills. It was believed that executive functioning would moderately associate with internalizing symptoms given the role of attention control, self-monitoring, and cognitive shifting in emotion regulation (Schmeichel & Tang, 2015; Schweizer et al., 2020). It was believed that learning and language difficulties would moderately associate with mood given the importance of these skills for daily functioning (Cattelino et al., 2021).
- 5) It was expected that larger stroke lesions would significantly predict the presence of psychosocial problems.

6) It was expected that patients with childhood stroke (when compared to patients with perinatal stroke) would have poorer ratings on measures of emotional and psychological wellbeing.

7) Amongst the predictor variables examined, it was hypothesized that family functioning would be most strongly predictive of youth emotional and social functioning, serving as a source of risk or resilience, depending upon the degree of communication, problem solving, and affective involvement within the family unit. It was also believed that parent mental health would be strongly associated with family functioning and anxiety/depression risk in youth.

Methods

Participants

This study examined children between the ages of 8 and 18 years with and without histories of stroke. The age range of participants was selected based on consistency with previous quantitative studies examining psychosocial outcomes in pediatric stroke, as well as the age ranges specified by measures that were administered in this study. In total, there were 65 participants: 31 with stroke history and 34 healthy controls. Stroke participants were patients within the Children's Stroke Program at the Hospital for Sick Children who were also enrolled in the Canadian Pediatric Ischemic Stroke Registry (deVeber et al., 2017). A telephone recruitment procedure was used to contact families who indicated interest in research and provided consent to be contacted for studies. Recruitment criteria for the stroke group consisted of: (1) ischemic stroke documented on magnetic resonance imaging (MRI) or computed tomography (CT); (2) stroke before the age of 18 years; (3) at least 6 months post-stroke at the time of testing; and (4) fluency in English. Exclusion criteria consisted of: (1) premature birth (less than 36 weeks gestation); (2) hypoxic-ischemic encephalopathy; (3) sickle cell disease; (4) psychosis; (5) Moyamoya disease; and (6) neurological disorders (e.g. head injury, malignancy, etc.). Typically

developing children were recruited through local advertisement, or were siblings and friends of pediatric stroke patients if the youth and caregiver both indicated interest and consented to participation. Children were excluded from the control group if they had experienced a head injury and/or if they had a condition that could impact neurodevelopment, such as premature birth (less than 36 weeks gestation), epilepsy, diabetes, or thyroid dysfunction. Children with learning disabilities or Attention-Deficit Hyperactivity Disorder (ADHD) were not excluded from participation in the stroke or control group since the literature has shown that attention and academic problems are common in the pediatric stroke population (Max et al., 2002; Roberts et al., 2019). Moreover, school achievement and behaviour were domains of interest within the current study.

We did not perform selective sampling with regard to sex, as we wanted our sample to be representative of true sex differences in the pediatric stroke population. Prior studies have indicated that males are more vulnerable to suffering stroke and represent approximately 55% - 60% of pediatric stroke cases (Fuentes et al., 2016). Stroke participants were categorized according to age at stroke, which was defined as follows: 1) presumed perinatal stroke (stroke presumed to have occurred during the perinatal period due to neurological deficits attributable to remote focal infarction on neuroimaging later in infancy); 2) neonatal stroke (occurrence of stroke during the first 28 days of life); 3) stroke at 1 month to 5 years; and 4) stroke at 6 to 18 years. Although there is no consensus with regard to the age cut-off that differentiates early and later onset childhood brain injury, the age of 5 years has been most commonly and consistently used in previous literature (Vargha-Khadem et al., 1994; Westmacott et al., 2010). Stroke lesion characteristics were also documented for all participants via medical records, as described below.

Neuroimaging Data and Medical Records

As a component of patient care and assessment at the Hospital for Sick Children, children and youth referred to the Stroke Program undergo a clinical MRI or a CT scan for medical diagnostic and prognostic purposes. Neuroimaging data and medical records were used to examine brain lesion characteristics and ensure that patients met study inclusion criteria. Team neurologists reviewed MRIs and CT scans of stroke patients at hospital clinic visits and coded lesion location as follows: 1) subcortical lesion: an infarct restricted to the basal ganglia and/or thalamus; 2) cortical lesion: an infarct localized to the cortex with no subcortical involvement; 3) combined lesion: an infarct involving the cortex plus basal ganglia and/or thalamus. This information was used in the current study to examine the significance of lesion severity as a predictor of outcome.

Medical records were also used to obtain recent information on the neurological status of stroke patients. The Pediatric Stroke Outcome Measure (PSOM) (deVeber et al., 2000) is an examination routinely administered to all patients within the Children's Stroke Program to assess neurological deficits. The neurologist assesses and scores the child in five different areas of neurological functioning: right sensorimotor, left sensorimotor, language production, language comprehension, and cognitive/behavioural. On each of these five subscales, the child is assigned a value indicating degree of deficit (0=no deficit, 0.5=mild deficit, 1=moderate deficit, 2=severe deficit). Scores are then summed to form a PSOM total score that ranges from 0 (no deficit) to 10 (maximum deficit) (Kitchen et al., 2012). Recent (i.e., within one year) PSOM scores were used within the current study to determine relevant neurological predictors of functioning.

Procedure and Measures

For individuals indicating interest in study enrollment, a complete description of the study and its objectives was provided to participants and their parents in-person. Consent was obtained from participants and their parents. In cases where a child did not have the capacity to consent, child assent was obtained in addition to parental consent. Capacity was assessed by a registered, certified psychologist throughout the duration of the study. Data collection took place at the Hospital for Sick Children or York University, depending on the location preference of the caregiver. All participants completed the Wechsler Abbreviated Scale of Intelligence - Second Edition (WASI-II), Color-Word Interference Test and Trail Making Test from the D-KEFS, Wide Range Achievement Test 4 (WRAT4), Rapid Picture Naming Task, The Revised Child Anxiety and Depression Scale (RCADS), and the KIDSCREEN-52 self-report version. Patients who had been administered intelligence tests within the past year as part of their Pediatric Stroke Program assessment did not receive the WASI-II. Instead, their existing intelligence test scores were used for the purposes of this study. This was done for both efficiency and validity (i.e., to prevent the practice effects that could occur through repeat administration). In order to provide data on child, family, and caregiver functioning, primary caregivers completed a demographic questionnaire, the Conners Comprehensive Behavior Rating Scales Clinical Index, The General Health Questionnaire, and the McMaster Family Assessment Device. It was specifically requested that a primary caregiver complete the forms since the study requires a knowledgeable informant who is in regular contact with the child and lives within the same home. Hospital medical records were consulted to obtain information on the eligibility of participants and their neurological status. All measures are listed in Table 1 and also described in detail below. At the conclusion of testing, participants and their caregivers were provided with compensation, which

consisted of a Cineplex movie ticket voucher and transportation reimbursement up to \$25.00.

The results of testing and related feedback were compiled in a brief report that was mailed to the family.

Table 1. Measures used in Study 1

Measure	Domain of Function	Description
CHILD MEASURES:		
<i>Wechsler Abbreviated Scale of Intelligence- Second Edition (WASI-II)</i> (Wechsler, 1999)	Intellectual functioning in the areas of verbal and perceptual reasoning	An abbreviated intelligence test that produces Verbal Comprehension, Perceptual Reasoning, and Full-Scale IQ scores
<i>Symbol Search Subtest from the WISC-V</i> (Wechsler, 2014)	Processing speed	Cross out specific symbols on a record form as quickly and efficiently as possible
<i>Trail Making Test from the D-KEFS</i> (Delis et al., 2001)	Cognitive flexibility, working memory, and visual attention	Alternate between connecting letters and numbers on a page, in sequential order
<i>The Color-Word Interference Test from the D-KEFS</i> (Delis et al., 2001)	Response inhibition	Colour words are presented in dissonant coloured ink and the participant is required to say the ink colours and inhibit the impulse to read the words
<i>Rapid Picture Naming Task from the Woodcock – Johnson III Tests of Cognitive Abilities</i> (Woodcock et al., 2001)	Rapid automated naming	Name pictures of common items and objects as quickly as possible within a 2-minute time limit
<i>Wide Range Achievement Test 4 (WRAT4)</i> (Wilkinson & Robertson, 2006)	Academic achievement	An achievement test that assesses basic academic skills of reading, spelling, and arithmetic
<i>The Revised Child Anxiety and Depression Scale (RCADS)</i> (Weiss & Chorpita, 2011)	Emotional and psychological wellbeing	A 47-item, youth self-report questionnaire that is designed for identifying 8-18 year-olds that are at risk for mood and anxiety disorders

<i>KIDSCREEN-52</i> (Ravens-Sieberer et al., 2005)	Health-related quality of life	A 52-item, youth self-report questionnaire that is designed to identify subjective health and well-being in children and adolescents
PARENT MEASURES:		
<i>Demographic Questionnaire</i>	Developmental, medical, and family histories	All caregivers will be asked to complete a questionnaire in order to collect information regarding participants' history and demographic background
<i>Conners Comprehensive Behavior Rating Scales, Clinical Index (CBRS-CI)</i> (Conners, 2008)	Emotional, academic, behavioural, and social problems in children	A 24-item parent-report questionnaire commonly used as a screening tool for disorders in children
<i>General Health Questionnaire (GHQ)</i> (Goldberg, 1978)	Parent mental health	A 12-item self-administered psychometric screening tool that is used to identify psychological distress in adults
<i>McMaster Family Assessment Device (FAD)</i> (Epstein et al., 1983)	Family functioning	A 12-item parent-rated measure that contains questions about family problem solving, communication, affective responses, roles, affective involvement, and behaviour control

WASI-II: Wechsler Abbreviated Scale of Intelligence - Second Edition (Wechsler, 1999). The WASI-II is an abbreviated intelligence test that consists of two to four subtests that have been taken from the WISC-IV: Wechsler Intelligence Scales for Children, Fourth Edition (Wechsler, 2003) and the Wechsler Adult Intelligence Scale, fourth edition (WAIS-IV) (Wechsler, 2008). It is standardized for use among individuals aged 6 to 90 years. The WASI-II produces Verbal Comprehension, Perceptual Reasoning, and Full-Scale IQ scores. The current study utilized the two subtest version of the WASI-II; specifically, the Matrix Reasoning and Vocabulary subtests were administered since they allowed for a quick and accurate estimate of Full Scale IQ that was not strongly biased by motor control abilities, which may be an area of

weakness among stroke participants (i.e., these tests do not involve motor manipulation of objects). Internal consistency reliability coefficients of the WASI-II range from 0.88 to 0.96 for Matrix Reasoning and 0.90 to 0.98 for Vocabulary. Stability coefficients for test-retest reliability have been found to range from 0.87 to 0.92. A correlational study found a strong relationship between WASI-II full scale IQ scores and the full scale IQ scores of the WAIS-III, thereby demonstrating concurrent validity; the correlation coefficients were 0.87 and 0.92 for the two and four subtest versions of the WASI, respectively (Irby & Floyd, 2013).

Symbol Search Subtest from the WISC-V: Wechsler Intelligence Scale for Children-Fifth Edition (Wechsler, 2014). The Wechsler Intelligence Scale for Children 5th Edition (WISC-V) is an individually-administered intelligence scale designed for youth ages 6 to 18 years, with Canadian standardization norms. Symbol Search, one of the subtests on the WISC-V, assesses processing speed. Participants were asked to cross out specific symbols on a record form as quickly and efficiently as possible. Internal consistency on the Symbol Search subtest ranges from 0.81 to 0.88, and inter-rater agreement ranges from 0.97 to 0.99, which is extremely high (Canivez & Watkins, 2016).

D-KEFS: Delis-Kaplan Executive Function System (Delis et al., 2001). The D-KEFS is designed to evaluate higher level cognitive functions in both children and adults, with norms extending from ages 8 – 89 years. Consisting of nine stand-alone tests, the Trail Making Test and Color-Word Interference Test are the components that were used within this study. The Trail Making Test was used to assess cognitive set shifting, and completion time was the primary performance measure, which was then converted to standard scores based on norms. The test has four baseline conditions (Visual Scanning, Number Sequencing, Letter Sequencing, and Motor Speed) and one higher-level condition (Letter-Number Switching). On Letter-Number

Switching, the test-taker was required to alternate between connecting letters and numbers on a page, in sequential order. Internal consistency coefficients on the Trail Making Test range from moderate to high, and for most age groups the total score reliability was good (a range of 0.59 to 0.79 for children and adolescents). For individuals aged 8-19 years, test-retest reliabilities were good and resulted in a correlation of 0.78 for Letter-Number Switching (Delis et al., 2001).

The Color-Word Interference Test was used to assess response inhibition. Completion time was the primary performance measure, which was then converted to standard scores based on norms. This task consisted of two baseline conditions (Color Naming and Word Reading) and two higher-level conditions (Inhibition and Inhibition-Switching). Both higher level conditions presented test-takers with colour words written in dissonant coloured ink (e.g., the word blue printed in red coloured ink) and the individual was required to say the ink colour and inhibit the tendency to read the word. The interference in reaction time commonly seen on this task is known as the “Stroop effect”. In the Inhibition-Switching condition of the Color-Word Interference Test, the test-taker was presented with the additional requirement of rule switching; the individual is required to name dissonant ink colours except for when the word is placed inside of a box (boxed words are to be read). Internal consistency coefficients on the Color-Word Interference Test were computed through split-half correlations and were found to be moderate to high for children and adolescents and ranged from 0.62 to 0.79. For individuals aged 8-19 years, test-retest reliabilities were good and resulted in correlations of 0.90 and 0.80 for the Inhibition and Inhibition-Switching conditions, respectively (Delis et al., 2001).

With regard to validity evidence, scores derived from the same D-KEFS test correlate more robustly than scores across different tests within the D-KEFS battery. Low positive correlations amongst D-KEFS tests indicate that the instruments are not interchangeable and

measure unique aspects of executive functioning. Scores on both the Trail Making Test and Color-Word Interference Test have been found to correlate more strongly with scores on the Wisconsin Card Sorting Task (a common test of higher-level cognitive functions) than on the California Verbal Learning Test (a test of verbal memory), thereby demonstrating convergent validity. Furthermore, scores on the Trail Making Tests and Color-Word Interference Test have been found to discriminate between clinical populations with different cognitive profiles, such as adults with Alzheimer's and Huntington's disease (Delis et al., 2001).

WRAT4: Wide Range Achievement Test 4 (Wilkinson & Robertson, 2006). The WRAT4 is an achievement test that aims to measure basic academic skills of reading, spelling, and arithmetic. It was first developed in 1941 by Bijou and Jastak and is currently in its fourth revision. The test is developed for individuals aged 5 to 94 years. The WRAT4 includes four subtests: Math Computation, Spelling, Sentence Comprehension, and Word-Reading. Norms provided include standard scores, percentiles, and grade levels. Split-half reliability scores range from 0.94 to 0.98 (Wilkinson & Robertson, 2006). A correlational study found a strong relationship between the WRAT4 and the Peabody Individual Achievement Test, demonstrating concurrent validity. The WRAT4 also correlates moderately with various IQ tests, with scores ranging from 0.40 to 0.70.

Rapid Picture Naming Task from the WJ-III COG: Woodcock–Johnson III Tests of Cognitive Abilities (Woodcock et al., 2001). The WJ-III COG test battery is a comprehensive set of individually administered norm-referenced tests for measuring intellectual abilities. The Rapid Picture Naming Task is the 18th subtest from this battery, and it was designed to test naming facility. Naming facility is characterized by the ability to quickly name objects and pictures on sight, which in turn indicates how quickly and accurately a child can retrieve words

from memory. Rapid picture naming skill has been found to be a strong predictor of reading ability due to its association with lexical access (Decker et al., 2013). Test-takers were required to name pictures of common items and objects as quickly as possible within a 2 minute time limit. Results were reported in standard scores. Median test-retest and split half reliabilities have been reported to be around 0.97 in samples of children and youth aged 5 to 19 years (Mather & Woodcock, 2001).

RCADS: The Revised Child Anxiety and Depression Scale (Weiss & Chorpita, 2011). The RCADS is a 47-item, youth self-report questionnaire that is designed for identifying 8-18 year-olds that are at risk for mood and anxiety disorders. It consists of 47 statements concerning emotional and psychological wellbeing that are rated on a four-point Likert scale from 0 (“never”) to 3 (“always”). Subscales include: separation anxiety disorder (SAD), social phobia (SP), generalized anxiety disorder (GAD), panic disorder (PD), obsessive compulsive disorder (OCD), and major depressive disorder (MDD). It also yields a Total Anxiety Scale (sum of the 5 anxiety subscales) and a Total Internalizing Scale (sum of all 6 subscales). Raw scores were converted to T-scores, with higher T-scores indicative of greater problems within each clinical domain (Weiss & Chorpita, 2011). Factor analytic studies support the six subscales of the RCADS and indicate that they are consistent with DSM-IV anxiety disorders and depression. Internal consistency is favorable and generally ranges from 0.78 to 0.88 (Chorpita et al., 2005). One week test-retest coefficients ranged from 0.65 to 0.80 (Chorpita et al., 2000). Convergent validity has also been demonstrated; RCADS scales have correlated positively and significantly with child and parent interview ratings and self-report criteria that targeted the same disorders (e.g., the Children’s Depression Inventory and the Revised Children’s Manifest Anxiety Scale) (Chorpita et al., 2005).

KIDSCREEN-52 (Ravens-Sieberer et al., 2005). The KIDSCREEN is a self-reported health-related quality of life (HRQoL) questionnaire for both healthy and chronically ill youth, ages 8-18 years. Developed within a European project funded by the European Commission, the KIDSCREEN included thirteen countries in its development to ensure cross-cultural validity. There are three versions: the KIDSCREEN-52, which includes 52 items and provides a detailed profile on 10 HRQoL dimensions, the KIDSCREEN-27, which includes 27 items and provides a profile on five HRQoL dimensions, and the KIDSCREEN-10, which includes 10 items and provides a global HRQoL score for basic monitoring and screening uses. The KIDSCREEN instruments are available in child-report and parent/proxy versions and have been translated and adapted for use in several languages. The current study utilized the KIDSCREEN-52 self-report version for children and youth.

The 10 dimensions in the KIDSCREEN-52 are the following: Physical, Psychological Well-Being, Moods and Emotions, Self-Perception, Autonomy, Parent Relations and Home Life, Social Support and Peers, School Environment, Social Acceptance, and Financial Resources. T-values and percentages are available stratified by age, gender, and socioeconomic status. Internal consistency reliability scores for the KIDSCREEN-52 range from 0.76 (Social Acceptance) to 0.89 (Financial Support) (Ravens-Sieberer et al., 2005). The relationship between national HRQoL instruments for children and adolescents and the KIDSCREEN versions were analyzed and showed satisfactory results, including high correlations between the KIDSCREEN instruments and children's health status (Herdman et al., 2007; Ravens-Sieberer et al., 2001).

Demographic Questionnaire. All caregivers were asked to complete a demographic questionnaire in order to collect information regarding participants' developmental, medical, and family histories. Maternal and paternal education was rated on an eight-point scale (1 = some

elementary school; 2= completed elementary school; 3 = some high school; 4 = completed high school; 5 = some college; 6 = completed college; 7 = university degree; 8 = postgraduate degree). Family income was rated on a seven-point scale (1 = under \$30,000; 2 = \$30,000 - \$49,999; 3 = \$50,000 - \$89,999; 4 = \$90,000 - \$139,999; 5 = \$140,000 - \$199,999; 6 = \$200,000 - \$299,999; 7 = Over \$300,000). The demographic questionnaire is provided in Appendix A.

Conners CBRS-CI: Conners Comprehensive Behavior Rating Scales, Clinical Index (Conners, 2008). Conners CBRS is a scale designed to provide a complete overview of concerns and disorders in young persons aged 6 to 18 years. The Clinical Index (Conners CBRS-CI) parent-report version of the Conners CBRS was used to measure emotional, academic, behavioural, and social problems in participants. The Conners CBRS-CI is commonly used as a screening tool for disorders in children since it was developed to correspond with diagnostic criteria as outlined within the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). The Clinical Index form consists of 24 statements that are rated by caregivers on a four-point Likert scale, indicating degree of agreement. Ratings produce scores on five scales which have been validated through factor analysis: Disruptive Behaviour Disorder Indicator, Learning and Language Disorder Indicator, Mood Disorder Indicator, Anxiety Disorder Indicator, and ADHD Indicator (Conners, 2008). Raw scores were converted to T-scores, and higher T-scores are indicative of greater problems within each clinical domain. Both internal consistency and test-retest reliability are good for the Conners CBRS-CI, parent form. Internal consistency coefficients range from 0.73 to 0.85, and two to four week test-retest reliability coefficients range from 0.83 to 0.91. Inter-rater reliability coefficients range from 0.55 to 0.90. Convergent and divergent validity have been supported through studies that have examined the relationship between the Conners

CBRS-CI and related measures. Discriminative validity was a core purpose in the design of the Conners CBRS-CI, and studies confirm that the scale is adept at distinguishing between clinical and non-clinical groups (Conners, 2008).

