AUTOBIOGRAPHICAL MEMORY IN YOUTH WITH STROKE

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ABSTRACT

Autobiographical memory (AM) consists of both memory for specific past personal events (episodic memory) and personal facts (semantic memory). An increasing amount of research has explored short term memory in youth following pediatric arterial ischemic stroke (AIS), however little work has been done examining long-term memory such as AM in this population. In the current study 28 youth with stroke and 32 age and sex-matched controls were administered the Children's Autobiographical Memory Interview (cAMI). Youth with stroke showed deficits in the recall of episodic AM, and overall memory recall in comparison to controls. Furthermore, there were significant relationships between area of stroke, lesion lateralization, and time since stroke and specific memory scores. This study unveils, to our knowledge that pediatric stroke is associated with a selective deficit in AM. These results have implications for the adjustment of youth following pediatric stroke, so that earlier diagnosis of memory deficits can occur and early implementation of intervention programs can be put in place to allow these youth to function maximally.

Key words: Pediatric Stroke, Memory, Autobiographical Memory, Neuropsychology

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Chapter 1: Literature Review

Pediatric stroke is an important cause of acquired brain injury in children (Fuentes et al., 2016), becoming increasingly recognized as such by health professionals and the public alike (Kirton & deVeber, 2009). Pediatric stroke can occur perinatally (i.e., several weeks prior to an infant's birth up to 28 days after birth) or during childhood (i.e., between 29 days and 18 years of age). Stroke is defined as "the abrupt onset of a focal neurologic deficit, such as disruption in strength, speech, vision, or cognition that is consistent with a vascular distribution" (Festa, Lazar, & Marshall, 2008, pg. 363), having an incidence rate of 25-37 per 100,000 infants and 1-13 per 100,000 children. Stroke is one of the top 10 causes of childhood death, with a mortality rate of 3.1 per 100,000 in children under 1 year (deVeber et al., 2000; Hartel et al., 2004). These statistics are likely to be an underestimate 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 (Cardenas, Rho, & Kirton, 2011). Complex long-term neurocognitive impairments commonly occur in this population, rendering youth with stroke particularly vulnerable to memory and learning difficulties. This dissertation examines long term memory, namely autobiographical memory (AM) in youth with and without histories of stroke, beginning with the first chapter which comprises a comprehensive literature review. The second chapter in this dissertation consists of the clinical study examining AM in pediatric stroke, followed by the final chapter summarizing key clinical implications and conclusions from the findings of the clinical study.

Pediatric Stroke

Mechanisms

Understanding the pathophysiology of stroke is imperative to appreciating its impact on the developing brain. Stroke occurs because of a disruption in the normal blood flow in the brain, which deprives the constituent cells of oxygen and nutrients and may ultimately lead to permanent tissue damage, referred to as an infarction (Festa et al., 2008). Strokes are classified according to three types: arterial ischemic stroke (AIS; stroke that results from an obstruction of blood flow caused by a narrowing or blood clot in an artery), cerebral sinovenous thrombosis (CSVT; stroke caused by a blood clot formed in the venous system of the brain), and intracranial hemorrhage (stroke caused by bleeding in the brain or subarachnoid space) (Festa et al., 2008). The population included in this dissertation comprises youth who have experienced an AIS. AIS is responsible for approximately half of all childhood stroke occurrences. AIS occurs when a blood clot or narrowing artery causes a significant restriction of blood flow to a particular region of the brain, resulting in neuronal death to this brain tissue. Two major mechanisms of AIS are thrombosis or embolus. A thrombotic stroke occurs when a blood clot (i.e., a thrombosis) forms locally on an artery or blood vessel and blocks the blood flow. On the other hand, an embolic stroke occurs when an intravascular mass (i.e., an embolus, such as a blood clot or piece of tissue) has detached itself from its point of origin and travels through the vascular system, eventually lodging itself into an artery or vessel and occluding blood flow.