GHQ: General Health Questionnaire (Goldberg, 1978). The GHQ is a self-administered psychometric screening tool that is used to identify psychological distress in adults. Specifically, the GHQ was designed to detect two main classes of problems: the inability to carry out one's normal healthy functions and the appearance of new phenomena of a distressing nature. The questionnaire consists of items with a four-point Likert scale for responses. There are multiple versions available (e.g., versions with 12, 28, 30 and 60 questions), with the 12-item version being most commonly used within research due to its brevity and comparable validity and reliability. Accordingly, the 12-item version of the GHQ (GHQ-12) was used within this study in order to yield an emotional distress/psychological disturbance score that is indicative of overall parent mental health. The GHQ-12 yields a total score, which is the sum of all of the rated items. The higher the score, the more severe the condition. Threshold values are based on past clinical use and research evidence, which suggests that a score equal to or greater than 12 out of a maximum score of 36 is indicative of potential psychopathology (Goldberg et al., 1997).

The test-retest coefficient on the GHQ-12 was found to be 0.90 after six months, and split-half reliability was 0.83. Alpha coefficients for the GHQ-12 ranged from 0.82 to 0.90 in four studies (McDowell, 2006). Additionally, the validity of the GHQ-12 has been studied in multiple clinical populations and it has been established as valid for use on adults and adolescents, but not children. Validation studies have confirmed sensitivity and specificity values to be 83.7% and 76.3%, respectively (McDowell, 2006). The GHQ correlates well with other tests of well-being, distress, and psychopathology, such as the Hospital Depression and Anxiety

Scale (McDowell, 2006; Robinson & Price, 1982).

McMaster FAD: Family Assessment Device (Epstein et al., 1983). The McMaster FAD is a 12-item parent-rated measure of family functioning. The measure contains statements about healthy and unhealthy functioning with respect to family problem solving, communication, affective responses, roles, emotional involvement, and behaviour control. The degree to which the rater agrees with each statement is rated on a 4-point Likert scale, which is then translated to point values (1-4 for positively worded items and transformed for negatively worded items) and summed. The total score is divided by the number of items answered in order to generate a General Functioning Scale, which represents a ratio of overall perceived functioning within the family unit (Ryan et al., 2005). The higher the General Functioning score, the more problematic the family member perceives the family's overall functioning. The clinical score threshold value for the General Functioning Scale ratio is 2.00; a score equal to or greater to this value indicates unhealthy functioning (Ryan et al., 2005). The McMaster FAD possesses adequate test-retest reliability, with a reliability estimate of 0.71 for the General Functioning Scale (Miller et al., 1985). Internal consistency was found to be .86 (Chronbach's alpha) and the split-half coefficient (Gutman) was 0.83 (Byles et al., 1988). Concurrent validity has been demonstrated with the Family Unit Inventory (FUI), an 80-item assessment instrument designed to assess a number of family dimensions. Correlations between the FAD and the scales of the FUI were significant ($r > 0.50$). In contrast, divergent validity studies have found low correlations between the FAD and social measures tapping into dissimilar constructs; for example, Pearson's correlation coefficients between the FAD and Marlowe-Crowne Social Desirability Scale ranged from -0.06 to -0.19. The FAD differentiates significantly between clinician-rated healthy and unhealthy families (Miller et al., 1985).

Statistical Design

Prior to inferential procedures, the data was analyzed to ensure that it met parametric test assumptions. Levene's test was used to assess homogeneity of variances across groups. The assumption of normality was examined through the Shapiro-Wilk test, skewness values (values over +/- 2 are indicative of non-normality), and by analyzing graphical representations of data distributions separated by group. An alpha significance level of .05 was adopted. In order to prevent the type I error inflation that accompanies multiple comparisons, the Benjamini-Hochberg procedure was used since this approach sufficiently controlled the false discovery rate while maximizing power (Holm, 1979). Partial eta-square values were computed as measures of effect size on inferential tests, where 0.01 = small, 0.06 = medium, 0.13 = large (Cohen, 1988). Group comparisons on demographic variables were conducted using Welch t-tests for continuous variables and Chi-square tests for categorical variables. Group differences across variables were examined using Analysis of Variance (ANOVA) tests. Exploratory analyses on variable relationships were conducted using Pearson's correlations. Significant correlations were followed with multiple regression procedures to determine relevant predictors of mental health outcomes.

Results

Power Analysis

The central goal of Study 1 was to test the null hypothesis that the two population means were equal. The criterion for significance (alpha) was set at 0.05. With a total sample size of 65, and a sample size of 31 for the stroke group and 34 for the control group, the study has a power of 84% to detect a statistically significant result through traditional F tests. Since variable prediction was another central goal for this study, power analysis was also conducted for the

proposed regression analyses. With an effect size of small to medium strength ($f^2=0.15$), and two predictor variables simultaneously entered into the multiple regression equation, the analysis has a power of 92% to detect a statistically significant multiple regression result. In summary, power findings suggested that the proposed ANOVA and regression analyses for the study should respectively have no more than 16% and 8% probabilities of making a Type II error (i.e., a false negative - the risk of failing to detect a true effect). Standards dictate that studies should have no more than a 20% probability of making a Type II error (Cohen, 1988).

Demographic Characteristics

Demographic and clinical characteristics of participants were determined from the demographic questionnaire completed by parents. Group comparisons of categorical demographic variables were made through Chi-Square tests. Groups did not differ in respect to sex, $\chi^2(1) = 0.152, p = .805$, maternal education, $\chi^2(5) = 10.849, p = .054$, paternal education, $\chi^2(6) = 5.791, p = .447$, family income, $\chi^2(6) = 7.108, p = .311$, ethnicity, $\chi^2(6) = 5.226, p = .515$, or parental marital status, $\chi^2(3) = 0.969, p = .809$. A Welch t-test revealed that the stroke and control groups were also comparable with respect to age at assessment, $t(63) = 0.480, p = .633$. A summary of demographic findings is presented in Table 2.

Clinical Characteristics

A review of health records provided information on the neurological characteristics of stroke participants. The pediatric stroke sample was comprised of slightly more males (54.8%) than females, which is consistent with medical literature documenting male predominance in pediatric stroke (Golomb et al., 2009). The average age at stroke was 2.21 years (range: 0.00 to 10.25 years), and the average time since stroke was 10.93 years (range: 2.75 to 17.91 years). The majority of stroke participants experienced stroke in early life (perinatal or neonatal) or between

1 month – 5 years. Age at stroke findings align with epidemiological studies indicating greatest risk of pediatric stroke in neonates and infants (Cárdenas et al., 2011). With regard to ischemic stroke subtype, 27 participants had arterial ischemic stroke (AIS), and four participants had cerebral venous sinus thrombosis (CVST). Medical history was negative for hemorrhagic stroke or hemorrhagic transformation (brain bleeds) in all participants. Regarding lesion location, 29.0% of stroke participants had cortical stroke, whereas 41.9% presented with subcortical stroke, and 16.1% had combined stroke to both cortical and subcortical regions. Infarcts were localized to white matter in 12.9% of stroke participants. Following stroke, 32.3% of the sample experienced hemiparesis (weakness on one side of the body). The mean PSOM score from the most recent neurological assessment was 1.75 out of 10, with a range of 5.0 (min: 0.0, max: 5.0).

A summary of the neurological characteristics of participants is presented in Table 2.

Table 2. Demographic characteristics of stroke and control participants and clinical characteristics of stroke participants

	Stroke	Control
Number of participants	31	34
Males, <i>N</i> (%)	17 (54.8)	17 (50)
Age at assessment, <i>years, M (SD)</i>	13.13 (2.91)	12.79 (2.85)
Maternal education ¹ , <i>M (SD)</i>	6.35 (0.95)	6.76 (1.42)
Paternal education ¹ , <i>M (SD)</i>	5.84 (1.64)	6.59 (1.44)
Family Income ² , <i>M (SD)</i>	4.32 (1.30)	4.52 (1.50)
<i>Ethnicity, no. of participants</i>		
Indigenous, First Nations, Inuit, Metis	1	0
Arab/West Asian	0	2
Asian American/Asian Pacific Islander	0	1
Black	1	2
Latino-a/Hispanic	0	0
South Asian	0	1
European Origin/White	26	25
Bi-racial/Multi-racial	3	3
Other	0	0
Age at stroke, <i>years, M (SD)</i>	2.21 (3.37)	
<i>Age at stroke, no. of participants</i>		

Presumed Perinatal	7
Neonatal	9
1 month-5 years	11
6-18 years	4
Time since stroke, <i>years, M (SD)</i>	10.93 (3.79)
Lesion laterality, <i>no. of participants</i>	
Right	12
Left	18
Bilateral	1
Lesion location, <i>no. of participants</i>	
Cortical	9
Subcortical	13
Combined	5
White matter	4
Total PSOM score, <i>M (min-max)</i>	1.75 (0.00-5.00)

1. Education is rated on an eight-point scale (see methods section for details)

2. Family income is rated on a seven-point scale (see methods section for details)

Intelligence

Intelligence variables were examined for parametric assumption agreement prior to analysis. Levene's test indicated that the assumption of homogeneity of variances was met for between-group comparisons of each intellectual index. Normality checks indicated that data was sufficiently normally distributed. One-factor, between-subjects ANOVAs were conducted to compare groups on intellectual outcomes. Results revealed that the stroke group had significantly lower mean scores on the Full Scale IQ Composite and Vocabulary subtest of the WASI-II. Stroke group performance was also significantly lower than controls on the Symbol Search Subtest of the WISC-V. Despite these differences, both groups possessed mean scores that were within the average range of functioning. There were no significant group differences for the Matrix Reasoning subtest on the WASI-II. Partial eta-squared values indicated medium effect sizes for Full Scale IQ, Vocabulary, and Symbol Search, and a small effect size for Matrix Reasoning. A summary of intelligence test findings is presented in Table 3.

Table 3. Intelligence mean scores and between-subjects ANOVA results for stroke and control participants

Intellectual Index¹	Stroke mean (SD)	Control mean (SD)	F-value	df	p-value	Partial Eta-Squared
Full Scale IQ, Standard score	102.16 (17.37)	111.47 (13.94)	5.72	1, 64	.020*	.08
Vocabulary, T-score	50.84 (10.38)	57.50 (9.40)	7.37	1, 64	.009*	.11
Matrix Reasoning, T-score	51.77 (12.37)	55.82 (9.05)	2.30	1, 64	.135	.04
Symbol Search, Scaled score	9.00 (3.80)	11.09 (2.78)	6.49	1, 64	.013*	.09

1. Full Scale IQ, Vocabulary, and Matrix Reasoning are indices from the WASI-II. Symbol Search is an index from the WISC-V.

*significant after application of the sequential Holm-Bonferroni procedure

Performance-Based Executive Functioning

Executive functioning variables were examined for parametric assumption agreement prior to analysis. Levene's test indicated that the assumption of homogeneity of variances was met for between-group comparisons of each intellectual index. Normality checks indicated that data was sufficiently normally distributed. One-factor, between-subjects ANOVAs were conducted. In comparison to controls, the stroke group had significantly poorer performance on the D-KEFS Trail Making Test (Number Letter Switching), and the partial eta-squared effect size was of medium strength. Significantly poorer stroke group performance was also noted on the D-KEFS Color-Word Interference Test with regard to both the Inhibition and Inhibition/Switching conditions. Partial eta-squared values indicated very strong effect sizes for both group differences on the Color-Word Interference conditions. According to test norms, stroke group mean scaled scores were in the low average range of performance. A summary of

executive function findings is presented in Table 4.

Table 4. Performance-based executive functioning mean scores and between-subjects ANOVA results for stroke and control participants

EF Test from D-KEFS¹	Stroke mean (SD)	Control mean (SD)	F-value	df	p-value	Partial Eta-Squared
Trail Making - Number Letter Switching	8.16 (3.47)	10.44 (3.34)	7.29	1, 64	.009*	.10
Color-Word Interference - Inhibition	7.65 (3.69)	11.26 (3.41)	16.91	1, 64	<.001*	.21
Color-Word Interference – Inhibition/ Switching	8.16 (3.58)	11.65 (2.64)	20.22	1, 64	<.001*	.24

1. Test means are in scaled scores

*significant after application of the sequential Holm-Bonferroni procedure

Learning and Language

Information on learning and language problems in participants was analyzed from the Learning and Language Disorder scale on the Conner's CBRS-CI parent questionnaire. High T-scores on this scale can indicate academic concerns and communication problems (i.e., difficulty with expressive/receptive language). Parametric assumption testing revealed a non-normal distribution for the control group due to significant kurtosis. Distribution shape for the stroke group was sufficiently normally distributed. A significant Levene's test statistic indicated unequal variances between-groups. Due to ANOVA assumption violation, a non-parametric approach was taken to the between-groups analysis of Learning and Language Disorder T-score. An independent samples Mann-Whitney U Test indicated that the Learning and Language Disorder median T-score was significantly greater for stroke participants ($Mdn = 52.00$) than for controls ($Mdn = 43.00$), $U = 256.00$, $p < .001$. Median differences reflect a large effect size.

Reading composite scores on the WRAT4 test were analyzed in order to report on potential differences in literacy achievement between groups. Levene's test indicated that the assumption of homogeneity of variances was met for between-group comparisons of each intellectual index. Normality checks indicated that data was sufficiently normally distributed. Accordingly, a one-factor, between-subjects ANOVA was conducted. The stroke group was found to have a significantly lower mean Reading Composite standard score ($M = 95.87$, $SD = 15.97$) in comparison to the control group ($M = 110.38$, $SD = 14.14$), $F(1,64) = 15.09$, $p < .001$, with a strong effect size, $partial\ eta\text{-squared} = .19$.

Finally, Rapid Picture Naming standard score from the WJ-III COG was analyzed due to the strong association between naming facility, lexical access, and literacy (Decker et al., 2013). Parametric assumption testing showed normal distributions and homogeneity of variances. A one-factor, between-subjects ANOVA indicated that there was no significant difference between means for the stroke ($M = 90.55$, $SD = 16.99$) and control ($M = 96.79$, $SD = 13.06$) groups, $F(1,64) = 2.79$, $p = .100$. The effect size for this comparison was small, $partial\ eta\text{-squared} = .04$.

Neurological Status

Scores on the PSOM neurological status exam were analyzed. Each stroke participant had been assigned a PSOM value based on neurological deficits present during their most recent clinic visit with the staff neurologist in the Children's Stroke Program. The total PSOM score can range from 0 (no deficit) to 10 (maximum deficit) and collectively reflects neurological functioning across five areas: right sensorimotor, left sensorimotor, language production, language comprehension, and cognitive/behavioural. On average, stroke participants were neurologically intact, with an average PSOM score of 1.75 ($SD = 1.42$). The minimum score was

0.0 while the maximum score was 5.0. Neurological status did not differ according to lesion laterality, $F(2,29) = 0.88, p = .428$, lesion location, $F(3,29) = 2.88, p = .055$, or age at stroke, $F(3,29) = 0.30, p = .828$.

Fine Motor Speed/Precision and Overall Physical Wellbeing

As previously noted, 32.3% of the stroke sample experienced hemiparesis following stroke (weakness on one side of the body). Our study assessed motor speed/precision of the dominant hand through the Motor Speed subtest of the Trail Making Test from the D-KEFS. Scores for the Motor Speed subtest were normally distributed, but the assumption of homogeneity of variance was violated. A one-factor, between-subjects Welch ANOVA was conducted, and revealed significant group differences on Motor Speed, with a large partial eta-squared effect size. The stroke group was slower to complete this motor task in comparison to controls and demonstrated greater fine motor precision errors.

The KIDSCREEN-52 contains a Physical Well-Being scale, which measures self-reported overall physical health, physical fitness, and energy levels. Tests of parametric assumption agreement for the Physical Well-Being scale indicated violation of the assumption of homogeneity of variances between groups. However, data were sufficiently normal in distribution. Accordingly, a one-factor, between-subjects Welch ANOVA was conducted. Results revealed a lack of significant difference between the stroke group and control group on mean scores for the Physical Well-Being scale. The partial eta-squared effect size for this mean comparison was small. A summary of motor speed and physical wellbeing findings is presented in Table 5.

Table 5. Motor speed and physical wellbeing mean scores and between-subjects ANOVA results for stroke and control participants

Physical Health Scale¹	Stroke mean (SD)	Control mean (SD)	Welch-Statistic	df	p-value	Partial Eta-Squared
Motor Speed, Trail Making Test, D-KEFS	9.35 (3.16)	12.15 (1.18)	21.49	1, 37.6	<.001*	.27
Physical Well-Being scale, KIDSCREEN-52	46.78 (7.53)	49.88 (11.30)	1.72	1, 57.9	.195	.03

1. The Physical Well-Being scale, KIDSCREEN-52 is in T-scores, and the Motor Speed subtest from the Trail Making Test, D-KEFS is in scaled scores.

*significant after application of the sequential Holm-Bonferroni procedure

Parent and Family Functioning

Relevant environmental variables consisted of the GHQ total score (parent mental health), McMaster FAD General Functioning Scale (family functioning), and the Parent Relations and Home Life scale from the KIDSCREEN-52 (relationship with parents). Prior to analysis, parent and family functioning variables were examined for parametric assumption agreement. Levene's test indicated that the assumption of homogeneity of variances was met for between-group comparisons of each dimension. Normality checks indicated that data was positively skewed for both variables, indicating that parents more frequently reported good mental health and high levels of family functioning. However, distributions were sufficient for ANOVA, given this test's robustness against slight deviations from normality. One-factor, between-subjects ANOVAs were conducted to compare groups on environmental outcomes. There were no significant group differences on the GHQ total score, McMaster FAD General Functioning Scale, or the Parent Relations and Home Life scale from the KIDSCREEN-52, and effect sizes were small for all comparisons. A summary of parent and family functioning

findings is presented in Table 6.

Table 6. Parent and family functioning mean scores and between-subjects ANOVA results for stroke and control participants

Parent / Family Function Variable¹	Stroke mean (SD)	Control mean (SD)	F-value	df	p-value	Partial Eta-Squared
GHQ total score	9.71 (3.60)	10.53 (3.90)	0.77	1, 64	.383	.01
General Functioning Scale, McMaster FAD	1.58 (0.49)	1.50 (0.53)	0.33	1, 64	.567	.01
Parent Relations and Home Life scale, KIDSCREEN-52	51.45 (8.52)	51.67 (9.25)	0.01	1, 64	.920	.01

1. The GHQ total score is the sum of all rated items. McMaster FAD General Functioning Scale is expressed as a ratio (see methods for expanded description). Parent Relations and Home Life scale from the KIDSCREEN-52 is measured in T-scores.

*significant after application of the sequential Holm-Bonferroni procedure

Additionally, stroke and control groups did not statistically differ on Chi-Square tests that compared the number of parents falling within a clinically significant range of mental health concern on the GHQ (scores > 12), $\chi^2(1) = 1.05$, $p = .223$. Another Chi-Square test was conducted to compare the number of families in the control and stroke groups falling within the dysfunctional range on their McMaster FAD ratio score (scores > 2.00), and a non-significant result indicated group equivalence on this factor, $\chi^2(1) = 0.05$, $p = .529$.

Pearson's correlational analyses were conducted to examine the relationship between parent mental health (GHQ total score) and family functioning (McMaster FAD General Functioning Scale). A significant positive relationship of medium strength emerged for the stroke group, $r(29) = .50$, $p = .002$, and indicated that higher ratings of parent psychopathology was associated with greater family dysfunction. A similar pattern emerged for the control group,

$r(32) = .46, p = .003$.

Psychosocial Outcomes and Mental Health

Mental health and social outcomes were investigated through analysis of questionnaire data. The prevalence of mental health related diagnoses in the stroke and healthy control samples were examined; diagnostic history was provided by parents on the demographic questionnaire and confirmed in stroke patients through cross referencing with neuropsychological assessment reports. The Conners CBRS-CI and demographic and history questionnaire yielded data on parent-reported child mental health symptoms, while the RCADS and KIDSCREEN-52 yielded data on self-reported mental health symptoms.