The three main arteries supplying the brain are the anterior cerebral arteries (ACAs), middle cerebral arteries (MCAs), and posterior cerebral arteries (PCAs) (Blumenfeld, 2010). The majority of perinatal strokes involve the territory of the left MCA (Stiles et al., 2010). The MCA splits into superior and inferior divisions in the Sylvian fissure, which supply the lateral cortex

above and below the Sylvian fissure, respectively (Blumenfeld, 2010). Specifically, the superior division supplies the insula, frontal lobe, and superior parietal regions, while the inferior division supplies the temporal and inferior parietal lobes (Festa et al., 2008, 364).

Risk Factors

Stroke can be fatal, and potentially devastating, causing permanent neurological problems in 50% to 80% of childhood survivors (Cárdenas et al., 2011). Recurrence rates of childhood AIS may reach 30% (Bernard, 2007; Lynch, Pavlakis, & Veber, 2005), thus understanding the associated risk factors of pediatric stroke is crucial. The leading risk factor for AIS infarcts is arteriopathy (i.e., disease of the arteries), with research reporting frequency rates of 50-80% with stroke (Amlie-Lefond et al., 2009; Beslow & Jordan, 2010). Commonly identified arteriopathies in pediatric stroke include Moyamoya disease (i.e., cerebrovascular disorder characterized by occlusion of the distal internal carotid arteries) and sickle cell disease (i.e., genetic blood disorder in which red blood cells are abnormally shaped) (Ciceri et al., 2011). Furthermore, congenital heart disease (i.e., structural heart defect present at birth) accounts for about 15-30% of cases of pediatric stroke (Ciceri et al., 2011; Friedman, 2009). Other cardiac conditions associated with risk of stroke include cardiomyopathy (i.e., chronic disorder of the heart muscle), cardiac tumors (i.e., abnormal growths in the heart), carditis (i.e., inflammation of the heart), endocarditis (i.e., inflammation of the endocardium, the innermost lining of the heart), artificial valves (i.e., device used to repair/replace damaged heart valves), and arrhythmias (i.e., abnormal heart rhythm) (Freidman, 2009).

Infections account for about one-quarter of pediatric strokes (Pavlakis & Levinson, 2009). Common infections associated with pediatric stroke include varicella (i.e., chicken pox), encephalitis, and meningitis (Ciceri et al., 2011; Fox & Fullerton, 2010; Friedman, 2009).

Infections are thought to lead to stroke via a systemic inflammatory response or infection of the endothelium (Pavlakis & Levinson, 2009). Moreover, common hematologic disorders linked to pediatric stroke include sickle cell disease, thrombophilias (group of genetic or acquired conditions associated with an increased risk of thrombosis), and iron deficiency anemia (Ciceri et al., 2011; Friedman, 2009; Pavlakis & Levinson, 2009). Sickle cell disease is the most important hematologic disorder associated with pediatric stroke, as the risk of stroke is 200 times greater in children with sickle cell disease than other children (Ciceri et al., 2011). Left untreated, more than 10% of pediatric patients with sickle cell disease will experience a stroke by 20 years of age (Ohene-Frempong et al., 1998).

For reasons that are not well understood, there are a significantly greater proportion of males affected by pediatric stroke (approximately 1.5:1) regardless of age, stroke subtype, or history of trauma (Golomb et al., 2009). Black children also have a greater incidence, even after accounting for higher rates of sickle cell disease (Cardenas et al., 2011). Additional risk factors for pediatric stroke include head trauma, malignancy, chemotherapy, toxins/drugs, and dehydration (Friedman, 2009). A variety of maternal risk factors have been associated with perinatal stroke, including history of infertility, preeclampsia (i.e., condition in pregnancy characterized by hypertension and kidney problems), chorioamnionitis (i.e., placental infection), emergency caesarean section, oligiohydramnious (i.e., low levels of amniotic fluid), infection during pregnancy, coagulation disorders, and older maternal age (Pavlakis & Levinson, 2009). Finally, between a third and a half of all pediatric stroke patients have idiopathic, or unexplained stroke with no associated risk factors (Lynch et al., 2002).