Diagnostic History of Psychological Disorders.

Diagnostic data from the clinical and demographic questionnaire were examined to determine the prevalence of mental health related diagnoses within the stroke and healthy control samples. Table 7 displays the number of children within the stroke and control groups that had a history of being diagnosed with an anxiety disorder, depression, ADHD, language disorder, learning disability, or other psychological / psychiatric diagnosis. None of the participants carried a diagnosis of depression. Diagnoses of anxiety disorder, ADHD, language disorder, and learning disability were present in both samples, with greater overall prevalence in the stroke group.

Table 7. Prevalence of mental health diagnoses within the sample

Diagnosis	n (stroke)	% of stroke sample	n (control)	% of control sample
Anxiety Disorder	6	19.4%	1	2.9%
Depression	0	0%	0	0%
Attention-Deficit Hyperactivity Disorder	4	12.9%	1	2.9%
Language Disorder	7	22.6%	4	11.8%
Learning Disability	14	45.2%	3	8.8%
Other psychological / psychiatric diagnosis	0	0%	0	0%

Parent-Reported Child Symptoms.

First, mean T-scores on mental health related subscales from the Conners CBRS-CI were examined for parametric assumption agreement. The assumptions of normality and homogeneity of variances were met, with the exception of positive skewness and kurtosis for the control group on the ADHD scale. In order to address assumption violation on the ADHD scale, an independent samples Mann-Whitney U Test was conducted. Although the stroke group median ($Mdn = 54.00$) reflected higher ADHD concerns in comparison to the control group median ($Mdn = 50.51$), the p -value was not significant after application of the sequential Holm-Bonferroni procedure, $U = 370.50$, $p = .040$. Median differences reflected a small to medium effect size. One-factor, between-subjects ANOVAs were conducted for mean T-scores on the Mood Disorder, Anxiety Disorder, and Disruptive Behaviour Disorder scales on the Conners CBRS-CI, and results indicated that there were no significant mean group differences. Partial eta-squared effect sizes were small for Mood Disorder and Disruptive Behaviour Disorder scales, and moderate for the Anxiety Disorder Scale. A summary of average T-scores on the Conners

CBRS-CI scales is presented in Table 8.

Table 8. Between-groups ANOVAs and Chi-square results for parent-reported child mental health outcomes on the Conners CBRS-CI

Mental Health Domain on Conners CBRS-CI	Stroke mean (SD)	Control mean (SD)	F- value	df	p- value	Partial Eta- Squared
Mood Disorder	57.35 (13.38)	53.06 (11.09)	2.00	1,64	.162	.03
Anxiety Disorder	62.52 (15.64)	56.21 (12.20)	3.32	1,64	.073	.05
Disruptive Behaviour Disorder	54.10 (12.56)	54.06 (12.11)	0.00	1, 64	.990	.00
Impairment Frequencies T-Score \geq 70 (Very Elevated)	Stroke % very elevated	Control % very elevated	Chi- Square Value	df	p- value	Phi
Mood Disorder	16.1%	8.8%	0.80	1	.303	.11
Anxiety Disorder	45.2%	14.7%	7.27	1	.007*	.33
Disruptive Behaviour Disorder	9.7%	14.7%	0.38	1	.408	.08
ADHD	6.5%	5.5%	0.01	1	.658	.01

Note: Conners CBRS-CI scale means are in T-Scores

*significant after application of the sequential Holm-Bonferroni procedure

Frequencies of impairment were also analyzed for parent-reported mental health outcomes. On the CBRS-CI, T-scores of 70 or above are considered to be in a very elevated range of clinical concern and represent areas of psychological distress (Conners, 2008). Chi-square analyses were conducted to compare the proportion of participants within each group that had a very elevated score on each domain of mental health. A significant difference in impairment frequency was present on the Anxiety Disorder scale; a substantial 45.2% of stroke participants had a T-score of 70 or higher on the Anxiety Disorder scale, in comparison to only 14.7% of controls. An effect size of moderate strength was detected for this difference. Non-significance and small effects were noted for the Chi-square comparisons of impairment

frequency on the Mood Disorder, Disruptive Behaviour Disorder, or ADHD scales. Percentages and Chi-square statistics on Conners CBRS-CI scale elevations can be found in Table 8.

Table 9. Chi-square tests on proportional outcomes for parent-reported domains of psychosocial concern on the clinical and demographic background questionnaire

	Stroke % yes	Control % yes	Chi- Square Value	df	p- value	Phi
<i>Demographic Questionnaire: Does your child have trouble with...</i>						
Anxiety?	35.5%	14.7%	3.77	1	.049	0.25
Low mood?	12.9%	0.0%	4.68	1	.046	0.27
Self-confidence?	29.0%	8.8%	4.40	1	.037	0.26
Interacting with peers?	19.4%	8.8%	1.51	1	.193	0.15
Emotion regulation?	41.9%	8.8%	9.58	1	.002*	0.38
Frustration tolerance?	25.8%	14.7%	1.25	1	.210	0.14
Attention?	22.6%	14.7%	0.67	1	.309	0.10
Hyperactivity?	6.5%	5.9%	0.01	1	.658	0.01
Inappropriate/ disinhibited behaviour?	3.2%	0.0%	1.11	1	.477	0.13
Being teased or bullied?	6.5%	2.9%	0.45	1	.465	0.08
Making friends?	25.8%	8.8%	3.33	1	.067	0.23
Getting along with others?	6.5%	2.9%	0.45	1	.465	0.08

*significant after application of the sequential Holm-Bonferroni procedure

The demographic and history questionnaire yielded data on the percentage of parents that identified current psychosocial concerns in their children according to a yes/no dichotomy. Table 9 contains the domains of social and emotional concerns that were queried within the demographic questionnaire and also presents Chi-square analyses on outcome frequencies. Significant differences were found on parent ratings for emotion regulation, and stroke patients were identified as being more likely to have emotion regulation concerns. Frequencies for self-

confidence, low mood, and anxiety approached significance, but did not survive the Holm–Bonferroni correction for multiple comparisons. Phi effect size values were medium for comparisons of emotion regulation, self-confidence, low mood, and anxiety. All other comparisons were non-significant with small effect sizes. Figure 1 is a histogram that visually presents the largest differences in outcome frequencies by group on the demographic questionnaire.

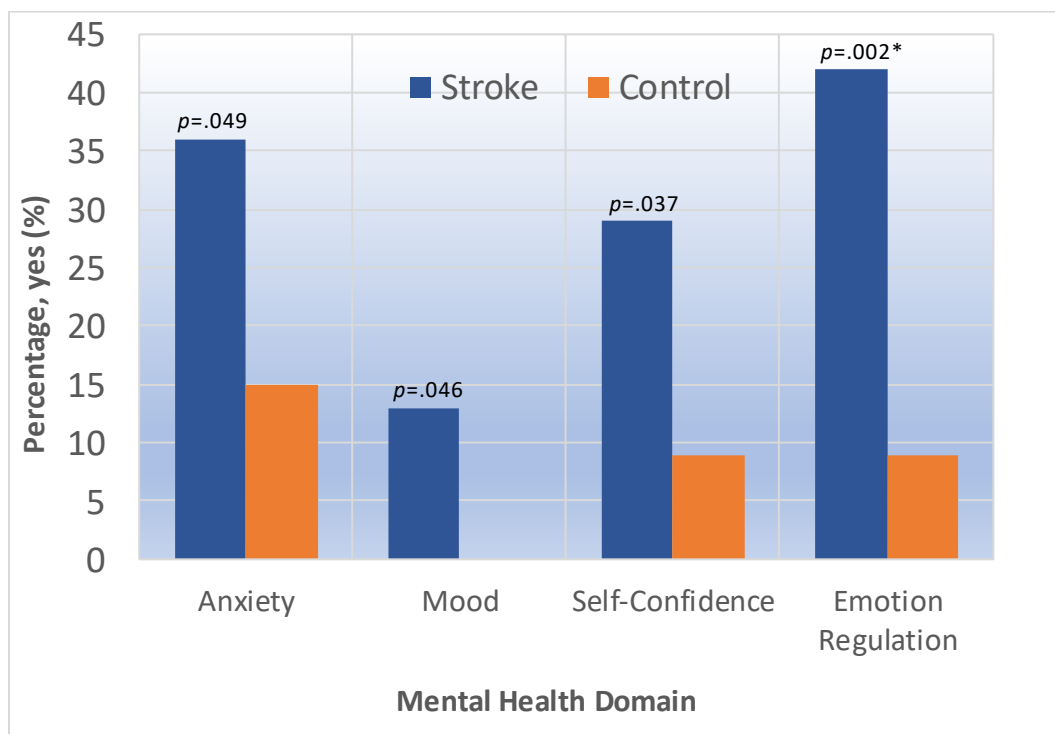


Figure 2. Percentage of participants identified with emotional concerns by parents on the demographic and history questionnaire.

Self-Reported Symptoms.

All scales on the self-reported RCADS questionnaire were examined for parametric assumption agreement. Data were sufficiently normal in distribution and the assumption of homogeneity of variances was met for all comparisons. One-factor, between-subjects ANOVAs were conducted for scales on the RCADS, and results indicated that there were no significant mean group differences. Partial eta-squared effect sizes were small. A summary of ANOVA

findings for the RCADS is presented in Table 10.

Psychosocial scales of the self-reported KIDSCREEN-52 were examined for parametric assumption agreement. The control group presented with significant kurtosis on the Social Support and Peers scale from the KIDSCREEN-52. Data distributions were within acceptable ranges of normality on all other scales. The assumption of homogeneity of variances was met for all psychosocial scales. An independent samples Mann-Whitney U Test on the Social Support and Peers scale (in T-scores) indicated that stroke group ($Mdn = 50.24$) and control group ($Mdn = 50.24$) medians were equivalent, $U = 480.50$, $p = .540$. Median differences reflect an effect size of 0.0. One-factor, between-subjects ANOVAs were conducted for all other psychosocial scales on the KIDSCREEN-52, and results indicated that there were no significant mean group differences. Partial eta-squared effect sizes were small. A summary of KIDSCREEN-52 psychosocial ANOVA findings is presented in Table 10.

Table 10. Self-reported psychosocial and mental health outcomes and between-subjects ANOVA results for stroke and control participants

Psychosocial / Mental Health Scale¹	Stroke mean (SD)	Control mean (SD)	F-value	df	p-value	Partial Eta-Squared
<i>RCADS</i>						
Separation Anxiety	49.35 (9.22)	48.44 (8.86)	0.17	1, 64	.685	.00
Generalized Anxiety	42.48 (9.62)	41.12 (8.95)	0.35	1, 64	.555	.01
Panic	47.23 (8.98)	47.68 (8.09)	0.05	1, 64	.832	.00
Social Phobia	46.00 (11.68)	44.24 (9.91)	0.43	1, 64	.512	.01
Obsessions/Compulsions	44.74 (10.18)	43.79 (8.29)	0.17	1, 64	.681	.00
Depression	46.03 (10.84)	45.86 (9.01)	0.04	1, 64	.848	.00
Total Anxiety Composite	44.71 (10.39)	43.53 (7.92)	0.27	1, 64	.606	.00

Total Anxiety and Depression Composite	44.74 (10.54)	43.68 (7.73)	0.22	1, 64	.642	.00
<i>KIDSCREEN-52</i>						
Psychological Well-Being	49.77 (8.55)	49.25 (7.92)	0.06	1, 64	.802	.00
Moods and Emotions	47.58 (8.71)	46.91 (6.84)	0.12	1, 64	.729	.00
Self-Perception	52.89 (10.24)	49.87 (9.56)	1.51	1, 64	.224	.02
Autonomy	49.99 (8.31)	48.30 (8.87)	0.62	1, 64	.433	.01
Peers and Social Support	50.12 (11.32)	51.17 (11.52)	0.14	1, 64	.713	.00
School Environment	53.85 (8.58)	51.55 (8.89)	1.13	1, 64	.293	.02
Bullying	46.59 (11.57)	50.05 (9.40)	1.76	1, 64	.189	.03

1. All scale means are in T-Scores

*significant after application of the sequential Holm-Bonferroni procedure

Predictors of Psychological Outcomes in Pediatric Stroke

Bivariate Pearson correlation coefficients were computed to investigate the strength of the relationship between psychological outcomes in pediatric stroke participants and cognitive, academic, social, neurological, family, and socioeconomic variables. A correlation matrix was constructed, which included the RCADS Total Anxiety and Depression composite, as well as all mental health scales on the Conners CBRS-CI. Cognitive variables of interest included Full-Scale IQ from the WASI-II and D-KEFS executive functioning scaled scores on the Color-Word Interference Test (Inhibition-Switching condition) and Trail Making Test (Letter Number Switching condition). Neurological functioning was captured through including the PSOM total score and Motor Speed scaled core on the Trail Making Test. Academic achievement variables were the Reading Composite standard score from the WRAT4 and the Learning and Language Disorder subscale T-score from the Conners CBRS-CI. Family environment was encapsulated through the McMaster FAD ratio score, GHQ total parent mental health score, the Parent

Relations and Home Life subscale T-score on the KIDSCREEN-52, and the Family Income scale from the demographic questionnaire. Social environment variables were also included, which involved T-scores from the Bullying, School Environment, and Peers and Social Support scales from the KIDSCREEN-52. The correlation matrix containing bivariate Pearson correlation coefficients for the above-described variables is presented in Table 11. Significant correlation values are bolded.

Table 11. Bivariate Pearson correlation coefficient matrix indicating relationships between psychological variables and environmental, cognitive, and neurological variables in pediatric stroke participants

	RCADS: Total Anxiety and Depression	Conners: Mood Disorder	Conners: Anxiety Disorder	Conners: Disruptive Behaviour Disorder	Conners: ADHD
WASI-II Full-Scale IQ	-.07	-.29	-.14	-.45**	-.16
D-KEFS Color-Word Interference ¹	-.07	-.41*	-.29	-.20	-.17
D-KEFS Trail Making ²	-.44**	-.38*	-.32*	-.17	-.21
PSOM total score	.08	.02	-.07	.12	-.02
D-KEFS Motor Speed ³	-.20	-.46**	-.27	-.24	-.16
WRAT4 Reading Composite	.15	-.38*	.01	-.30	-.02
Conners: Learning and Language Disorder	-.08	.58**	.20	.41*	.13
McMaster Family Assessment Device	.00	.29	.18	.12	.14
GHQ total parent mental health score	-.21	.41*	.25	.44**	.24

KIDSCREEN-52: Parent Relations and Home Life	-.21	-.10	-.11	-.21	-.13
Family Income	-.06	-.36*	-.24	-.14	-.21
KIDSCREEN-52: Bullying	-.45**	-.19	-.20	.03	-.18
KIDSCREEN-52: School Environment	-.28	-.03	-.22	.26	-.01
KIDSCREEN-52: Peers and Social Support	-.21	-.25	-.43**	-.01	-.06

¹Inhibition-Switching condition from the Color-Word Interference Test of the D-KEFS.

²Letter Number Switching condition from the Trail Making Test of the D-KEFS.

³Motor Speed condition from the Trail Making Test of the D-KEFS.

Note: Standardized scores were used for all correlations, where applicable. RCADS, Conners CBRS-CI, D-KEFS, and KIDSCREEN-52 subscales are in T-scores. WASI-II Full-Scale IQ and WRAT4 Reading Composite are in standard scores. McMaster FAD General Functioning Scale is in ratio scores (computation described in methods section).

* $<.05$

** $<.01$

Significant correlations in Table 11 were followed with multiple linear regression analyses to develop a model for predicting mental health outcomes. Full multiple regression statistics for all computed models can be found in Table 12. The assumptions of linearity, independent errors, and homoscedasticity were met for all linear regressions. In addition, collinearity diagnostics revealed acceptable tolerance and variance inflation (VIF) values. Firstly, a multiple regression was carried out to investigate whether scores on Trail Making and Bullying could significantly predict stroke participants' self-reported Total Anxiety and Depression on the RCADS. The results of the regression indicated that the model explained 33.1% of the variance and that the model was a significant predictor of Total Anxiety and Depression, $F(2,28) = 6.93, p=.004$. Both Trail Making ($B = -1.11, p=.028$) and Bullying ($B = -0.34, p=.024$) contributed significantly to the model. The same multiple regression equation was carried out in the control group, and the model was not significant $F(2,28) = 1.56, p=.226$.

Next, multiple regression was carried out in the stroke group to examine whether Motor Speed and Conners Learning and Language Disorder scores could significantly predict participants' parent-reported scores on Conners Mood Disorder. The results of the regression indicated that the model explained 52.2% of the variance and that the model was a significant predictor of Conners Mood Disorder, $F(2,28) = 15.30, p < .001$. Both Motor Speed ($B = -1.83, p = .003$) and Conners Learning and Language Disorder scores ($B = -0.48, p < .001$) contributed significantly to the model. The same multiple regression equation was carried out in the control group. The results indicated that the model explained 40.7% of the variance in the control group and that the model was a significant predictor of Conners Mood Disorder, $F(2,31) = 10.65, p < .001$. Although Motor Speed ($B = -0.38, p = .782$) was not a significant predictor in the control group, Conners Learning and Language Disorder ($B = -0.73, p < .001$) contributed significantly to the model.

Following significant Pearson's correlations, linear regression was carried out in the stroke group to examine if KIDSCREEN-52: Peers and Social Support score could significantly predict participants' scores on Conners Anxiety Disorder. The results of the regression indicated that the model explained 18.2% of the variance and that the model was a significant predictor of Conners Mood Disorder, $F(1,29) = 6.46, p = .017$. In other words, KIDSCREEN-52: Peers and Social Support ($B = -0.59, p = .017$) contributed significantly to the model. The same multiple regression equation was carried out in the control group, and the model was not significant $F(1,32) = 1.03, p = .317$.

Multiple regression was carried out in the stroke group to examine whether WASI-II Full-Scale IQ and GHQ total parent mental health score could significantly predict participants' parent-reported scores on Conners Disruptive Behaviour Disorder. The results of the regression

indicated that the model explained 29.1% of the variance and that the model was a significant predictor of Conners Disruptive Behaviour Disorder, $F(2,28) = 5.75, p=.008$. While parent mental health contributed significantly to the model ($B=1.12, p=.008$), WASI-II Full-Scale IQ did not ($B = -0.25, p=.055$). When the same linear regression equation was carried out in the control group it explained 36.1% of the variance, and the model was a significant predictor of Conners Disruptive Behaviour Disorder, $F(2,31) = 8.77, p=.001$. Both parent mental health ($B=1.02, p=.042$) and WASI Full-Scale IQ ($B = -0.34, p=.015$) contributed significantly to the model in the control group.

Table 12. Multiple linear regression models examining predictors of mental health outcomes in the stroke and control groups

Outcome Measure	Group	Predictor Variables	B	β	t	p	R²
RCADS: Total Anxiety and Depression	Stroke	1. Trail Making	-1.11	-.37	-2.32	.028*	.331
		2. KIDSCREEN-52: Bullying	-0.34	-.38	-2.39	.024*	
	Control	1. Trail Making	-0.06	-.03	-0.16	.876	.092
		2. KIDSCREEN-52: Bullying	-0.25	-.30	-1.73	.094	
Conners: Mood Disorder	Stroke	1. Motor Speed	-1.83	-.43	-3.30	.003*	.522
		2. Conners: Learning and Language Disorder	0.48	.56	4.27	<.001*	
	Control	1. Motor Speed	-0.38	-.04	-0.28	.782	.407
		2. Conners: Learning and Language Disorder	0.73	.63	4.31	<.001*	

Conners: Anxiety Disorder	Stroke	1. KIDSCREEN-52: Peers and Social Support	-0.59	-.43	-2.54	.017*	.182
	Control	1. KIDSCREEN-52: Peers and Social Support	0.19	.18	1.02	.317	.031
Conners: Disruptive Behaviour Disorder	Stroke	1. WASI-II Full- Scale IQ	-0.25	-.34	-1.90	.055	.291
		2. GHQ total parent mental health score	1.12	.32	2.01	.008*	
	Control	1. WASI-II Full- Scale IQ	-0.34	-.40	-2.56	.015*	.361
		2. GHQ total parent mental health score	1.02	.33	2.12	.042*	

*Significant p-value

Neurological and clinical characteristics were also investigated as potential factors related to mental health outcomes in pediatric stroke. Lesion location, lesion laterality, biological sex, age at stroke grouping, and age at assessment were explored with regard to potential influences on self-reported Total Anxiety and Depression on the RCADS, as well as mental-health related scales from the parent-reported Conners CBRS-CI. One-factor, between-subjects ANOVAs were conducted, and there were no significant differences in mean scores for any of the psychological outcome variables based on lesion laterality, lesion location, biological sex, age at stroke grouping, or age at assessment (all p-values > 0.155). However, when age at stroke was investigated as a continuous rather than categorical variable, Pearson's correlation indicated that younger age at stroke was associated with significantly higher scores on the Anxiety Disorder subscale of the Conners CBRS-CI $r(29) = -.38, p = .017$.

Time since stroke was subsequently investigated as a potential correlate of mental health

outcomes, and findings converged with continuous age at stroke results. Pearson's correlation indicated that greater time since stroke was associated with significantly higher scores on the Anxiety Disorder subscale of the Conners CBRS-CI, $r(29) = .48, p = .003$. Graphical representation confirmed a linear relationship. Additional analyses were conducted to untangle the effects of time since stroke from age at stroke and age at assessment. Children with stroke around the time of birth (perinatal/neonatal stroke) were separated in analyses and compared to the remaining stroke sample (childhood stroke). Results indicated that the relationship between time since stroke and anxiety was specific to children with perinatal/neonatal stroke, $r(15) = .50, p = .025$. In this group of children, time since stroke was almost identical to age at assessment, and findings suggest that the passage of time was associated with increased anxiety symptoms specifically for children who had a stroke event around the time of birth. Linear regression was conducted with time since stroke entered as the independent variable and Anxiety Disorder T-Score (Conners CBRS-CI) entered as the dependent outcome variable. The regression model was statistically significant, $F(1,14) = 4.62, p = .049$. Time since stroke accounted for 25% of the variance in Anxiety Disorder outcome ($B = 2.40, t = 2.15, R^2 = .248$) in the perinatal/neonatal stroke group. Figure 2 presents a scatterplot for participants with perinatal and neonatal stroke and shows the data points for the relationship between time since stroke and Anxiety Disorder T-score on the Conners CBRS-CI. The scatterplot includes the line of best fit for the linear relationship between the variables.

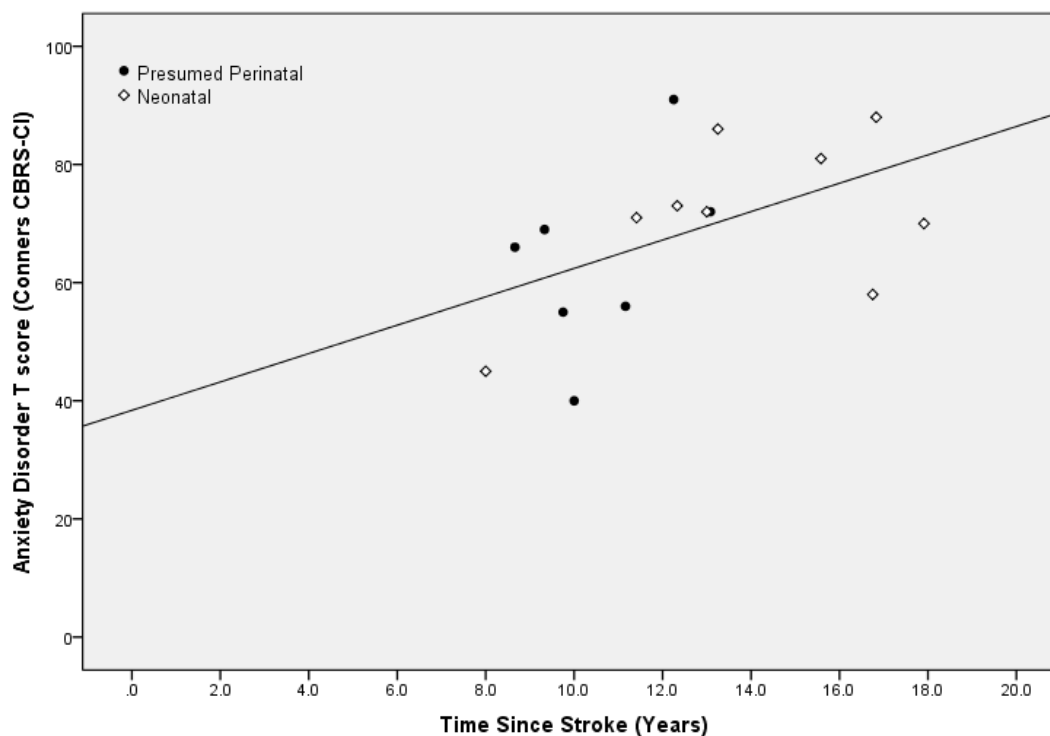


Figure 3. Scatterplot of the relationship between time since stroke (X-Axis) and Anxiety Disorder T-score (Y-Axis) in participants with perinatal and neonatal stroke.

Finally, Motor Speed was correlated with relevant variables from the self-reported KIDSCREEN-52 in order to investigate hypotheses relating to motor functioning and physical disability. In children with stroke, Motor Speed positively correlated with Self-Perception, $r(29) = .44, p = .007$, and Physical Wellbeing, $r(29) = .38, p = .010$. The Physical Wellbeing scale positively correlated with self-reported Psychological Wellbeing, $r(29) = .47, p = .004$, Self-Perception, $r(29) = .56, p < .001$, Autonomy, $r(29) = .32, p = .039$, Peer Support, $r(29) = .45, p = .005$, and School Satisfaction, $r(29) = .45, p = .006$. Post-hoc linear regressions confirmed that Physical Wellbeing was a significant predictor when the above variables were entered into the model (all $\beta > .35, p < .010$). Physical Wellbeing was a particularly strong predictor of Self-Perception, $F(1,29) = 13.48, p = .001 (B = 0.77, t = 3.67, R^2 = .317)$.

Discussion

The current quantitative project examined social, emotional, and behavioural outcomes in

pediatric stroke, with a focus on mood, anxiety, peer relationships, and social competence. At the group level, stroke participants did not significantly differ from control participants on parent or child reported mean scores of mental health or psychosocial functioning. However, a more nuanced analysis on impairment frequencies suggested that 45.2% of stroke participants had a very elevated score ($\geq 98^{\text{th}}$ percentile) on parent-reported anxiety in comparison to only 14.7% of controls. Moreover, 19.4% of stroke participants carried a diagnostic history clinically significant for an anxiety disorder in comparison to only 2.9% of controls. Clinical diagnoses of ADHD (12.9%), language disorder (22.6%), and learning disability (45.2%) were also highly prevalent in the stroke group, and had been identified by regulated health professionals prior to study participation. Using a simple yes/no dichotomy, stroke participants were classified as having significantly greater difficulties with emotion regulation by parents, and difficulties with making friends, self-confidence, and mood approached significance.

Results suggest that considerable variability exists in the mental health presentation of pediatric stroke patients, and that mean scores may not effectively encapsulate the heterogeneity in psychosocial outcomes within this population. Although many patients fared extremely well and presented with few, if any, concerns, a subset of stroke participants demonstrated concerning levels of mental health difficulties in one or more areas of functioning, with anxiety representing a salient domain. Elevated rates of internalizing symptoms represent some of the most prominent psychiatric concerns documented in the limited body of pediatric stroke literature focusing on mental health outcomes (Greenham, Anderson, Cooper, et al., 2017; Max et al., 2002; O’Keeffe et al., 2012, 2017).

Given the considerable psychosocial heterogeneity present in our sample, it was helpful to examine a wide array of cognitive, neurological, and environmental variables that could

represent important factors in shaping pathways towards mental health risk or resilience in pediatric stroke. Firstly, stroke and control groups were compared on these variables, and significant group differences were found for intellectual reasoning, performance-based executive functioning, general learning, reading, and language, with the stroke group achieving lower scores on each measure. Groups were equivalent in their rapid picture naming, which is a simple indication of naming facility. This finding indicates that stroke participants had appropriate speed and accuracy of word retrieval, but struggled with more complex, higher order tasks of language and learning. The stroke sample was relatively neurologically intact, as indicated by PSOM scores in the mild to moderate range. However, hemiparesis was common, with 32.3% of the stroke sample affected by unilateral motor weakness. Our study assessed motor speed/precision of the dominant hand, and the stroke group was slower to complete the neuromotor task in comparison to controls and demonstrated more fine motor precision errors. Groups were equivalent on mean scores representing parent mental health and family functioning.

Correlational analyses were followed by post-hoc linear regressions, and several significant relationships were elucidated. In the stroke group, higher child anxiety symptoms, as indicated by parent-ratings, was predicted by lower levels of peer social support. Collectively, Total Anxiety and Depression, as self-reported by stroke participants, was predicted by lower executive function scores on the Trail Making Test (indicative of visual attention and task switching ability) and higher levels of self-reported bullying experiences. The evidence base surrounding childhood bullying and peer social support converges with our study's findings, and indicates that chronic peer difficulties relate to the presence of internalizing symptoms and reduction in well-being among youth (Menesini et al., 2009). Children with stroke history are

more likely to experience impairments in social function and reduced social acceptance from peers (Everts et al., 2008; Neuner et al., 2011). When stroke occurs in childhood, changes in friendships with peers commonly occurs, and may relate to poor post-stroke adjustment (Greenham, Anderson, Cooper, et al., 2017). Social support is generally protective against the development of anxiety and mood concerns in children and youth. Peer support can act as a buffer against stress and promote feelings of acceptance, self-worth, and belongingness (L. M. Rodriguez et al., 2021). Preadolescents with at least one close and supportive friendship have been found to show greater enjoyment, sensitivity, loyalty, mutual affection, and overall higher quality of life (King et al., 2016). Close friendships predict greater interpersonal happiness and also appear to reduce the odds of experiencing peer victimization and rejection; if bullying does occur, supportive friendships have been found to buffer the negative effects (Kendrick et al., 2012). There are numerous mechanisms by which friendships convey mental health benefits, and these processes likely include the provision of warmth, affection, nurturance, interpersonal skill building, and mastery of age-related tasks (King et al., 2016; L. M. Rodriguez et al., 2021).

The prediction of self-reported anxiety and mood symptoms from Trail Making Test performance in child participants may be explained by the problem solving and attention control aspects of executive functioning in regulating one's stress response (Schmeichel & Tang, 2015). Executive dysfunction, such as impairment in cognitive shifting and attention control, has been implicated in poor stress regulation. Reduced executive function capacity is thought to relate to a ruminative or perseverative cognitive style and poor problem solving strategies when faced with stressors (Homaifar et al., 2014). Executive functions are cognitive processes that organize and guide behaviour towards one's goals, and share key features with emotion awareness, such as voluntary attention to emotions and clarity of emotional type and source (Eckland et al., 2021;

Schweizer et al., 2020). Emotion awareness and some aspects of executive functioning have been found to be a key factor in the development and maintenance of depression (Eckland et al., 2021). Inhibition of cognitive interference (Color Word Interference Test) did not emerge as a significant predictor of internalizing symptoms in our sample, and findings suggest that inhibiting emotional experience may not be an adaptive or relevant cognitive strategy. Effective coping in pediatric stroke appears to relate more strongly to executive processes that promote the ability to problem solve and shift one's focus to other things (i.e., not getting "stuck" in a particular mindset).

In the stroke group, linear regression linked child mood symptoms, as rated by parents, with fine motor speed/precision and learning and language difficulties. Thus, in addition to the abovementioned connection between internalizing concerns and executive functioning, increased mood symptoms were also predicted by reduced fine motor coordination with the dominant-hand and poorer learning and language outcomes. Published literature suggests that physical, cognitive, and learning disabilities place children with brain injuries at increased risk of mood related symptoms and can reduce overall sense of emotional wellbeing (Anderson et al., 2014; Blom et al., 2007; Christerson & Strömberg, 2010; Ganesan et al., 2000). The relationship between disability status and mood is complex, and potential mechanisms may encompass social comparison, reduced self-esteem, and reduced social and academic participation (Blom et al., 2007; Ledochowski et al., 2020; Lo et al., 2014; Yvon et al., 2018). Indeed, our analyses on stroke participants' physical wellbeing appear to provide support for the various mechanisms that have been outlined in the literature. Our study hypotheses predicted that physical disability in stroke patients would be related to poorer scores in physical well-being, self-perception, and social acceptance. Results confirmed that children with better motor precision were more likely

to rate themselves favorably with regard to their self-perception. They also provided higher ratings on overall physical wellbeing, which is an umbrella variable that would encompass neuromotor functioning and general health. The physical wellbeing variable significantly predicted self-reported psychological wellbeing, self-perception, autonomy, peer support, and satisfaction/engagement/success at school. Visible physical disability, difficulty with functional tasks of daily life, and reduced autonomy may place children at increased risk in multiple domains, such as reduced self-concept, social isolation, and poorer school experiences. Collectively, these adverse experiences can impact mental health and psychological wellbeing (Yvon et al., 2018).

Parent mental health and family functioning presented very similarly across stroke and control groups with respect to both mean scores and frequency of clinical-level concerns (i.e., scores falling in the elevated concern range). This finding speaks to the profound resilience demonstrated by the parents of our stroke patients, as there is evidence to indicate that stress and caregiver burden is compounded in families of children with acquired brain injury due to learning, cognitive, medical, and rehabilitative needs (Lehman et al., 2020; McKeivitt et al., 2019; Sherman et al., 2021; Tyerman et al., 2017). Within the present study, parents of stroke patients demonstrated good coping and parenting practices on average, although variability was present. In the stroke group, 29.0% of parents and 25.8% of families presented with clinical-range concerns with respect to score elevations on parent mental health and family functioning, respectively, and similar rates were observed in the control group. Higher ratings of parent psychopathology were associated with greater family dysfunction in both control and stroke groups. Although parent mental health did not associate with internalizing symptoms in children, it significantly predicted child disruptive behaviour in both groups. Findings indicate that higher

levels of psychological stress/mental health symptoms in parents are associated with increased risk of oppositionality, rule breaking, and aggression in children. Parenting skills and the types of interactions that exist between the parent and child have been implicated in both the manifestation and treatment of oppositional behaviour in children (Dedousis-Wallace et al., 2021). A positive parent-child relationship is strongly associated with better behavioural outcomes in children (Lunkenheimer et al., 2020). Parent-child relationships characterized by affection, trust, care, structure, assertive discipline, and realistic expectations are more likely to occur in the context of adaptive coping and good mental health in parents (De Falco et al., 2014).

This study assessed child mental health as reported by parents and children. Both parent-report and self-report have merit when evaluating mental health in children and youth. The underreporting of psychopathology by young children is a concern widely recognized in the field of clinical psychology, and often necessitates parent report in psychological assessments (Barbosa et al., 2002). Underreporting in children has been commonly documented in regard to behavioural concerns, such as oppositionality, aggression, and impulsivity (Kuhn et al., 2017; Steward et al., 2017). However, as suggested in its terminology, internalizing concerns, like anxiety and depression, involve internal emotional experiences and symptoms that are not always perceptible by parents (Eg et al., 2018; Michael & Merrell, 1998; Moretti et al., 1985). By including both child and parent perspectives in the evaluation of mental health, researchers can come to a comprehensive understanding of psychological outcomes and profiles. Across a diversity of measures, the combination of parent and youth reports have been found to be more discriminating and produce more effective mental health screening when compared to reliance on a single informant (Kuhn et al., 2017).

Age and time related analyses revealed that perinatal/neonatal stroke and greater time

since stroke were associated with significantly higher scores on the Anxiety Disorder subscale of the Conners CBRS-CI. Time since stroke was parallel to age at assessment because stroke had occurred around the time of birth. Findings suggest that the passage of time was associated with increased anxiety symptoms in this group of children and emphasizes the vulnerability of the young brain. There were no other significant age or time related relationships. Results were contrary to our hypothesis predicting that older age of pediatric stroke would be associated with poorer mental health outcomes due to potential loss of function and adaptation to post-stroke deficits. Our results were also surprising given that children with perinatal-onset stroke have demonstrated a trend for better social outcomes in the literature (Anderson et al., 2014; Cnossen et al., 2010). However, early brain injury has also been associated with time-delayed deficits that can become more pronounced over time. With respect to developmental trajectory, the skill gap relative to same-aged peers can widen with age resulting in increasing cognitive difficulties, all in the context of greater academic and behavioural expectations from peers, teachers, and parents (Fuentes et al., 2016; Westmacott et al., 2009). Age and time since stroke findings within the current study indicate that the disrupted developmental trajectory associated with early brain injury may be a significant risk factor for anxiety symptoms. Mechanisms may be neurological and/or could also relate to the stress associated with emerging deficits.

Lesion laterality, lesion location, and biological sex proved to be insignificant factors in determining mean scores on any of the psychological outcome variables. To date, there have been mixed and inconsistent published research findings regarding the significance of lesion related variables, such as infarct size and location within the brain, in predicting emotional and behavioural outcomes in children with stroke. Larger lesions are generally associated with poorer cognitive outcomes and increased likelihood of physical disability, and have occasionally been

linked with emotional control difficulties (Ghotra et al., 2015; Jiang et al., 2021; Lo et al., 2014). However, some studies have conveyed that within the context of multiple prominent social factors, lesion characteristics may not be as relevant to mental health, especially as time post-stroke increases (Anderson et al., 2014; Gordon et al., 2002; Greenham, 2010). Research should also consider the indirect effects of lesion severity on psychosocial wellbeing via impact on cognition, school achievement, and motor functioning. Our study took a nonspecific approach to measuring lesion severity through utilizing a broad classification system for lesion location, which encompassed cortical, subcortical, or combined lesion locations. Children with combined lesions generally have greater lesion volume and extent of parenchymal damage (Westmacott et al., 2010). Future research can take a volumetric approach in order to quantitatively report on the precise relationship between lesion size and mental health in pediatric stroke.

In summary, the current study set out to determine the neurological, cognitive, and environmental elements that can act as mental health stressors or promote resiliency in the context of pediatric stroke. Identification of predictive factors is crucial for informing intervention planning. Our findings highlight the saliency of internalizing concerns in children with stroke history, and emphasize the relevance of physical disability, learning disability, cognitive functioning, and peer/family support in determining mental health outcomes. Given the internalizing concerns and risk factors identified in Study 1, the following qualitative study was ideally positioned to investigate and understand emotional experience from the perspectives of pediatric informants by utilizing individual semi-structured interviews and thematic analysis. Qualitative methodology provides an understanding of how individuals subjectively perceive and give meaning to their social reality (Willig, 2019). Thus, the following study allowed us to extend and deepen our understanding of psychosocial phenomena in pediatric stroke.

STUDY 2

The Lived Experiences of Pediatric Stroke Survivors: A Qualitative Perspective on Mental Health Outcomes and Quality of Life

To date, there is no published literature that has qualitatively investigated the lived experience of pediatric stroke from the perspective of children and adolescents. In-depth interviews can be extraordinarily informative and can elucidate personal and subjective aspects of experience that cannot be effectively measured or represented through quantitative measures alone (Kelle, 2006). Qualitative research is primarily concerned with meaning, in that it aims to capture expressive information about participants' experiences (e.g., events, beliefs, values, feelings, perspectives and motivations), and convey how participants make sense and meaning of them. Moreover, qualitative research assists in understanding the implications and consequences of those perspectives and experiences for participants and for other people (Willig, 2012).

Three qualitative papers have been published on the lived experience of having a child with stroke (Martins et al., 2021; McKevitt et al., 2019; Soufi et al., 2017). The parent-focused studies involved semi-structured interviews that gathered information about the perspectives of parents caring for a child with stroke. Topics of interest included experiences within the medical system, impact on the child and emerging needs, advocacy, parenting stress, resilience, family adaptation, and strategies used to support their child. Here, the qualitative emphasis was on the psychological impact of pediatric stroke on caregivers and how they navigated their child's diagnosis and rehabilitative needs. The authors of these investigations maintain that the emergent themes gleaned from parent interviews provide a wider and more comprehensive picture of pediatric stroke than indicated by clinical outcomes alone (McKevitt et al., 2019). This method can provide another means of capturing parents' struggles and triumphs with respect to caring for

a child with a severe neurological condition (Soufi et al., 2017) and can also inform the development of child- and family-centred care (McKevitt et al., 2019).