Clinical Presentation

Presentation of neurological symptoms of pediatric stroke depend on a variety of factors, including the underlying cause or risk factor, location and size of the lesion, and the age at time of stroke. Childhood stroke symptomatology may include acute hemiparesis, seizures, vertigo, lethargy, and dysphasia. Half of AIS perinatal strokes are asymptomatic and diagnosed retrospectively upon noticing that the child has an early hand preference or motor asymmetry around 6 months of age, indicating hemiparesis. Conversely, symptomatic perinatal AIS may be diagnosed more quickly if the infant suffers from seizures within the first few weeks of life. Initial clinical presentation of stroke varies more in children than in adults, particularly since brain injury is being sustained in a period of rapid brain development. As a result of this disruption, youth with histories of AIS have a multitude of different impairments such as intellectual disability, neurocognitive deficits, socio-emotional difficulties, mental health issues, seizure disorders, motor impairments, and cortical sensory problems (Max et al., 2002). A majority of pediatric stroke survivors possess deficits in a wide variety of neuropsychological domains, including intelligence, executive functioning, language, visual spatial abilities and memory (Allman & Scott, 2013; Everts et al., 2008, Härtel et al., 2004, Nass & Trauner, 2004; O'Keeffe et al., 2012; Westmacott et al., 2009).

Neuropsychological Profile

Intelligence

A majority of pediatric stroke survivors suffer from neuropsychological sequelae across a wide range of cognitive domains. Studies focused on general intellect have documented that children with stroke often perform at the lower end of the average range on measures of general intellectual functioning (Hajek et al., 2014; O'Keeffe et al., 2017; Westmacott et al., 2009),

typically between scaled scores of 90 and 95 (Everts et al., 2008; Max et al., 2002; O'Keeffe et al., 2012), however, there is wide variation in full scale IQ also frequently reported (e.g., range full scale IQ = 52–132). In addition, scores on full scale IQ and index measures are often significantly lower than normative population means (Ganesan et al., 2000; Hajek et al., 2014; O'Keeffe et al., 2014; Westmacott et al., 2009, 2018). Children with stroke consistently perform significantly lower on full scale IQ, verbal IQ, and performance IQ than healthy siblings (Schatz & Buzan, 2006). Some studies report that intellectual functioning after pediatric stroke remains relatively stable over time (Aram & Eisele, 1994; Ballantyne et al., 2008), while other studies reveal emerging cognitive deficits during the school-age years (Westmacott et al., 2009). Multiple factors likely account for this variability in intellectual outcomes, including age at stroke, age at assessment, lesion characteristics, and presence of seizure disorders. However, there is a consensus that stroke patients have overall intellectual functioning in the lower end of the average range (O'Keeffe et al., 2017).

Executive Functioning

Difficulties with executive functioning are especially common, and typically span attentional control, cognitive flexibility, goal setting, and information processing. Several studies have shown that children with a history of stroke have performed in the low average range and scored significantly lower than the normative population, indicating deficits in attentional control, cognitive flexibility, sequencing, switching, working memory, information processing, and behavioral aspects of executive function (Murphy et al., 2017; O'Keeffe et al., 2014). 30% of participants in one sample were impaired on these executive function tasks (O'Keeffe et al., 2014). Parents and teachers also identified significant difficulties in the areas of behavioral and emotional regulation, metacognitive skills, and global everyday executive function abilities