One such study was a multi-centered investigation in France (Soufi et al., 2017) where researchers interviewed 14 caregivers of children between 1 month and 17 years of age who survived an ischemic or hemorrhagic stroke within 1-5 years of the date of participation. Interviews were audio-recorded, transcribed verbatim, and analyzed using constant comparison and content analysis. Six main narrative themes were identified in parent interviews. The first theme encompassed *unawareness of stroke and brutality of diagnosis*, as most parents were initially shocked to learn that their child had a stroke, were previously unaware of stroke in childhood, and experienced feelings of helplessness, fear, confusion, and despair. Parent distress often surrounded fear of their child's death, fear of recurrences, and concerns surrounding long term impairment and disabilities. *Lack of information regarding disease condition and feeling abandoned after discharge from hospital* were also emergent themes. Parents generally felt that there was lack of information available regarding investigations, treatment, and prognosis of their child's stroke. A *focus on functional recovery* was a theme encapsulating parents' positive perceptions of physical recovery and rehabilitation post-stroke and the emphasis that is typically placed on the physiological aspect of clinical care. *Late awareness of behavioural/cognitive disorders* was also reported. Behavioural change and cognitive disability generally became more apparent in children over time. Oftentimes these issues were subtle and went unrecognized by educators; consequently, parents found that they had to advocate for their child and raise community awareness about the developmental consequences of pediatric stroke. Finally, and most notably, parents from this multi-centred study (Soufi et al., 2017) indicated *need for psychological/social support and family adaptation*. More than half of parents shared child

mental health concerns, which mainly encompassed anxiety, phobias or depressive symptoms. Parents described emerging conflicts with their children and difficulty managing cognitive and psychological concerns, which often adversely impacted parent mental health. The need for educational supports and mental health services was emphasized. The burden of care fell more heavily on mothers, who often reported taking time off work and sacrificing professional careers. However, increased family time usually benefitted the parent-child relationship and fostered feelings of closeness, love, and support.

Another qualitative study on parents' experiences of childhood stroke was undertaken in London, England across three regional neurology services/clinics (McKevitt et al., 2019). Topic guided interviews were conducted with 12 parents and fully transcribed. Purposeful sampling was utilized to select patients of different childhood ages, time since stroke, and levels of neurological disability. A thematic analysis revealed a number of common perceptions and experiences across interviews. Similar to themes reported in the above-described study from France, this England-based qualitative study found that pediatric stroke was experienced as shocking and unexpected by parents. Stroke is a condition commonly associated with aging rather than childhood, and parents are often taken off-guard by the diagnosis, even when their child presented with acute neurological symptoms. Relatedly, parents found that there was poor awareness of pediatric stroke in the community, which resulted in variable support from educators and primary care providers. However, acute hospital care during the stroke crisis was described as excellent, and parents were also happy with physical rehabilitative services. Some parents shared that they experienced ongoing anxiety and worried about the implications of stroke for their child's future health and wellbeing. Given the idiopathic nature of many pediatric strokes, parental guilt was reported, and often related to the concern that the stroke

could have somehow been prevented, or fear that it was caused by something that the parents did or did not do. Periods of insomnia and tearfulness were reported. Impact on family function included financial strain associated with childhood disability (e.g., medical appointments, missed work) and tension in family relationships that accompanied demands to care for the child.

With regard to impact of stroke on the child, McKeivitt and colleagues (2019) indicated that most parents qualitatively reported physical disability, with a range of physical sequelae (e.g., hemiparesis, fine motor difficulties, poor coordination, fatigue) and functional difficulties with adaptive daily living tasks. Five parents discussed the cognitive consequences of stroke, which spanned impairments in processing speed, memory, academics and language. Psychological and emotional problems in the child were also reported, and included suicidal ideation, self-harm, low mood, aggression, anxiety, social withdrawal, and feeling self-conscious about physical disability. Reduced social participation was presented as a concern and was attributed to difficulties with mental health and cognition. Physical disability impacted some children's ability to partake in social leisure activities. Social exclusion and reduced peer support were also described due to others' negative perceptions of the child affected by stroke. Parents felt that they lacked access to information and supports that could help them navigate the multiple, emergent needs of their child, themselves, and the family. When available, support from other parents of children with stroke was highly valued and very helpful. Most parents shared that they prioritized establishing a sense of normality for the child and family and proactively sought ways to promote what they considered to be normative relationships and participation in daily activities.

A combined exploratory quantitative and qualitative investigation of parents' lived experiences related to their child's neonatal arterial ischemic stroke was conducted at Geneva

University Hospitals in Switzerland (Martins et al., 2021). Quantitative data came from medical records and focused on epidemiology, neuroimaging, and chronology of care, while qualitative interviews of 12 parents examined caregiver experiences and perceptions of child quality of life. In the initial post-stroke time period, confusion about long term prognosis was a predominant theme, as parents reported imagining the worst with respect to their child's future outcome and were fearful of future severe disability and stroke recurrence. Although physical and cognitive deficits were reported in the years following stroke, parents shared that their child's overall functional outcome was better than their initial pessimistic projection. However, hypervigilance (monitoring for another health crisis) and rumination about new emerging deficits were generally persistent over time, and reportedly impacted family quality of life and parent mental health.

Taken together, the qualitative literature on parenting a child with pediatric stroke suggests that there are long-standing implications of stroke for the child and family. There appears to be widespread lack of awareness of pediatric stroke, along with the cognitive and psychological symptoms that can emerge following this type of childhood brain injury (McKevitt et al., 2019; Soufi et al., 2017). Parents discussed positive experiences with acute care and physical rehabilitation, but indicated large service gaps and pervasive needs related to education and mental health. Family adaptation was a prevalent theme, and parents proactively sought ways to assist their child and establish a sense of normalcy. However, this was sometimes accompanied by increased parent stress and personal sacrifices, with potential impact on family functioning (Martins et al., 2021; McKevitt et al., 2019). Prognostic ambiguity, late diagnosis, and late intervention were also factors associated with poor parent mental health. A need for better support and guidance from tertiary and community services was noted (Martins et al., 2021; McKevitt et al., 2019; Soufi et al., 2017).

Given the high rates of internalizing concerns observed in Study 1, we believe that the current qualitative study provides a much-needed, complimentary perspective in examining the internal emotional world of pediatric stroke patients. Although parents have provided a systems level qualitative outlook on medical experiences and family functioning in prior research, it is important to present the pediatric voice when encapsulating children's lived experience of stroke. A qualitative investigation of pediatric stroke from the viewpoint of children and adolescents is important because children's first-hand experiences may be different from the impressions gleaned by parents. Mental health and physical health are very personal, and parents rarely have a full understanding of their child's emotional life; it is children themselves that can provide insight into the lens through which they perceive their life history and the world at large (Eg et al., 2018; Moretti et al., 1985). Since the parent experience of pediatric stroke has been previously presented, we endeavored to fill a gap in the pediatric stroke literature by qualitatively focusing on the child and youth voice.

Qualitative interviews and analyses provide the opportunity to explore complex psychological phenomena that are difficult to measure with a numerical empirical approach (Willig, 2012). Given the numerous advantages of qualitative research, this methodology was applied to investigate the psychosocial experiences of pediatric stroke survivors and related areas of interest, such as coping mechanisms, family relationships, and perceptions of stroke. In this way, we endeavored to gain insight into the inner emotional world of this group of children and report on their lived experiences. We aimed to encapsulate the patient voice in our analyses by presenting mental health and wellbeing from the point of view of the child participant. We were particularly interested in how children identified with their stroke diagnosis and the meaning-making process surrounding this experience. Through the lens of pediatric stroke, we enquired

about how children perceive their abilities, life circumstances, future potential, and how they relate to peers.

Methods

Participants

The primary goal of Study 2 was to interview survivors of pediatric stroke in order to obtain insight into potential commonalities of personal experience. The study qualitatively examined 14 children and youth with a history of stroke who were between the ages of 8 to 18 years. All participants were from the Children's Stroke Program at the Hospital for Sick Children, and recruitment procedures were identical to Study 1. During recruitment, children were invited to complete an hour-long semi-structured interview on social-emotional functioning. In addition to completing the neuropsychological measures in Study 1, some pediatric stroke participants agreed to also undertake this hour-long interview process. Accordingly, a subset of patients from Study 1 participated in Study 2. Pediatric stroke participants were self-selected based on interest in being interviewed and acceptability of time-commitment (i.e., the participant was able and willing to dedicate an extra hour of his/her time towards the study following completion of quantitative procedures). Consent and inclusion criteria were identical to Study 1. Study 2 pediatric stroke patients were statistically equivalent to Study 1 pediatric stroke patients that did not participate in the interview process (i.e., individuals that did not proceed to Study 2). When these groups were inferentially compared, mean scores were similar across a variety of outcomes, including current age, time since stroke, intelligence, quality of life indicators, and psychosocial functioning.

Procedure

In order to obtain an in-depth understanding of the lived experience of pediatric stroke

survivors, individual interviews were conducted with participants. All participants that consented to the interview were enrolled and completed the full interview procedure. Participants were maximally enrolled in order to promote saturation of data collection, which is the point where no new themes or concepts emerge after interviewing new participants. The interview, which was approximately 60 minutes in length, was audio-recorded and later transcribed verbatim. All interviews were conducted in a private research room at the Hospital for Sick Children. Only the child and interviewer were present. The semi-structured interview questions spanned a wide variety of topics, including mood, coping, social relationships, school life, family functioning, and mental health. Questions were developed to be open-ended, non-leading (i.e., adopted a balanced perspective in phrasing), and to facilitate reflection and elaboration.

Hypotheses were withheld for Study 2, as this component of the project utilized an inductive, data-driven approach to the thematic analysis of qualitative interviews. Data were coded without attempting to place them into a pre-existing coding frame or fit them into the analytic preconceptions of the researchers. Themes were identified from the raw data and were linked to the original words of the interviewees. By suspending the researchers' theoretical and analytic interests, it was believed that a detailed and rich description of the overall data would be achieved.

Analytical memos were created throughout data collection and encapsulated the personal, reflexive, epistemological, and theoretical aspects of the analysis (Rennie et al., 1988). Memos consisted of notes and small analyses concerning concepts/patterns present in the data and reflections on aspects of the primary researcher's interpretations. In addition to providing an organizational framework for the findings that that would later be presented as the results of Study 2, memos also allowed the primary researcher to reflect on her beliefs, biases, and

ideologies. Personal reflection on expectations and belief systems was undertaken to promote neutrality within the coding conceptualization processes. Memos were consistently compared to their associated transcript text and codes were reviewed for accuracy in light of the researchers' beliefs (e.g., consideration of alternative meaning units that could apply). However, we strongly recognize that all coding was influenced by the researchers given their active role in data analyses; analyses are a co-constructive process and cannot be considered impartial, as they encompass both the views of the participant and the interpretational lens of the researcher. Codes were closely aligned with the phrasing utilized by participants in order to minimize researcher interpretation. Consensual validation of thematic categories was attained through review with members the research team as well as consultation with professionals who did not have involvement in the current project. Discrepancy was resolved through debate and discussion.

Author Reflexivity/Positionality Statement

As the primary researcher for this dissertation and qualitative project, I am required to acknowledge my positionality as a clinician in training who has actively worked with stroke patients for several years at a pediatric hospital. While training within the Children's Stroke Program, I have assessed patients with psychosocial difficulties, communicated mental health diagnoses under supervision, and provided recommendations to support emotion regulation. I have also authored several publications on pediatric stroke, which allowed me to become familiar with the literature on mental health risk following pediatric acquired brain injury. Given my experiences and professional interests, I was required to manage my expectations surrounding outcomes in the current project, such as the belief that children with stroke are more vulnerable to internalizing symptoms and social difficulties. To this end, the above-described analytical memoing and validation procedures were utilized.

Measures

Semi-structured Interview (see Appendix B). The study researchers created the semi-structured qualitative interview by developing open-ended questions designed to stimulate discussion regarding pertinent areas of the stroke participants' daily life, memories, and psychological experiences. The interview can be found in Appendix B, which lists primary questions (provided to all participants) and potential prompts and follow-up questions that were sometimes used. A prompt was used when the interviewer felt that it could help the child elaborate, or when the child required conversational scaffolding due to difficulties with verbal comprehension or expression. Areas of inquiry included potential memories of the stroke event (if applicable, such as in cases of childhood stroke), how stroke is discussed and perceived within the family, how the child relates to peers, ability to make friends, the child's self-perception and identity, academic experiences, ability to learn new things, mood, family functioning and social support, frequency and sources of worry, and coping mechanisms. Patients were explicitly asked about the ways in which stroke may have shaped their identity and daily life.

Analytic Design: Thematic Analysis

The interview transcripts were qualitatively analyzed using thematic analysis methodology (Braun & Clarke, 2006). Thematic analysis is a deliberate and rigorous method of qualitative research that allows for theoretical flexibility since it can be guided by concepts from various fields and is utilized in numerous research approaches. However, thematic analysis is commonly thought to belong to the experiential or phenomenological qualitative research tradition, which is poised to describe the "lived experiences" of particular social groups and examine factors that underpin particular psychological phenomena (Braun & Clarke, 2021).

Similarly, our themes were generated using a “realist” and reflexive analytic method to encompass patient’s experiences from their point of view (Willig, 2012). Rather than imposing the researcher’s assumptions, thematic analysis allowed for themes to be generated from the data. Coding for the current project was reflective of the patient’s views, utilized their words and phrasing, and attempted to present how participants make sense of their personal and social world (Braun et al., 2019). Participants’ experiences were given primacy; the subjective experience of stroke participants, including their feelings, thoughts and questions, were the focus of this investigation.

Coding and theme generation was completed using NVivo12 software by QSR International. Data familiarization was the first phase of thematic analysis and involved reading the transcripts in full and noting initial ideas relevant to the phenomenon of interest (i.e., children’s lived experience of pediatric stroke, quality of life, and psychological experiences). Initial codes were subsequently generated. In the coding procedure, units of transcript data were provided codes that encapsulated their meaning. This procedure was systematically performed across all interview transcripts, collating data relevant to each code. The codes were organized into themes, gathering all data relevant into each theme. New categories were carried forward and revised until all essential themes were concisely captured. A hierarchical category structure was created, with lower order categories being the defining properties of higher order categories. Themes were consistently reviewed and refined to ensure that they accurately reflected the coded extracts and the full dataset. A thematic map was generated within NVivo12 using the hierarchical coding structure and data visualization techniques available within the software program. Definitions were created for each theme based on their content and relation to the overall analysis and the story that it conveyed. Finally, a report was produced that presented the

thematic analysis results in a comprehensive and compelling manner. The write-up contained vivid extracts taken from the transcripts of patient interviews in order to illustrate the meaning of themes and capture the essence of children's experiences within the broader context of the analytic narrative.

Results

Demographic and Clinical Characteristics

Fourteen children demonstrated interest in Study 2, consented to participation, and were interviewed. As displayed in Table 13, children varied in terms of age at participation, age at stroke, and most recent PSOM neurological functioning score. The sample consisted of 7 males and 7 females that ranged in age from 8.0 years to 18.4 years ($M = 13.76$, $SD = 3.35$). Four children had no neurological deficits, five children had mild deficits, and five children had moderate to severe deficits. Interviews ranged from 30 minutes to 1 hour. A tendency towards longer interviews and greater elaboration was observed in older children and children with normative expressive language skills. Younger children required greater use of interview prompts in order to facilitate the conversation and encourage reflection.

Table 13. Characteristics of interviewed participants

Participant No.	Gender	Age at Participation (Years)	Age at Time of Stroke	Stroke Mechanism	Current Total PSOM Score
1	Male	17.91	Neonatal	CVST	0.0
2	Male	16.75	Neonatal	AIS	5.0
3	Female	16.83	Neonatal	AIS	4.0
4	Female	18.41	1mo – 5 yrs	AIS	0.0
5	Male	15.58	Neonatal	CVST	0.5
6	Female	15.41	1mo – 5 yrs	AIS	0.0
7	Male	13.08	Presumed Perinatal	CVST	1.0
8	Female	12.25	Presumed Perinatal	AIS	2.0
9	Male	14.16	1mo – 5 yrs	AIS	1.5
10	Male	14.25	1mo – 5 yrs	AIS	3.0
11	Female	8.00	Neonatal	AIS	0.5

12	Female	8.58	Presumed Perinatal	AIS	0.0
13	Male	10.00	Presumed Perinatal	AIS	2.5
14	Female	11.41	1mo – 5 yrs	AIS	0.5

Thematic Analysis Results

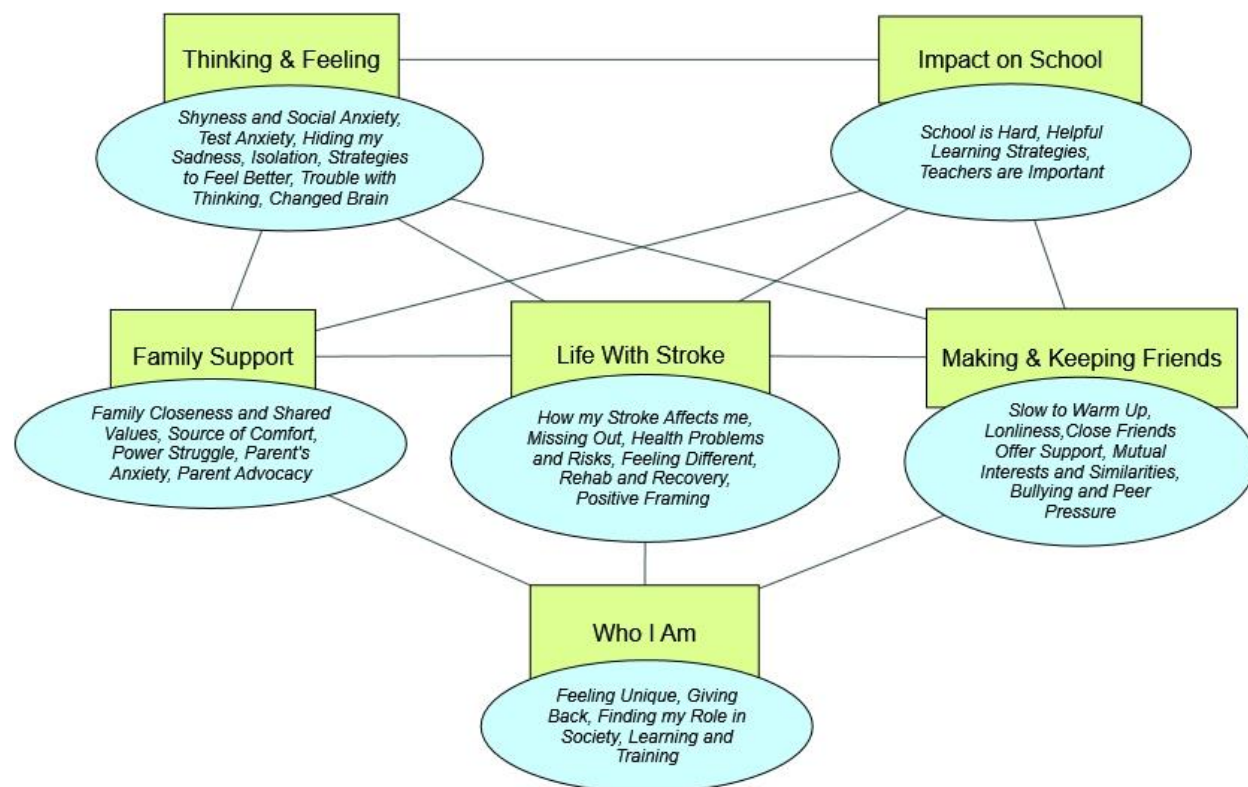


Figure 4. Thematic map demonstrating the major themes generated from the dataset along with the associations and overlap between overarching themes and subthemes.

Six major themes were generated from the data using thematic analysis: Life with Stroke, Thinking and Feeling, Impact on School, Family Support, Who I am, and Making and Keeping Friends. The definition of each theme is presented below along with the categories and codes that are subsumed within the theme. Quotes of interest are provided in order to illustrate the meaning of themes and capture the essence of children's experiences. Figure 3 presents a thematic map of the dataset and demonstrates relationships between themes based on the overlap of content areas, as some codes applied to multiple themes when classifications were mapped in NVivo. Higher-

order qualitative categories and their defining properties are also presented in Table 14 within Appendix C.

Life with Stroke.

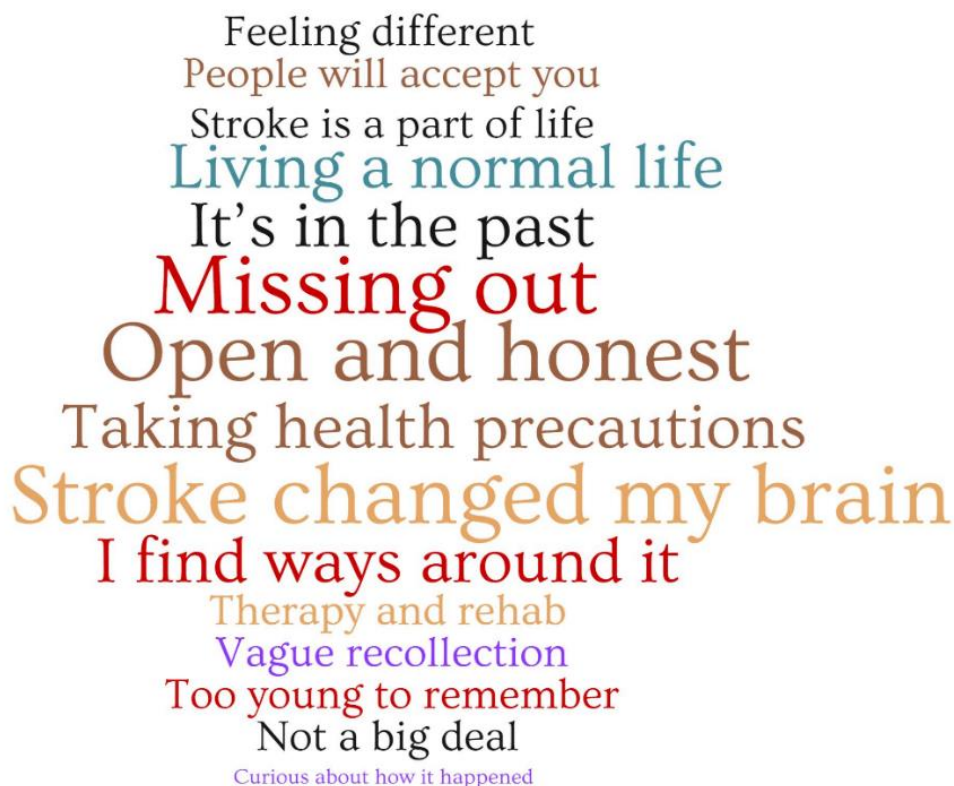


Figure 5. Word cloud representing the most common codes surrounding patients' perceptions of living with stroke.

One of the first themes identified across interviews was *Life with Stroke*, which encapsulated children's views and understanding of their stroke, the perceived impact of their stroke on daily life, and how their physical functioning and overall lifestyle compares to other children their age. Children reported on the early impact of stroke on their health and wellbeing and conveyed how this impact has changed over time from the perspective of rehabilitation and recovery.

Children began by sharing their memories, stories, and attitudes surrounding the stroke. Twelve children reported that they were quite young at the time of their stroke, and therefore had

no memory of the event. Two children indicated having a vague recollection of their stroke, and recalled neurological symptoms such as facial paralysis: “my face felt funny and went to one side.” Children’s knowledge and understanding of their stroke was often framed by their parents’ stories. Parents were portrayed as being honest and straightforward about the stroke, as participants felt that their parents wanted them to feel comfortable talking about it and asking questions. Curiosity about stroke was conveyed and most participants had asked their parents to share details about the condition, with queries such as “I asked them about what part of the brain it happened in.” Children also questioned how events unfolded on the day of the stroke, with four participants taking an interest in what had happened at the hospital. Although there was a history of these conversations, children relayed that they rarely discussed stroke with family anymore since it is something that happened in the distant past. Participants did not perceive the stroke to be a frightening event and said that they knew about it for as long as they could remember. Although participants were not impacted by disturbing memories of stroke, they relayed that the stroke has been a significant event in their life, but also something that is in the past and from which they are moving forward and recovering. However, participants readily acknowledged that stroke continues to impact their daily life in several ways.

Participants had extensive insights and commentary into the ways in which they felt their stroke affects them. Children relayed that stroke changed the way their brain and body works, and reported that they missed out on certain experiences in life as a result (e.g., social and recreational activities). Disability was notable and examples provided included motor weaknesses, coordination problems, or sensory abnormalities involving the hand, arm, and/or leg on one side of the body. Missing out on enjoyed activities due to disability or health risks was associated with a sense of sadness and frustration. For instance, some patients explained that they

feel less skillful and successful because of missed opportunities to practice important skills as a result of stroke disability:

If I can change anything, maybe I would... I don't know. I wish I were in more activities out of school. I feel like I'm not involved in many recreational activities like sports and different clubs that many people do, because I wasn't able to do them when I was young. So now that I've developed my motor skills and I'm open to these activities, many kids have been in it for a long time. So, if I were to go back to a sport, I feel like I would be different in it. I feel like if I started younger, then I would've been more successful now.

Relatedly, participants conveyed that stroke impacts social inclusion through disability and creates feelings of “being different from others.” Despite feeling different, all participants reported that they were living a “normal life” because they have been able to partially or fully recover from stroke-related disability. Many children were able to adapt to their difficulties or find ways around them, such as through the support of technology (e.g., replacing handwriting with typing on a laptop keyboard) or by using their stronger hand. The effectiveness of physical rehabilitation and/or occupational therapy was emphasized in five cases. Rehabilitation and recovery were associated with a positive framing of stroke, and children expressed feeling fortunate because things could have been much worse.

If I were to think of it as a terrible experience instead of thinking of it as a good recovery, I would be a lot more upset in talking about it...I think that there are a lot of good things that have come out of this. I've been open to more experiences with new people. I've seen a lot of doctors and I've seen a lot of new environments that I wouldn't have been open to. Like at SickKids, I was known by many doctors in the neurology department. I think that coming here and having them know me made me feel special and made me feel more

strong in talking to new people, I guess.

As exemplified in the above quote, children discussed the good things that have come from stroke, such as meeting inspirational clinicians and receiving special attention.

Some participants expressed that they were taking health precautions because of their medical history. Three teenagers reported that they have never used alcohol, cigarettes, marijuana, or other drugs, and plan to avoid substance use throughout their lifetime. A sense of medical fragility and vulnerability was shared, and teens wanted to lead as healthy a life as possible. Surviving stroke gave them an appreciation for life and they wanted to respect their bodies. This meant that they would have to think differently from other youth and withstand peer pressure:

I am not into social trends or anything like that. I honestly find a lot of stuff that people do kind of ridiculous. I don't, like, I wouldn't give into peer pressure for smoking or drugs or anything like that. Mostly because the effects on my system with all the stuff that's already in my body, like my Aspirin to keep my blood from clotting, and stuff like that. The effects could be very bad. I find kids doing drugs at this age kind of ridiculous. But for me I like to keep my head clear - I like thinking straight. I don't like people influencing me in any way.

In describing reservations towards drug use, this youth referred to the potential interaction between drugs and his anticoagulant medications. The desire to think clearly was also emphasized, and this individual went on to discuss the potential adverse effects that drug use could have on his cognitive abilities.

Who I Am.

Participants described feeling unique and were proud of their values and personal

identity. Strong themes of reciprocity and generativity emerged. Children were touched by the kindness of clinicians and the helpfulness of medical and rehabilitation services that they received as part of their stroke care. As a result, children wanted to give back to society in some capacity. Five children shared that they wanted to work in a “helping profession”, with examples including plans to become a social worker, nurse, or doctor. Volunteer work in the community was also common, especially with medically complex children or vulnerable populations. Having survived stroke, three participants felt that they were in an ideal position to serve as a role model and guiding light for other children with stroke, with one child stating: “It’s kind of a way to bring hope to other kids. These kids will see these people who managed to pull through, and say ‘I can pull through too’ sort of thing.” In some instances, giving back to the community was tied to spirituality or religious beliefs:

The stroke affected me because of the fact that angels, God above, people in the hospital to my own family ... they have all helped me in a sense through their prayers ... through attention after I got out of the hospital. After all of that help I really want to give back to the community in a sense to say thank you....I feel that it’s my calling It makes me very proud to be alive. I’m proud of myself to be able to help be a part of something.

Personal development, learning, training, and productivity were prioritized in order to reach career goals, find one’s role in society, and make a meaningful / valuable contribution. Some participants reflected on the educational path that they were likely to take in order to meet their professional goals (e.g., enrolling in a certain college or university program). Regardless of whether children were aware of their educational or professional trajectory, independence and self-sufficiency were projected as being important for the future.

With respect to feeling unique, most participants spoke about having special talents or

qualities that set them apart from others. Artistic and musical skills were emphasized, with four participants describing themselves as “creative,” while three other children asserted that “I’m good at working with my hands”. Some participants also described possessing humanitarian qualities, and were proud of this facet of their identity:

Well, this might sound really weird, but every single person in my family says I can feel their emotions, so I am really good at connecting with people through emotions. I can feel when somebody is sad or really happy, or stuff like that. And I am really good with kids.

Making and Keeping Friends.

A preference for stroke history to remain private was indicated in six participants, who relayed that they are careful about who they share this information with, and generally only speak about stroke with trusted family members and close friends. These participants conveyed a sense of vulnerability and concern about what others may think about them. However, a theme of “being upfront” emerged in seven participants, who indicated that they shared their stroke history with several friends and acquaintances, especially when others were curious about their visible physical disability. This group of children generally felt a sense of trust that they would not be judged or victimized by peers based on their stroke medical history. They conveyed that being open and honest about stroke provides peers with a health context for disability and difficulties. This level of understanding reportedly enhanced compassion and acceptance from others.

Difficulty with making or maintaining friendships was reported by half of the sample. Participants reported having a hard time knowing how to approach and socialize with other children and there was a general struggle with navigating social situations. Withdrawal and loneliness were sometimes reported:

When I walk into a classroom I get into the back corner and you don't ever see me. Put my hood over my head and do what I have to do. And yeah. I am the first one in the classroom, in the back corner, and first one to leave.

Fear of rejection due to negative social experiences was associated with keeping to one's self and a sense of "feeling different". The theme of "Bullying and Peer Pressure" was coded in nine participants who had recently experienced social pressure or antagonistic behaviour from other children that involved a power imbalance. In most cases, bullying was described as relatively minor and resolved quickly. However, bullying was occasionally severe and sometimes resulted in avoidance of school:

I would like to change the bullying, where people have been bullying me and stuff because it's just making me feel lonely and down all the time. And it always gets me nervous for the next day to happen. I always want to stay home and not go to school and stuff.... I feel like they're getting everybody on their side and thinking I am the bad person. Last week or the week before I got called 'a snake' ... and um ... and then they just talk about me. If I am sitting over there, they laugh at me sometimes and give me certain looks with their eyes.

Social rejection and chronicity of bullying problems was reported to be stressful, troubling, and to have adversely impacted the ability to trust other children, including peers that had no involvement in the bullying experiences. Avoidance and retreating (i.e., keeping to oneself) were the primary strategies utilized to manage these difficulties.

Despite having experienced bullying and aversive social experiences, most of the sample acknowledged having close and long-term friends. They spoke about friends that they have retained over time from earlier in childhood; when asked about the significance of their long-

term friendships, the participants shared that these peers are dependable, supportive, and just seem to understand them on a deeper level. Moreover, close friends were described as a source of comfort and confidence. Seven participants described themselves as “slow to warm up” in the sense that it takes some time before they feel comfortable opening up to others. Having a trusted friend present in the group facilitated social interactions and decreased anxiety:

Sometimes I find it difficult just because I am shy, but once I start talking to people, like, if I am with somebody else that I am comfortable around and I talk to the other person, then I feel more comfortable around them and then we can become friends and stuff.

Bonding over mutual interests and similarities was also discussed with respect to making and keeping friends. Shared extracurriculars were a protective factor that engendered feelings of belongingness, joy, and fun:

We've just kind of started becoming more friends since we entered youth group for young peoples, so yeah I have started making more friendships You just find things you have in common. What you like doing in your spare time and if it's the same.

Thinking and Feeling.



Figure 6. Word cloud representing the most common codes encapsulating children's mental health and coping.

The major theme of “Thinking and Feeling” was derived from abundant data related to children’s emotional and cognitive experiences. Nine participants endorsed the belief that stroke had “changed their brain.” Various effects of stroke on psychological functioning were described and attributed to the effects of brain injury: *“I do think that stroke has changed the way that I think because it made me more cautious of things and it may have contributed to how I think and my thinking process now.”* Five children expressed that stroke impacted their emotional processing: *“What I was told was that the stroke, the strokes, plural, happened in the emotional part of my brain.”* Although some children reported that their stroke altered brain functioning such that they were more sensitive and nervous, other participants felt that stroke resulted in poor emotional awareness and reduced ability to connect with others. With respect to stroke and cognition, altered brain functioning was associated with a slower working pace relative to same-

aged peers: “*People with strokes just take longer on tests and work more slowly.*”

Using a number of prompts, participants were questioned about their emotional world, mood, and self-perceptions. Anxiety symptoms were discussed by 12 individuals who conveyed that they were distressed by their anxiety and felt that it interfered with their ability to engage in daily life. Shyness and social anxiety were especially common, and was represented in emergent themes concerning withdrawal, being self-conscious, fearing social judgement (“I’ll be judged”), and being lost in anxious thoughts. Social rejection or bullying experiences, as discussed in the above section on making and keeping friends, may have precipitated or exacerbated socially anxious thoughts. Twelve participants reported feeling self-conscious about their appearance or behaviour, and avoided being the center of attention due to fear of social judgment and rejection. In some cases, the fear of being noticed was related to stroke disability:

Yeah, but in grade 1, like, I was the only one wearing a leg brace. I felt like ... I just wanted to ... Even when it was still pretty warm out I wore pants for the rest of the school year because I didn’t want like, kids to see my brace and stuff like that... Also, I am pretty shy... I’ll raise my hand and answer questions, but I don’t like doing projects where I have to speak in front of the class. You’re looking at everyone and they are looking at you because they have to keep eye contact on you. So it looks like they are judging you by looking at you.

Children were worried about appearing different from others or standing out, and the above quote provides a particularly prominent example of insecurity associated with visible stroke-related disability and rehabilitation through use of an ankle foot orthosis or “leg brace”.

Difficulty giving class presentations due to anxiety was described by six children and youth:

I get anxious during presentations. I get up there and a lot of the times I, I would ask uh...

a lot of the times I would ask my teachers to say either do a one-on-one presentation, or to pick and choose certain individuals, and say 'You know what, let's do it where it's just you, those three individuals'. Mostly, like, three acquaintances or friends, and then I would present it to them only.

Tendency towards shyness and fear of social judgement and rejection were also reported to interfere with making friends and enjoying social life: *"There is always that little bit of me that's wondering what others think of me... I get really, just tense. More so if I had to go someone's house for something."* Trying new things could especially seem daunting in the context of socially anxious thoughts: *"I feel like it's possible that I could've done more stuff, more sports. It's honestly been a big fear of mine to try new things and meet new people. It's been kind of hard for that."* Avoidance of new experiences and social situations alleviated anxiety in the short term but ultimately increased feelings of loneliness and isolation.

Worries of a generalized nature were described by four youth, who reported that uncertainty and unpredictability in life are upsetting to them: *"Life in general worries me because I don't know what's going to happen. I can't tell my future. And I'm definitely afraid of the unknown."* Unpredictability surrounding transitions provoked anticipatory anxiety; feared transitions spanned a wide variety of situations amongst children, and included starting new classes, waiting for end of term grades, transitioning to high school, and pondering what happens to consciousness following death. "Imagining the worst" was a theme coded in five participants. A younger participant described fearing that her worst nightmares would come true, which involved becoming separated from her parents and abandoned in a grocery store. A teenage participant provided perspective on the broad nature of her recurring thoughts surrounding worst-case-scenarios, where she imagined family members becoming ill or dying and her best friend

betraying her by siding with her bullies. This participant went on to say “*My mom has told me I am worrying about stupid stuff. Like, I don't have to put so much thought into it or worry about that so much.*”

Test anxiety and fear of failure was a predominant theme in five participants. Academic and performance-related worries were associated with difficulty focusing during tests and trouble falling asleep at night due to racing thoughts about the upcoming school day. High school students reported feeling particularly overwhelmed and anxious during exam time:

I think I worry a lot more than people my age. I especially notice this during the month of the exams in high school. I think last semester I had four exams, and I noticed, even my friends who had four exams, I studied a lot and I worried a lot more and I don't think it was very healthy. I think that during that time, even people around me would notice, and say 'you seem very scared or worried.' At the end of the day, everyone was still scared. It was just that I had not processed it in the best way, thinking about it.

With regard to mood, seven interviews were coded for “hiding my sadness”, which is a theme reflecting children’s tendency to conceal their sorrow and disappointment. Some children felt alone and misunderstood, expressing that no one could possibly relate to their difficult experiences and emotions. Hiding one’s sadness also functioned as a coping mechanism so that the child did not have to confront their difficult emotions or feel as though they were “burdening” their parents or friends with sad/dark thoughts. Expressing one’s sadness could also be seen as a slippery-slope towards poor decision making and “being out of control”:

During my life, I feel like I've kind of absently learned that I should hide my feelings and not feel them. Even though people are trying teach me to feel and express my feelings, it's kind of difficult to unlearn the habit. I've already learned that feelings shouldn't be felt

because that leads to bad decision making and impulsive decisions.

Not all participants experienced mood concerns, however, and the majority of interviews indicated that children had stable affect. Five children self-identified as positive optimists who are mostly happy. As one participant put it: *“I’m a pretty positive person. I’m never in a terrible mood for no reason...I’ve always put forward positive thoughts before negative.”*

Although experiential avoidance and emotional repression were endorsed by some individuals, diversity in coping mechanisms was notable, and many participants reported utilization of adaptive coping strategies that were helpful for managing big emotions. “Strategies to feel better” encompassed listening to music, using distraction, spirituality, meditation, positive self-talk, and putting things in perspective. Six children and youth talked about the importance of stepping away and taking time for oneself in order to improve mood and reduce stress:

In my personality, I do worry a lot, which could have been a factor of anxiety or something. But I do feel like, if I do need to calm down, I have the capability to. So it’s not uncontrollable, it’s just sometimes... I just need a minute or two to reflect and think about what’s going on.

Eight children sought advice from others during difficult times. Family and friends were seen as positive sources of emotional support. Younger children usually reached out to their parents when they were upset, while teenagers were most likely to speak to their closest friends:

I have a really close friend. I have two, but in particular, I’ve been talking to one lately and I just say, “I’m feeling really bad today,” and we have a good long conversation about how both of us are feeling. It’s a good relationship because we help each other out.

“Trouble with Thinking” emerged across nine interviews, and represented difficulty with cognitive tasks, like attention and memory, such that it interfered with daily functioning and/or

the ability to complete school work. Three children described themselves as forgetful because they had a hard time with memorizing facts and keeping track of information. Five participants asserted that they had a hard time focusing on learning materials: *“My brain doesn't allow me to sit down and focus for long.”* Concentration difficulties were described, especially as it pertained to sustained attention:

Just having to sit down and read a novel, Shakespeare. Reading takes more energy out of me than information going in my head ... Last year my civics and careers teacher would talk a lot and we didn't really learn stuff so I just kind of zoned out. In grade 9 we were watching a movie in science and I kind of fell asleep then but I didn't really realize it.

Low stamina was reported by six participants who described a tendency towards tiredness and exhaustion. Fatigue especially set in towards the latter half of the school day: *“Mental or physical fatigue? Uh probably a bit of both. I get tired near third period. Sometimes I just get super tired and I can't think and I feel like I just need to have a nap.”*

Impact on School.

All children acknowledged both good and difficult aspects of school. Math was the most commonly reported area of struggle, followed by reading and writing. Children frequently struggled in more than one subject, and occasionally associated academic difficulties with the effects of their stroke: *“I attribute it because there are a whole bunch of subjects that are really hard for me. English and Math are really hard sometimes. Sometimes I think it's because of my stroke and stuff.”* School and learning were described as “effortful” by 10 participants who expressed that they had to dedicate more time and energy to academic activities in order to attain the same or lower grades than their peers. Frustration with low school achievement and social comparison with peers negatively impacted self-esteem.

Sometimes I get upset and wish I could do better. All my friends are in academic classes and I am in applied and stuff. And they have like, you know, when the schools come and you can ask them what or if you want to go into careers in nursing or medical and they give you information about that school program. They did a university thing and I went with my friends, and I kept saying that I wish I was in university classes because it seems so fun and stuff. So yeah.