(Deotto et al., 2019; O'Keeffe et al., 2014). According to a recent review by Rivella and Viterboi (2021), children with stroke had lower performance in executive functioning tasks, in particular inhibition, relative to typically developing children. Five out of the 22 studies reported lower scores in inhibitory processes than in working memory processes or cognitive flexibility, regardless of age at stroke onset or lesion characteristics (Araujo et al., 2017; Bosenbark et al., 2018, 2017; O'Keeffe et al., 2012; Westmacott, McDonald, deVeber et al., 2018). Most studies also show that an older age at stroke onset was related to better performance in executive functioning (Bosenbark et al., 2017; Fuentes, Westmacott et al., 2017; Westmacott et al., 2009). An interesting result was reported by Westmacott et al. (2009), who found an interaction between the age at stroke onset and lesion location. In fact, they found that in a group with subcortical lesions, the perinatal group had significantly poorer results in working memory than both the 1-month-old to 5-year-old group and the 6- to 16-year-old group. In contrast, in the cortical group, lower scores were found for children aged from 1 month to 5 years. In the combined cortical-subcortical group, there were no differences related to the age of onset. These results suggest that there are different periods of vulnerability for working memory deficits depending on the lesion location and subcortical involvement.

Language

Children with stroke generally perform relatively well on language assessments, with no significant differences reported on expressive or receptive language measures (Block, Nanson, & Lowry, 1999) and the majority (73%) perform in the average or above average range on receptive skills (Ganesan et al., 2000). However, children with stroke show persistent difficulties in higher-order language abilities (e.g., discourse, semantics, etc.) (Avila et al., 2010; Chapman et al., 2003). For example, children required extra time to complete complex language tasks

accurately (Block et al., 1999); phonological and syntactic impairments were noted in 40.6% of a group of children with stroke, even when conversational language and pragmatics were not impaired (Avila et al., 2010). Children with stroke were also found to produce a greater number of lower-level concrete interpretations, significantly shorter sentences, and lower scores in measures of information content and organization than control groups (Chapman, et al, 2003). Chevignard et al. (2016) identified impairment in children with stroke on four language skills tested (receptive and expressive, semantic, and syntax) with significant impairment (scores < 2 SD) in 53% of the group for word finding, 38% for syntactic comprehension, and 47% for syntactic expression. Furthermore, functional neuroimaging findings indicate the reorganization of language areas to the right hemisphere following left perinatal stroke, regardless of the extent of the lesion (Tillema et al., 2008).

Visual-Spatial Processing

Children with histories of stroke demonstrate persistent deficits in visual-spatial processing (Akshoomoff et al., 2002; Nass & Trauner, 2004; Schatz et al., 2000). Impairments have been reported on visual–motor integration (Max et al., 2004), visual construction (Mosch et al., 2005), and perceptual motor skills (Everts et al., 2008). On drawing tasks, young children with perinatal stroke show evidence of impairment regardless of the side of the lesion (Akshoomoff et al., 2002; Stiles, et al., 1997). A double-dissociation in global-local processing has consistently been reported in the pediatric stroke literature, with children with damage to the right hemisphere showing difficulty with processing overall visual patterns and children with damage to the left hemisphere showing deficits in processing details (Schatz et al., 2000; Stiles, 2008). These findings confirm the right hemispheric specialization of visual-spatial processing present early in development.