Feeling overwhelmed with schoolwork during busy times of the school year was also discussed: *“I find it difficult when I have too many tasks put on me because then I am stressed out because I wish to finish the tasks to the best of my ability.”*

Ten children had access to accommodations, which were often part of an individual education plan. Four children indicated that they had time-related accommodations in order to compensate for a slower pace of working and thinking. This group of children conveyed that they required additional time to complete tasks in order to keep up with academic standards. Other accommodations included access to a resource room, preferential seating in the classroom, use of a laptop, alterations to the way information was presented, and alterations to the way students completed assignments or tests. All children with accommodations found the supports to be helpful; however, one youth was embarrassed by requiring extra help since it had previously made her a target for bullying:

Sometimes, at the beginning, when I was first starting elementary school, it was kind of tricky because I was getting bullied. There were people calling me stupid and stuff and um, my grade 6 teacher let me have an old copy of the test that we were doing so I could use that as a review and stuff, and everybody thought ‘it’s not fair that she gets it and we don’t’ and stuff. So it was kind of hard to talk about that.

Teachers were perceived as an important part of the learning experience. “Helpful teachers” were seen as kind and supportive educators with an engaging teaching style; they recognized children’s learning difficulties and found effective ways of offering support. Children were more likely to want to attend class and engage in difficult subject material if they liked their teacher and felt comfortable approaching them for clarification or extra help. Comprehension difficulties were reported by five participants who said that they often required elaboration and/or simplification of task instructions from their teachers:

I can get my teacher or my resource teacher to read over the questions and talk me through it and try to explain it in a better way. So, um, I had troubles with my bio exam, so I was a little nervous and stuff, so the teacher kind of came over, and I told her, so she would write it down for me.

In addition to motivational and supportive teachers, good aspects of school were also reported to encompass spending time with friends and being involved in fun subjects and extracurriculars, with examples including music, business, woodworking, gym, and social studies.

Helpful learning strategies were reviewed and discussed. Seven participants found that they benefitted from using repetition as a memory strategy and asserted that regular practice is important for learning. Staying organized, eliminating distractions, and writing things down for later reference were also important for supporting memory and learning. As implied earlier, asking teachers for help and actively using available accommodations were central to optimizing one’s academic experience. Taking a break when feeling fatigued or overwhelmed with academic material was also seen as an important component of school success:

Just take a break. If I am getting frustrated from something, go do something else for a little bit then come back to it. Like on a test if I can't figure something out, I'll just go to

the next question and then go back to it.

Family Support.

When asked about home life, children and youth shared that family is a significant source of comfort and support. Parent involvement and advocacy was a central component in school success, as parents were able to ensure that children had access to appropriate accommodations and also provided assistance with homework and studying. Participants felt that they could go to their parents with their problems, since parents were able to provide both validation and advice:

Honestly, I have a pretty safe environment at home where I feel comfortable to talk with my parents. If I am worried, then they're a pretty good outlet for me. It's a pretty understanding place for me to explain what I'm going through and that really helps me, if I'm going through something.

Parents were considered role models for important values, such as respect and kindness. Additionally, children were often assigned household tasks and expectations within the family unit, which cultivated responsibility and independence. However, burgeoning independence in pre-teen and adolescent participants also came with power-struggles with parents. Parents and teens sometimes disagreed on house rules (e.g., keep your room tidy) and diet (i.e., what constitutes health eating). One teen reportedly disagreed with her mother over educational choices and her anticipated career path, as her mother did not want her to become a nurse due to the high stress-levels that can be associated with the profession. Minor disagreements with parents were described more generally in six participants. Nine participants also spoke about the commonality of sibling bickering:

Sometimes me and my brother get in fights but I think that is normal for siblings. We fight about stupid stuff. We'll just go into our rooms and take a chill pill, and after the next

hour or something we are watching a movie together, spending sibling time together.

Sibling closeness and affection emerged as a protective factor that fostered feelings of belongingness and wellbeing. In some cases, children also described a strong connection with grandparents.

Parental worries and anxieties were noted in eight interviews. Content in this area represented the concerns that parents held regarding their child's physical wellbeing, especially from the perspective of stroke:

My parents worry about me because of the effects of the stroke, so they are definitely more protective of me. They worry if I say things like 'I hit my head' or something of the sorts, or 'I got hurt,' because those types of things would be worse than the average kid for me.

Parents viewed their child as medically vulnerable and were protective of their health. Children often recognized their parents' concerns and were careful in their daily activities. However, mild irritation was expressed in children whose parents frequently "checked in" about their wellbeing: "My parents always ask stuff like: Are you eating enough? Are you hurt? Are you feeling okay?"

Discussion

The current qualitative study provided an in-depth view into the lived experiences of 14 pediatric stroke patients, especially as it relates to mental health, coping, and daily functioning. The accounts of our child and youth participants illuminate the profound impact that pediatric stroke can have on children's personal identity, self-efficacy, learning, behaviour, and psychosocial functioning. Children relayed that stroke changed the way their brain and body works, and commonly reported on physical disability, cognitive weaknesses, feeling different from others, periods of sadness, shyness, and social anxiety. Despite these challenges, an

enormous degree of resiliency was also demonstrated in children's insights into coping, adaptation, and helpful learning strategies. The supportive role of family and friends was also highlighted, and parents represented an important source of comfort and advocacy for learning and mental health needs. Notably, children were often able to adopt positive framing of their stroke and meaningfully integrate their health experiences into their identity and values.

Although children had no memory of their stroke or only a vague recollection of the event, they were able to describe the pervasive impact of stroke in different domains of their daily life. Social inclusion and recreational participation (e.g., enrolment in sports and other social extracurriculars) were identified as an important facet of life satisfaction by participants. Missing out on enjoyed activities due to disability or health risks was associated with a sense of sadness and frustration. Findings emphasize that social participation can be adversely impacted by stroke disability, and that children presenting with sensory and/or motor deficits may benefit from services that encourage inclusion and facilitate connection with peers. Pediatric neuropsychologists can support the mental wellbeing of children with stroke by evaluating and supporting social connectedness in clinical assessments. Social isolation is especially relevant in the context of the COVID-19 pandemic and the documented downstream effects of extended lockdowns, limited social programs, and remote learning on the mental health of neurologically at-risk children (Williams et al., 2021).

Fear of social judgement was common among pediatric stroke survivors, and social anxiety was coded as a predominant psychological concern in our qualitative interview reports. Social comparison and self-consciousness were conveyed, and were sometimes connected to stroke disability and deficit. For instance, children reported feeling different from others if they presented with significant motor weakness / hemiparesis or when they required the use of a

visible physiotherapy device, such as an ankle foot orthosis or arm brace. Feeling different from one's peers often precipitated anxiety about standing out and being negatively judged. Stigma was attached to both physical rehabilitation and learning needs (e.g., use of a classroom laptop to complete schoolwork), and could sometimes make children a target for bullying. It will be important for clinicians and educators to work towards empowering pediatric stroke survivors and reducing stigma associated with disability or use of required supports. There is poor awareness of pediatric stroke in communities and schools; enhanced public education about acquired brain injury in children is required and may be helpful towards reducing stigma, preventing bullying, and ensuring that children feel comfortable and supported. Anti-bullying programs have historically been helpful for children with special needs (Raskauskas & Modell, 2011). There are many programs and approaches that could work in schools, communities and homes to disable bullying and empower vulnerable children. For instance, social and emotional learning (SEL) has been added to curriculums to help children develop foundational skills in managing emotions, caring for others, decision making, and ethical handling of situations (Dusenbury et al., 2015). Such programs have resulted in significant improvements in students' social skills and classroom behaviour (Payton et al., 2008).

Our findings speak to the importance of psychological assessment and treatment planning surrounding internalizing symptoms in children with stroke. Participants endorsed the belief that stroke had impacted their brain functioning and described various effects of stroke on their mental health and wellbeing. Psychological concerns encompassed internalizing symptoms such as cautiousness, sensitivity, nervousness, restlessness, difficulty controlling worry, test anxiety, and withdrawal. A subset of children described experiencing regular feelings of sadness and reflected on a tendency to conceal their sorrow and disappointment rather than share their sad

feelings with others. Concealment functioned as a form of experiential avoidance and also stemmed from a desire to not “burden” others with heavy emotions and personal problems. Consequently, parents may have poor awareness of the presence or severity of mood-related problems and could underreport symptoms in children with stroke. This finding highlights the significance of comprehensive psychological assessment and treatment planning in children with stroke history and emphasizes the relevance of including self-report inventories and individual child interviews when collecting data on mental health.

Two published pieces of qualitative research briefly described psychological symptoms in children with stroke, as reported by their parents during semi-structured interviews. Findings converged with the current study in that there were reports of anxiety, social phobia, and mood concerns (McKevitt et al., 2019; Soufi et al., 2017). Concerning levels of mental health problems were notable in the paper by McKevitt and colleagues (2019), however, which reported suicidal ideation, self-harm, and aggression in children. The severe mental health problems documented in this qualitative paper can potentially be attributed to unique sample characteristics encompassing a collection of risk factors, including higher neurological severity, greater family stress, and parent depression. In contrast, positive family functioning was generally described by our sample, with reports of supportive, attentive, and validating parents. Generalizability of McKevitt’s findings to the broader stroke population is also questionable due to lack of methodological results concerning the age of child at study participation or stroke mechanism (McKevitt et al., 2019).

Regarding perceptions of cognitive function, difficulties with attention, memory, and fatigue were described, with implications for academic performance. Teachers were identified as an important source of help and support, and most participants said that they felt comfortable

approaching their teachers for assistance. Parents were also actively involved in their child's learning and often advocated for appropriate school accommodations. Despite receiving formal school supports, often in the form of an individual education plan, some children continued to feel overwhelmed with school and experienced test anxiety and fear of failure. Consideration should be given to whether children need adjustments to their learning plans in order to make school accessible and fair. However, some children may experience anxiety even in the context of developmentally appropriate learning and could benefit from cognitive and behavioural psychological interventions in order to manage unfounded worries about academic performance.

Despite reports of internalizing symptoms and learning challenges, resiliency and adaptability were salient throughout interview content. Several children demonstrated extraordinary insight into adaptive coping mechanisms during times of stress, and endorsed beneficial strategies such as listening to music, distraction, spirituality, meditation, positive self-talk, putting things in perspective, stepping away, taking time for oneself, and seeking out trusted friends and family for emotional support. Children often reported that they had been able to adapt to their physical and cognitive disabilities over time by finding ways to compensate for deficits, such as through the support of technology or rehabilitation. They also provided insight into personally helpful learning strategies, with reports about the relevance of repetition and context for dedicating information to memory. Staying organized, eliminating distractions, taking breaks, and writing things down for later reference were also described as important for supporting memory and learning. Adaptive coping when faced with stressful challenges is an important factor in the maintenance of good mental health as it can act as a buffer against the development of clinical psychopathology (Wright et al., 2010). Positive coping can be encouraged and further developed in the pediatric stroke population as a component of

preventative psychological care.

It was fascinating to note that pediatric stroke can be positively integrated into a child's personal identity, value system, and life narrative. Children discussed special life experiences that stemmed from their stroke, such as having the opportunity to meet kind, knowledgeable clinicians and hospital staff. Children were inspired by the helpfulness of medical and rehabilitation services that they received as part of their stroke care, which was associated with strong themes of reciprocity and generativity. A desire to "give back" emerged in the data, and some participants felt that they could identify with and help other children with disabilities or brain injury. Having lived through stroke meant that they had important knowledge and perspectives to offer the world, and there were career path aspirations specific to the "helping professions," such as nursing, medicine, and clinical scientific research. Relatedly, the extant literature suggests that a special focus on health-related occupations is present in adult survivors of childhood cancer (Szilagy et al., 2019). It has been suggested that health experiences can shape and influence young people's career choices via impact on self-image and values (Staniec, 2021; Szilagy et al., 2019). For instance, children who experienced positive recovery from a medical condition may be more likely to prioritize societal benefit and value the powerful impact of medicine/clinical care, especially when the condition was perceived as impactful and important in their lives. Immersion within a medical context as part of treatment and follow-up care can also normalize and naturalize a career choice within a similar field (Staniec, 2021).

Positive framing surrounding stroke outcome was also endorsed; participants expressed feeling fortunate because their stroke could have resulted in more severe medical consequences. Surviving stroke gave some children an appreciation for life, which was reflected in teenagers' decision to abstain from substance use. Teenagers were taking health precautions because of

their medical history and wanted to lead a healthy lifestyle characterized by respect for their body. Drug use was perceived as risky and cognitively impairing, and participants wanted to avoid doing anything that could exacerbate difficulties or introduce new health concerns. A desire to think clearly was expressed and teens wanted to protect their cognitive functioning. Health-related conscientiousness may represent a protective factor against the lifetime development of a substance abuse disorder in this population. More generally, childhood health conscientiousness trait has been found to be a robust predictor of longevity due to the implementation of health-promoting behaviours (Friedman et al., 1995; Friedman & Hampson, 2021; Kern et al., 2009).

GENERAL DISCUSSION

Pediatric stroke is a significant neurological event that disrupts brain development and impacts emerging cognitive skills (deVeber et al., 2017). Although deficits in motor, language, and cognitive domains are well-recognized sequela, considerably less is known about mental health and psychosocial outcomes following this type of pediatric brain injury (Lehman et al., 2020; Lo et al., 2020; Westmacott et al., 2018). Good mental health is a critical aspect of healthy child development and is intertwined with quality of life, long term adjustment, levels of engagement, and functioning within the community (Greenham, Anderson, Hearps, et al., 2017). There are multiple factors that may place children with stroke at elevated risk for psychosocial difficulties. Academic underachievement, physical disabilities, learning disabilities, attention problems, and social skills deficits have all been consistently documented in pediatric stroke, and can represent intrinsic, proximal factors affecting mental health functioning (Anderson et al., 2014; Yvon et al., 2018). Family factors have also been identified as salient environmental variables in childhood psychosocial risk and resiliency (Greenham et al., 2015). Thus, in addition to investigating functioning in various domains of mental health, this study also set out to identify important predictors of outcome, with the goal of informing preventative mental health practices and early interventions.

The current project was approached through a mixed methodology framework in order to collect data that was both rich and comprehensive. Quantitative and qualitative methods fulfilled different yet complementary purposes within our study design. Numerical data on self and parent ratings of mental health provided a broad perspective that enabled us to examine patterns in the data in order to make generalizations about the population and establish variable relationships. This was supplemented by comprehensive patient interviews that offered depth of perspective

and directly reflected the participants' point of view. Mixed methods research allows for an integrated approach when addressing complex phenomena (Ivankova & Wingo, 2018; Kelle, 2006). A mixed methodological approach to our research question also allowed for multiple operationalization and triangulation of data. Comparing results across studies was part of the validation process to ensure that explained variance was the result of an underlying phenomenon as opposed to arbitrary findings specific to their methodology (R. B. Johnson et al., 2007). Convergence of findings enhances confidence in conclusions drawn (Hanson et al., 2005). We set forth to examine convergence, inconsistency, and potential contradiction in findings across studies in order to establish a comprehensive and accurate narrative concerning mental health in pediatric stroke.

Quantitative and qualitative findings of the current project converged in several respects. The emotion regulation and anxiety concerns that were reported by parents in Study 1 were also reflected in the interviews of pediatric stroke participants, albeit in richer qualitative detail. In both studies, a considerable proportion of patients were noted to have difficulty controlling feelings of worry, and also presented with reduced self-confidence and some indications of sadness. Bullying, physical disability, and cognitive/learning difficulties were associated with mental health risk in both studies. Qualitative interviews were helpful in elucidating the specific nature of anxiety symptoms. Children's worries tended to surround social situations (i.e., class presentations, making friends, being judged by peers, and being perceived as different) and academic evaluation (i.e., tests and grades). There were also generalized fears reported by a subset of children (e.g., imagining worst case scenarios and being afraid of uncertainty). Although substance use was not assessed within the context of Study 1, interview participants spoke about the importance of abstaining from drug use in order to avoid negative health effects.

Health conscientiousness was an emergent theme in qualitative data, and suggested that there may be protective effects against the development of substance use disorder in some children with stroke.

Heterogeneity of psychosocial outcomes across pediatric stroke participants was a uniting factor across studies. In both qualitative and quantitative methods, a subset of participants presented with concerning levels of mental health difficulties in one or more areas of functioning, with anxiety representing a salient domain. Higher frequencies of concerns were present in the qualitative sample, however, as reported by pediatric stroke patients during interviews. For example, anxiety symptoms were discussed by 12 individuals (85% of the qualitative sample) who conveyed that they were distressed by their anxiety and felt that it interfered with their ability to engage in daily life. By comparison, 45.2% of parents rated that their child had very clinically elevated levels of anxiety. With regard to mood, half of the interviews were coded for “hiding my sadness”, which reflected feeling alone and misunderstood in the midst of one’s struggles, and a tendency to conceal the resulting sorrow and disappointment. On background questionnaires, 41.9% of parents rated that their child had emotion regulation concerns, and 12.9% indicated low mood. While half of interviewed children described difficulty making and maintaining friendships, 25.8% of parents rated problems in this area for their child. Mental health presentation was varied for both groups, but parents may be underreporting difficulties in their child due to incomplete awareness of their difficulties and struggles. Although some children reported confiding in friends and family when upset, other children coped by ignoring problems and hiding their internalizing symptoms.

There were common risk factors implicated in the mental health presentation of the children in our studies, and these risk factors appeared to account for a considerable proportion

of the variance in psychological outcomes. As noted above, experiences surrounding bullying, physical disability, and cognitive/learning difficulties were associated with increased incidence of anxiety, pessimism, and low self-confidence. Interviews were actively coded for these associations, and linear regression analyses inferentially confirmed predictive relationships between variables. Protective factors were also notable, and high levels of resiliency and positive coping were present in our stroke participants across methodologies. Published research on quality of life in pediatric stroke has portrayed a concerning picture with respect to psychosocial functioning (Hurvitz et al., 2004; Max et al., 2002; O’Keeffe et al., 2012, 2014, 2017), and the most severe end of psychiatric manifestation has reportedly encompassed suicidality, self-harm, and aggression (McKevitt et al., 2019). In contrast, our sample displayed comparatively lower rates of clinically significant psychopathology and demonstrated impressive emotional insight and problem-focused coping. Distal and proximal factors that can support resiliency include moderate to high socioeconomic status, the presence of supportive caregivers, parent modeling of healthy emotion regulation, good family functioning, mild neurological deficits, and access to school remediation / accommodations and community supports (Greenham, Anderson, Cooper, et al., 2017; Greenham et al., 2015; O’Keeffe et al., 2017). A substantial number of our participants had access to protective resources and supports, which can collectively act to buffer stress and improve function from a biopsychosocial perspective.

Families are in a unique position to scaffold and support recovery and development following brain injury (LeBlond et al., 2021; Wade et al., 2011). Given the established importance of environmental variables in children’s psychological risk and resiliency, it was initially surprising that parent mental health and family functioning variables did not significantly associate with internalizing symptoms in Study 1. Parent mental health solely

predicted childhood behaviour regulation. In qualitative interviews, however, participants highlighted the role of parental warmth, care, and advocacy in their mental health, and often regarded parents as an important source of comfort and wisdom. Some children expressed irritation at their parents' overprotectiveness or "checking-in" behaviours related to health and wellbeing given their potential medical vulnerability related to stroke history and prevention. On average, our parent participants demonstrated good coping and parenting practices. A high-quality home environment has been found to mitigate differences in daily functioning that can result from brain injury. When comparing children with mild TBI, moderate TBI, severe TBI, and orthopedic control children, the greatest emotional, behavioural, and functional group differences were observed in the context of a poor-quality home environment (Wade et al., 2016). By extension, differences in psychological functioning based on stroke history are likely to be amplified in the context of poor parenting practices, poor parent coping, family dysfunction, and low socioeconomic status. Inclusion of a more diverse sample with respect to parents' stress, education, and income may have resulted in larger group differences and stronger variable associations.

Despite prominent interview content surrounding social and performance related anxieties in the lives of pediatric stroke patients, self-report standardized questionnaires from Study 1 did not quantitatively capture group differences in scales of mental health. Elevated ratings of mental health problems were exclusively present on parent-report measures. The self-report RCADS was administered to children and adolescents in our study as a nuanced tool capable of measuring various symptoms of anxiety and depression. It diagnostically represents common psychiatric disorder classification systems by providing indices on social phobia, generalized anxiety, panic, separation anxiety, obsessions/compulsions, and depression (Chorpita

et al., 2000; Weiss & Chorpita, 2011). The self-report KIDSCREEN-52 was also included in our assessment battery for its ability to assess psychosocial determinants of mental health (Ravens-Sieberer et al., 2005). By modeling psychiatric diagnostic criteria (e.g., DSM-based principles) in their phrasing, however, questionnaires may be less likely to capture the everyday difficulties experienced and endorsed by children (De Leeuw et al., 2004). The face validity of childhood inventories can be improved by providing specific examples of the difficulties / symptoms that they are querying. This is especially important for elementary-aged child respondents or children with language-based disorders or cognitive deficits (Bell, 2007).