Memory and Learning

Characteristics of memory and learning outcomes following perinatal stroke are currently limited with mixed findings. Of the few studies investigating memory outcomes following perinatal stroke, most have found memory deficits compared to controls (Hajek et al., 2014; Lansing et al., 2004; Westmacott et al., 2009), although some evidence has also been presented demonstrating no significant group differences (Bosenbark et al., 2018). Findings report subtle, non-lateralized verbal memory deficits in children with histories of stroke relative to controls (Block et al., 1999; Lansing et al., 2004). The verbal learning and memory profiles of children with histories of stroke is characterized by reduced encoding (i.e. process by which sensory information is modified and stored in the brain), lower use of learning strategies to enhance recall, and reduced delayed free recall and recognition (Lansing et al., 2004). Poorer immediate memory performance has also been identified (Kolk et al., 2011), and some weaknesses in visual memory recall were also found (Allman & Scott, 2013), which may be associated with visuospatial difficulties. Jacomb et al. (2018) examined longitudinal changes in memory scores over time and found that children with stroke present with very little improvement or decline in their verbal memory abilities. Perinatal stroke is associated with poorer performance overall (Lansing et al., 2004). In addition, evidence indicates that children with stroke secondary to sickle cell disease display deficits in prospective memory (McCauley & Pedroza, 2010). A recent study by Virani et al (2022) found that participants with a history of perinatal stroke performed significantly worse with medium effect sizes on all scaled scores of the Child and Adolescent Memory Profile (CHAMP; Sherman & Brooks, 2015). The worse performance on tasks of both verbal and visual learning and memory in this population compared to healthy controls is important as there is scant literature having examined memory test validity in this population.

More research is needed to explore a broad range of memory functioning namely long-term memory functioning.

Stroke Sequelae

Cognitive functioning following pediatric stroke can depend upon several factors, including age at injury, time since stroke, lesion location and laterization (Max et al, 2010). Researchers have postulated that the developmental stage of the brain at the time of injury may influence outcomes but have not yet reached a consensus regarding whether age at onset correlates directly with recovery (Allman & Scott, 2013). A large population-based study of children with AIS found that 69% of children aged less than 1 year at time of stroke had poor functional outcome, compared with 49% of children who had stroke at an older age (Mallick et al., 2016). However, U-shaped trends have also been identified for cognitive domains, such as executive function, along with inconsistent findings about predictive risk factors suggesting that further research is clearly warranted (Max et al, 2010). There is ongoing debate around the plasticity or vulnerability of the developing brain following early brain injury, such as stroke (Hartel et al., 2004). The dominant position for many years, named the *plasticity hypothesis,* supports the theory that the increased plasticity of a child's brain, compared to that of an adult, facilitates reorganization after stroke injury (Max et al, 2010). For example. scientists found that pediatric patients suffering from left hemisphere lesions showed considerable plasticity and reorganization for language function compared to adults (Ballantyne et al., 2008). In opposition to this theory, some researchers have uncovered increasing evidence supporting an *early vulnerability hypothesis,* which suggests that younger brains may be more vulnerable to trauma (Westmacott et al., 2009). Children are less likely than adults to exhibit deficits that specifically map on to lesion location and lateralization, but research has shown that an early brain injury

may lead to more widespread cognitive dysfunction across multiple domains compared to a later brain injury (Banich et al., 1990). Early injury is thought to disrupt the course of myelinization, thereby rendering the developing brain less capable of supporting higher-level cognitive skills, such as working memory (Max, 2004). Moreover, Westmacott et al. (2009) point out that, because later-maturing brain regions rely on the development of early-maturing brain regions, damage in one brain region early in development has the potential to disrupt the maturation of other brain regions later in development. Consequently, children often "grow into" their deficits later in development and show difficulties in higher-order cognitive skills (Westmacott et al., 2009). Mixed findings have been reported regarding the precise age range associated with the best cognitive outcomes. For example, some researchers have reported that the best outcomes are associated with stroke occurring between 5 and 10 years of age (Everts et al., 2008; Nass & Trauner, 2004) while others have found that the best outcomes are associated with stroke occurring between 1 and 5 years (Allman & Scott, 2013). A recent study by Abgottspon et al., (2022), showed a non-linear effect of age at stroke on cognitive outcomes, suggesting that stroke during a critical period of cognitive development has a particularly detrimental effect on outcomes. This is further supported by neuroimaging research, revealing that functional and structural brain development is a nonlinear process with critical periods for plasticity as well as maturational processes (Gogtay, et al. 2004).

Furthermore, the relationship between age at stroke and cognitive outcomes has been reported to be moderated by lesion location (Westmacott et al., 2009; Nass & Trauner, 2004). Stroke can occur in multiple regions of the brain and prior studies of lesion location and outcomes following pediatric stroke have often divided ischemic infarction analysis into injury that has affected cortical, subcortical, or combined areas (e.g., Westmacott et al., 2009).

Cognitive sequelae are more severe in children with stroke involving both cortical and subcortical regions (i.e., infarct involving the cortex plus basal ganglia and/or thalamus) compared to stroke affecting either cortical or subcortical regions alone, even after accounting for lesion size (Westmacott et al., 2009). The well-documented lateralized linguistic, cognitive, and emotional differences reported following left and right hemisphere stroke in adulthood are not as clearly defined following childhood stroke (Mosch, Max, & Tranel, 2005).For instance, many studies did not find a significant effect for lesion laterality, the difference in affected hemispheres in the lesioned brain, in language recovery after perinatal stroke (Ballantyne et al., 2008; Trauner et al., 2013; Westmacott et al., 2009). However, left hemisphere perinatal stroke patients whose language dominance has shifted to the right hemisphere as a compensatory part of the recovery process, have been found to have relatively poor language outcomes (Mosch, Max, & Tranel, 2005).

Summary

Childhood stroke is defined as cerebrovascular events that occur from 29 days of life up to 18 years of age. AIS is responsible for approximately half of all childhood stroke occurrences. The basic mechanisms of AIS include embolus and thrombosis. Although numerous risk factors have been identified in pediatric stroke, an understanding of the underlying etiology remains unclear in many cases, with one-third being idiopathic and half presenting with more than one risk factor (Friedman, 2009). The most common etiologic categories for pediatric stroke include cardiac disorders, arteriopathies, infections, and hematologic disorders. The vascular territory most implicated in pediatric stroke is the left MCA. Given that the MCA supplies blood to brain structures that are critical for language (i.e., Broca's area, Wernicke's area), motor functioning (i.e., motor cortex, striatum, globus pallidus, internal capsule), sensation (i.e., sensory cortex), it

is not surprising that blockages affecting this circulation can result in a wide variety of neurologic sequelae.

Neuropsychological difficulties are a major area of clinical research interest in childhood stroke. While IQ levels of children with stroke are often at the lower end of the average (Hajek et al., 2014; O'Keeffe et al., 2014; Westmacott et al., 2009) or low average range (Chevignard et al., 2016; Jacomb et al., 2018), a larger proportion of children with stroke remain at the lower end of the normative distribution than would be expected in the general population (O'Keeffe et al., 2017; Westmacott et al., 2018). Childhood stroke affects expressive and higher-level language functions. While there is inconsistency surrounding memory and visuospatial domains, subtle deficits can occur. There is strong evidence that children with stroke are particularly vulnerable to deficits in the areas of cognitive flexibility, working memory, speed of information processing, encoding, attention, and other executive functions including behavioral and emotional regulation. These impairments have a significant impact on general intellectual abilities and the acquisition of new information. Long-term memory, namely AM, represents a domain that has been largely unexplored in children with histories of stroke, therefore rendering our understanding of the neuropsychological profile of this population incomplete.

Autobiographical Memory (AM)

Memory is not a unified ability but rather a set of dynamic, integrated systems (Squire 2004) and can be broadly conceptualized as consisting of two major systems, declarative and nondeclarative memory. Nondeclarative memory includes multiple subsystems including procedural knowledge, such as knowledge of how to do things, skills, and actions that are well-practiced and done with little to no conscious awareness, including most forms of conditioning and priming (Squire 2004). In contrast, declarative memory is explicit and available to consciousness. This is the form of memory that encompasses AM. AM includes both specific details about past experiences as well as