It is also important to note that our quantitative questionnaire data was collected using forced choice Likert-style rating scales and did not utilize questions that invite open-ended feedback. In contrast, qualitative interviews gave participants the chance to provide information in their own words, and also allowed the interviewer to seek clarification and elaboration on responses when required. Although qualitative coding and interpretation is required, one-on-one interviews provide children with optimal opportunity to reflect on their experiences and express their perspectives in a detailed and comprehensive manner (Kelle, 2006). When queried using this method, our participants disclosed numerous detailed accounts surrounding the context and content of their anxieties and other mental health experiences. Taken together, it seems likely that differences in information-gathering methods underpin the discrepancy in child-reported mental health concerns observed between Study 1 and Study 2 in the current project. Findings underscore the value of utilizing child-focused clinical interviews in neuropsychological practice. When used in conjunction with rating scales, a clinical discussion with the child can be a central component in identifying psychological problems and understanding the impact of brain injury. Formal or informal interviews with children can ensure that clinicians make appropriate

diagnoses and provide relevant recommendations and referrals (Spence, 2018; Summerfeldt et al., 2020).

Limitations and Future Directions

There are several important limitations within the current project. A self-selection bias likely impacted the families that chose to enroll in our research, given that time, commuting, childcare requirements, and family stress pose a significant barrier to research participation. Families that are better-resourced are generally more likely to contribute their time to scientific research, which in turn, limits the generalizability of findings. In line with this assertion, frequency distributions of our family variables revealed positively skewed data for parent mental health and family functioning variables, indicating that parents more frequently reported good mental health and high levels of family functioning. A generally high functioning parent sample posed a limitation within the current study and restricts the conclusions that can be drawn regarding these family variables. Additionally, children who chose to participate in our qualitative study may have systematically differed from children who underwent quantitative procedures but refused to be interviewed.

There were also limitations encompassing the quantitative group comparisons that utilized inferential statistics. With respect to the cognitive status of our participants, the control group was slightly advanced in intellectual functioning, attaining a mean score within a high average range of performance. High average scores within the control sample may have impacted statistical comparisons by inflating the difference between groups. Despite acceptable power analysis results, statistical comparisons may have been impacted by small sample sizes. Research on rare neurological pediatric populations is characterized by small sample sizes, and the current study is no exception. In addition to reduced stroke group recruitment, our exclusion

criteria further restricted eligible participants; however, this was necessary for ensuring the representativeness of the pediatric stroke sample.

We would also like to acknowledge the high proportion of college and university educated parents. Our stroke and control samples generally reported moderate to high family income, which impacted analyses involving socioeconomic status. A positive correlation between child mental health and socioeconomic status was not made within the current study, despite the fact that this relationship has been documented in the literature. For example, there is strong evidence to show that children from families living in poverty have a heightened risk for depression, anxiety, antisocial behavior, and dropping out of school (Leventhal & Brooks-Gunn, 2000; Poulain et al., 2020). Mental health risk appears greatest in families of lowest socioeconomic status, and a threshold effect may result in a weaker relationship in families of moderate to high socioeconomic status (Peverill et al., 2021). Future research can overcome some selection-bias through purposeful sampling of families with fewer economic and social resources. We also recognize the high proportion of White/European origin families in our study, which further restricts generalizability. This is particularly relevant given increased mental health disparities for racialized and marginalized communities (Liu & Modir, 2020; D. X. Rodriguez et al., 2021).

It is important to note that difficulties with learning, executive attention control, and reduced motor speed can be both a cause and symptom of internalizing symptoms (e.g., low mood), and directionality cannot be inferred from cross sectional analyses (Calvete et al., 2013). For instance, as suggested earlier, motor and cognitive difficulties may result in poor self-perception, decreased self-esteem, and low academic performance, thereby increasing risk for low mood (Homaifar et al., 2014). However, low mood can produce psychomotor slowing,

inattention, and difficulty sustaining effort on learning tasks (Verboom et al., 2014). The potential for bidirectional variable relationships must be taken into consideration when contemplating causality surrounding mental health. Follow-up longitudinal studies are recommended for untangling directionality and the complex timing of these variable relationships.

Limitations associated with thematic analysis research include lack of statistical representativeness and difficulty validating results and confirming generalizability of findings to the larger clinical population (Queirós et al., 2017). Results can be difficult to replicate given that each interview is unique (semi-structured) and dialogue between each participant and the interviewer is a co-constructive process (Griffin, 2002). The analytic procedure involves interpretation on the part of the researcher, and the impact of personal biases, hypotheses, and preconceptions must be consistently reviewed and monitored (Rogers, 2018; Saldana, 2011). The primary researcher actively engaged in theoretical memoing and personal reflection throughout the analytic process, but bias cannot be completely eliminated. The thematic analysis that was undertaken in Study 2 was a reflexive process that did not pretend to be neutral. All qualitative research is influenced by the coder, and the resulting categories reflect researcher interpretation. Furthermore, various theoretical qualitative camps make differing claims about the applicability of findings; for instance, a Constructionist would assert that results mainly provide insight into the individual perceptions of pediatric stroke patients, which are based upon highly personal experiences. In contrast, a Critical-Realist researcher would be more likely to make a claim about the objectivity of participants' experiences in order to glean information about potential trends and commonalities (Brulé, 2021). Regardless, causality between variables and events cannot necessarily be inferred from interview data alone.

Given that Study 2 participants were a subset of individuals that participated in Study 1, a self-selection bias may have fundamentally altered the sample characteristics of the participants that were interviewed, and could partially account for the discrepancy in child-reported mental health concerns observed between studies. For instance, self-selection bias may have acted to increase the concerns reported in Study 2, as youth with adverse experiences (e.g., bullying and peer rejection) may have been more motivated to be interviewed and share their perspectives. Notably, Study 2 participants did not statistically differ in their demographic, clinical, quality of life, or psychosocial characteristics when compared to Study 1 pediatric stroke patients that did not progress to Study 2. However, the children and youth who were qualitatively interviewed may have systematically differed on variables and characteristics that were not effectively captured in quantitative measures from Study 1.

With respect to memories of stroke and characterization of the condition, Study 2 generated themes surrounding “vague recollection”, “too young to remember”, and “it’s in the past” as a result of the young age at which participants experienced stroke. In order to encapsulate the experience of stroke in later childhood, it will be important for future qualitative research to selectively recruit children that experienced stroke within the 6-12 years age range. Lack of representation from this rare stroke age group represents a Study 2 limitation that likely impacted the generation of qualitative themes surrounding the depiction of the stroke event and its significance in daily life. Future qualitative interviews can explore memories of pre- and post-stroke functioning to gather the lived experience of pediatric stroke survivors who were more recently and vividly impacted by acquired brain injury. Content may be less optimistic and could potentially indicate the presence of a personally traumatic event. Relatedly, stroke in young and middle-aged adults has been associated with higher rates of posttraumatic stress disorder (PTSD)

due to the stress and fear associated with surviving a significant adverse health event (Garton et al., 2017).

Conclusion

The current project utilized a comprehensive mixed methodology framework in the investigation of post-stroke psychosocial outcomes in order to expand upon the current literature and examine previously unexplored relationships surrounding mental health risk. Our results suggest that considerable variability exists in the mental health presentation of pediatric stroke patients. Pediatric stroke survivors appear to be a resilient group of children with regard to mental health, despite the fact that many patients have experienced adversity and setbacks relative to their same-aged peers. A subset of our stroke participants demonstrated concerning levels of mental health difficulties in one or more areas of functioning, however, with anxiety representing a salient domain. Regression analyses and qualitative interviews highlighted the relevance of physical disability, learning disability, cognitive functioning, and peer/family social support in the psychological presentation of children and youth. Clinically, the results of the current project assist with identification of stroke patients that are at increased risk for manifesting significant and impairing internalizing problems. In this regard, findings emphasize the importance of early treatment and the coordination of services to meet the multiple, complex needs of children and youth with stroke.

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Appendices

Appendix A: Demographic Questionnaire

DEMOGRAPHICS AND HISTORY QUESTIONNAIRE

Please note that you can skip any questions that you do not want to answer

SECTION 1: GENERAL INFORMATION

In your own words, describe any concerns that you may have about your child's physical or cognitive development, school (e.g., reading, writing, math), behaviour, or social/emotional development:

- a. _____
- b. _____
- c. _____
- d. _____

SECTION 2: DEVELOPMENTAL HISTORY

1. What is your child's handedness?: LEFT RIGHT BOTH

2. Has your child ever had or been diagnosed with (if yes, please provide more information):

ADHD	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Anxiety	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Autism Spectrum Disorder	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Depression	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Diabetes	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Epilepsy	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Febrile Convulsion	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Gifted and Talented	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Head Injury	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Hearing Problems	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Hospitalization	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Language Disorder	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Learning Disability	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Operations	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Other Chronic Illness	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Other Psychiatric Illness	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____
Premature Birth	<input type="checkbox"/> no	<input type="checkbox"/> yes – explain: _____

Sensory Difficulties no yes – explain: _____
 Thyroid Dysfunction no yes – explain: _____
 Vision Problems no yes – explain: _____
 Other no yes – explain: _____

3. Did / Does your child have trouble with any of the following? Please circle any problems and check off if they were from the past or are current concerns:

	Problem in the past that has resolved	Ongoing problem currently
Anxiety		
Low mood		
Self- Confidence		
Making Friends		
Interacting with Peers		
Understanding Social Cues		
Fatigue/Energy Level		
Understanding Humour		
Complying with Rules & Requests		
Frustration Tolerance		
Regulating Emotions		
Disinhibited or Inappropriate Behaviour		
Being Teased or Bullied		

If yes, please explain:

Has your child, either now or in the past, received psychological help or therapy? If yes, please describe the type of therapy, when it was received, and for how long:

SECTION 3: SCHOOL HISTORY

1. Current Grade: _____ Placement: Regular _____ Resource: _____ Special Ed.: _____
2. Any difficulties at school with the following?

	Problem in the past that has resolved	Ongoing problem currently
Attention		
Hyperactivity		
Math		
Reading		
Spelling		

4. Does anyone in the family (or extended family) have a history of **emotional or psychiatric illnesses** (e.g., depression, anxiety, schizophrenia)? If yes, who? What type of mental illness?

5. What is your child's native (first) language? _____

6. If not English, at what age did your child start speaking English? _____

7. What other languages are used in your home? _____

8. What is the highest educational level of the mother? (please circle a number below)

- 1 = some elementary school;
- 2 = completed elementary school;
- 3 = some high school;
- 4 = completed high school;
- 5 = some college;
- 6 = completed college;
- 7 = university degree;
- 8 = postgraduate degree

9. What is the mother's job? _____

Currently employed? Yes/No
Full-time or Part-time?

10. What is the highest educational level of the father? (please circle a number below)

- 1 = some elementary school;
- 2 = completed elementary school;
- 3 = some high school;
- 4 = completed high school;
- 5 = some college;
- 6 = completed college;
- 7 = university degree;
- 8 = postgraduate degree

11. What is the father's job? _____

Currently employed? Yes/No
Full-time or Part-time?

12. Does your child have a job? Yes/No

If yes, what is the job? _____

How many hours per week on average? _____

13. Household Income: (please circle)

- < \$30,000
- \$30,000 - \$49,999
- \$50,000 - \$89,999
- \$90,000 - \$139,999
- \$140,000 - \$199,999
- \$200,000 - \$299,999
- Over \$300,000

Appendix B: Semi-Structured Qualitative Interview

Introduction

Now I'm going to ask you some questions about your life, like how you've felt these past few weeks, how school is going, how you feel with your family, and some other things. There are no right or wrong answers, I just want to hear from you. Please try to tell me as much information as you can so that I can best understand your experiences. But if you feel uncomfortable answering a question, you don't need to answer it. Just tell me and we'll move on to the next question. You can ask me to stop anytime during the interview if you decide that you don't want to continue. That's totally okay. If we think that you are becoming upset by the questions then we will stop the interview.

Remember that I will be tape-recording our conversation. Everything you say will be kept confidential. (*Younger kids: do you know what that means? It means everything you tell me is private and will stay between you and me. I won't repeat it to anyone.*) Your name is not written on the tape, so no one will know it is you. If you are not sure what a question means or what I am asking about, please ask me. You will not get in trouble for anything you share. You can ask me questions anytime during the interview.

Ok, we're almost ready! Thank you for agreeing to talk with me. I'm going to ask you questions because I want to learn from you and from other kids and teens who have had a stroke what your experiences are like. What you tell me can help doctors and researchers like me better understand what life is like when you've had a stroke, and we can work on finding ways to better help in the future.

Before we start, do you have any questions for me? (.....) Let's begin.

Stroke

- How did you learn about your stroke?
 - Do you remember it or were you too young?
 - Do your parents talk about your stroke? What do they say?
- Do you feel that your stroke has affected you in daily life? How so (academically, socially, emotionally etc)?
- Does your stroke influence your family in any way? How? (e.g., do your parents worry about your health or your abilities?)
- Do you feel different from others because of your stroke? How are others different from you? How well do people know/understand you?
- Are you treated differently because of your stroke? By family? Peers?

- What are your hopes / goals for the future? Do you ever think about your stroke when planning for the future? (If yes, have them expand)
- Are there any good things that have happened because of your stroke?
- Do you talk to other people about your stroke (family, friends)? Do you feel like you can? What is it like to talk about your stroke?
- Is there anything about your life that you would change?
- What do you feel are your strengths (things that you are very good at)?

School (this section will be administered to participants who are in elementary school or high school)

- What grade are you in? What school are you in?

Academic motivation and self-esteem

- Do you feel that school is important? What about learning? Grades? Why/why not?
- Tell me some of the best things about school.

Potential Prompt:

- Tell me about a time at school when you felt proud.
- What do you do well in school?
- Do you compare yourself to other students sometimes?

Potential Prompts:

- How do you think you're different and how do you think you're alike?
- Do you feel like you work as hard as your classmates to get the same grades? More, less?

Academic performance and difficulties

- Tell me about the difficult parts of school and what you feel might be hard for you.

Potential Prompts:

- Why do you think you're experiencing these difficulties?
- Do you get any help in school, like less homework or extra time for tests? (i.e. do you have any accommodations?)
- What does it feel like when you [problem child mentioned] (e.g. blank out, can't focus, class too loud, teacher speaking too quickly)?

- Tell me about how you feel in a classroom. Are you comfortable? Are you shy?

Potential Prompts:

- Do you raise your hand and talk easily? (versus staying quiet)
 - How do you feel when you are called on by the teacher? (Nervous to talk? Shy? Comfortable? Supported?)
 - Do you give oral presentations sometimes, or give a talk? What's that like?
- Are there ever times when you can't finish a test, or you can't stay in class? Tell me about that. What happens?

Potential Prompts:

- What is usually the problem (e.g., headache, fatigue, difficulty speaking)?
- Do you usually have trouble explaining why to the teacher immediately? If yes, what do you do? (e.g., leave anyway, stay, get a friend to explain)
- How do you feel in that moment?
- How do you feel later?
- Do you tell your teacher about it later? Do you talk to them yourself, or does someone else talk to them (e.g., friend, parent)?

School Coping

- Do you ever get tired in school? What does that feel like (mental fatigue vs physical fatigue)?
- What do you do when you need a break, or when you need to get up and walk?
Older participants: do you feel like you advocate for yourself, to make sure you're getting what you need? In what situations do you typically self-advocate? How do you feel about it? (e.g., independent, frustrated, heard, ignored?)
- Do you have any techniques or tricks to help yourself learn better? (e.g., note-taking, breathing...)
- Let's talk about your teachers. How do you feel about your teachers?

Potential Prompts:

- Can you tell me about some good and bad times with your teachers recently?
- Is there anything you wish your teachers understood about you and how you learn?
- If you had your own teacher and you could tell them the best ways for you to learn, what would you say? i.e. What could teachers do to help you learn better?

- Let's say you had a friend who also had a stroke and who was having trouble going back to school. What advice would you give him/her?

Social Relationships with Peers

- I'd like to know about your friends. Tell me about your friendships.
 - Potential Prompts - Inquire as to number, closeness, context, age. For example:
 - Are they acquaintances (i.e., people that you are friendly with but don't hang out with much) or are they close friends?
 - What kinds of things do you like to do with your friends? (common activities and interests)
 - Are your friends the same age as you or are they older/younger? (If friends are of a different age grouping, enquire as to why they think that is).
- How easy is it to make friends? How about keeping friends over time ... is that easy or difficult? How come?
- Do you ever get into disagreements/fights with your friends? How often and what about? Conflict resolution?
- Have you ever had any problems with peer pressure or bullying? When? What happened?

Relationships with Family

- How would you describe your relationship with your family? Who are you most/least close to in the family? Why is that?
- Was there ever a time when you would argue a lot with your parents? What was that like? (inquire about reason, frequency, and if/how conflict is resolved)
- What kind of things do your parents stress about? Does it affect you?

Anxiety Now I'm going to ask you some questions about emotions...

- Most people have fears or things that they worry about. What kinds of things do you worry about? Tell me about that.
- Do you think you worry more than other people your age? How much of the day do you spend worrying?

Potential Prompts:

- Was there ever a time when you felt uptight or tense a lot...like you just couldn't relax and felt on edge? (If answer is yes): I'm interested in hearing about an example of this, if you can give

one.

- Some people worry a real lot about what other people think about them. Is this true of you? (If yes): Tell me about this. Did you worry that other people thought you were stupid or that you did things funny?
- Some people feel very shy around others that they don't know. They feel as if they just can't say anything. Do you ever feel like that? What is that like? How long does it usually take you to warm up?
- Question for children and youth: Some kids really hate to answer questions in class, talk or present in front of others, go to parties, join clubs, or eat in front of other kids (ask about all situations). Do any of these things ever really bother you? Which ones make you feel the most uncomfortable? What is that like?

Mood

- On a scale from 1 to 10, with 1 being very sad and 10 being very happy, how would you rate your mood?...
 - On most days?
 - At home?
 - With friends?
 - At school?

(Enquire about areas of low or high ratings. What is different about that context)
- Have you ever felt sad, blue, down, or empty? What sorts of things make you feel this way? How often?
- Can other people tell when you are sad? How can they tell?

Coping

- When you are sad, angry, or worried, are there certain things that you do to help yourself feel better? Are there things that make it worse?
- If you're having a bad day is there someone that you can talk to about it? Are there certain people who understand you better and can help you with your worried or sad feelings? Who?

Potential Prompts:

- There are many things that people do when they have negative feelings. Have you done any of the following lately:
 - Distraction? (e.g. hobbies and fun activities)

- Relaxation (e.g., listening to music, deep breathing, counting to 10)
- Retreating? (being alone)
- Aggression? (e.g., kicking or punching something, yelling at others)
- Seeking help from others? (e.g., parents, friends)

➤ **Is there anything else that you would like to share?**

Appendix C: List of Qualitative Categories

Table 14. *Higher-order qualitative categories and their defining properties*

Category	<i>n</i>
Life with Stroke	
No Memory of the Stroke	12
Stories About my Stroke	9
How my Stroke Affects Me	14
Missing Out	10
Health Precautions and Risks	3
Feeling Different from Others	10
Rehab and Recovery	5
Positive Framing	4
Who I Am	
Feeling Unique and Special	11
Giving Back	6
Finding my Role in Society	13
Learning and Training	12
Making and Keeping Friends	
Upfront with Friends About my Stroke	7
Careful About Sharing Stroke History with Friends	6
Making Friends is Tough	7
Slow to Warm Up	7

Loneliness	4
Close Friends Offer Support	8
Mutual Interests and Similarities	11
Bullying and Peer Pressure	9
Thinking and Feeling	
Shyness and Social Anxiety	12
Test Anxiety	5
Imagining Worst-Case Scenarios	5
Positivity and Optimism	5
Hiding my Sadness	7
Isolation	7
Strategies to Feel Better	12
Trouble with Thinking	9
Changed Brain	9
Impact on School	
School is Hard	10
Feeling Overwhelmed	9
Helpful Learning Strategies	11
Teachers are Important	7
Good Aspects of School	5
Family Support	
Family Closeness and Shared Values	12
Source of Comfort	7

Parent Advocacy	5
Power Struggle	6
Parental Worries and Anxiety	8