world- and self-related knowledge in which those experiences are embedded. These domains align with the distinction between episodic or semantic AM as delineated by Tulving (1972). Episodic AM refers to remembering specific past events and involves the recollection of vivid sensory, perceptual, and emotional details, such as one's 10th birthday (Addis et al., 2004; St-Laurent, Moscovitch, Levine, & McAndrews, 2009; Tulving, 2002). Semantic AM refers to the recollection of personal facts, traits, or general self-knowledge, independent of any sense of re-experiencing a past event (e.g., the name of one's elementary school; Levine et al., 2002; Tulving, 2002).Tulving coined the term autonoetic awareness to describe the subjective state of mental time travel that marks a recollected event as part of one's personal past, a specific hallmark of episodic AM (Tulving, 2002) differentiating itself from semantic AM and other forms of declarative memory.

The Socio-Cultural Developmental Model

The Socio-Cultural Developmental Model of AM proposed by Nelson and Fivush (2004), notes how AM is a fundamentally distinctive form of memory that emerges across development. According to the model, AM involves basic memory abilities, as well as a developing an understanding of temporal relations, narrative, self and of mental states. The theorists argue that memory of self in the past is embedded within a social cultural milieu in which particular forms and contents of experiences are valued and shared (Nelson & Fivush, 2004). The theory notes how there is a gradual emergence of AM across the preschool years. More specifically, episodic AM is associated with a later and more gradual developmental trajectory across childhood than semantic AM. The model also notes how language is a fundamental socio-cultural tool in the development of the AM system and that there are cultural and individual differences in AM across the lifespan (Nelson & Fivush, 2004). As such, AM is accounted for within developmental, cognitive, and cultural perspectives. Another important assumption of this theory is that AM incorporates many different concepts and skills such as narrative understanding,

temporal concepts, self-concepts and consciousness, and that each of these social processes follows a different course of development (Nelson & Fivush, 2004).

Figure 1 outlines how the sources and sequence of the emergence of AM occurs during the early childhood period. According to the model, this system is socially constituted, in that what is remembered is a function of the social cultural context within which the child lives. The child experiences social interactions from birth, and from these emerge the intentionality of others and self and a core self. Intentionality means that infants act on goals and understand that others do as well (Tomasello, 1999) and the concept of the core self is that infants are aware of their own goals and actions in distinction to those of others (Damasio, 1999). The developmental process from this point involves the infusion of new skills and social experiences. For example, the first two additions to the system are the beginnings of language comprehension and expression and the establishment of the cognitive self. As infants become language-using toddlers, parents begin to engage in talk about past and future events with them, helping to assist a child's developing concept of time in terms of specific temporal position, a necessity for establishing order in AM (Nelson & Fivush, 2004). Emergent capacities of language development such as complex syntax and semantics are established, and extended discourse through stories and conversations come to be understood and participated in (Nelson, 1996). Conversations and stories also foster a newly emerging sense of the distinctiveness of self and others. This level also recognizes the differences between mental states of the self and of others that are evident in theory of mind (Nelson, 2003). Experience with different forms of narrative particularly in conversation about personal episodes, provides a model for organizing one's own episodic memories. The changes that take place in the early childhood years are integrative across social and cognitive systems. There is continuity across development into adulthood as

each of these different cognitive influences comes into play and intersects with the others within the social and cognitive system of the developing child, creating a dramatic change in the capacity of memory for personal episodes (Nelson & Fivush, 2004). Given this, the development of AM should be further examined in special populations such as youth with pediatric stroke. It is postulated that children who display delays and/or deficiencies in the development of these cognitive and social factors can help us elucidate capacity and expression of AMs and the correlations with neurological factors underlying this type of memory.

Figure 1

The Socio-Cultural Developmental Model

"Figure 1 has been removed due to copyright restrictions. It was a photograph of the *Socio-Cultural Developmental Model*. Original source: Nelson, K., & Fivush, R. (2004). The emergence of autobiographical memory: A social cultural developmental theory. *Psychological Review, 111,* 486-511. https://doi.org/10.1037/0033-295X.111.2.486"

Note. Hypothetical relations in developments from 1 to 5 years of age leading to the emergence of autobiographical memory (AM). Large arrows indicate more direct influence; double-headed arrows indicate reciprocal influences. Years (yr.) in the bottom scale indicate approximate age when influences come into play on average in normal development. Areas above the center are presumed to be endogenous and those below more exogenous as sources of development (Nelson & Fivush, 2004)

Functionality

AM is a personal history that defines who one is across time and contexts, thus providing a sense of continuity and coherence for an individual, intimately linking to one's self concept (Conway, Singer, & Tagini, 2004). One critical aspect of self-knowledge is the sense of a self temporally extended in time that provides continuity of experience. For example, individuals with dense amnesias who are unable to recall specific past experiences self-report a keen sense of loss and that they are no longer "themselves" (Hirst 1994). Furthermore, AMs are framed within social-cultural narratives of a life that help define self in relation to others. As such, AMs serve to create and maintain social and emotional bonds with others (Fivush 2008). Research indicates that even children as young as 8 years know what a typical life within their culture looks like and what events are most likely to happen though the knowledge of life scripts (Bernsten & Bohn 2010), and this information is carried into adolescence and adulthood.

Furthermore, intergenerational narratives such as family stories of one's parents and their parents before them, provide more specific frames for defining self in relation to others (Fivush, Bohanek, & Zaman, 2011). These kinds of stories serve to create a sense of connection to family, and it has been found that adolescents who know more of these stories and tell these stories in more detailed and elaborated ways show higher levels of identity achievement and emotional well-being (Nelson & Fivush, 2004). Research has indicated that sharing the events of our lives with others is a frequent and important social activity and there is a clear human tendency to tell others about our experiences to maintain social bonds (Pillemer, 2021). Reminiscing is also intimately related to both physical and psychological health (Nelson & Fivush, 2004). In terms of memories of specific autobiographical events, a substantial body of research demonstrates that the ability to create emotionally coherent narratives of specific stressful experiences is related to well-being (Frattaroli 2006). For example, individuals who can construct narratives that provide

explanatory frameworks and resolve emotional experiences subsequently display higher levels of self-reported well-being, better physical health as indexed by doctor visits and immune system functioning (Nelson & Fivush, 2004). Also, individuals who share the positive events of their day with others also show higher levels of emotional well-being (Frederickson 2001). Thus, the way in which we remember and share specific autobiographical events bears significantly on our well-being.

Developmentally, children learn how to create more elaborated and coherent autobiographical narratives through participating in adult-guided reminiscing (Nelson & Fivush, 2004). Mothers who reminisce about emotional experiences with their children in more elaborated and coherent ways have children who show higher levels of emotional understanding and regulation (Nelson & Fivush, 2004). More specifically, mothers who provide more explanations and emotional expressions when recalling highly stressful events with their children have children who show higher levels of coping skills and lower levels of depression and anxiety (Fivush & Sales 2006). Individuals who can create more coherent life narratives that span their childhood and early adulthood and create a coherent story of self, show higher levels of emotional well-being (McAdams 2001). In particular, individuals who are able to create a life narrative that presents difficult and stressful life experiences as opportunities and springboards for growth show higher levels of identity achievement in adolescence and emerging adulthood (McLean, Pasupathi, & Pals, 2009), generativity and emotional well-being in middle adulthood (McAdams 2001), and a sense of integrity and acceptance in old age (Webster 2001). Thus, AM is pivotal to our sense of self and is imperative to one's well-being across development, serving as a core element of human functioning.

Autobiographical Memory in Typically Developing Children and Youth.

Much of our understanding of AM is based on investigations of autobiographical event narratives through interviews. Interviews allow for a description of AM events in addition to participant's thoughts and emotions related to the event (Nelson and Fivush, 2004). The research displays that AM and the ability to narrate a past event emerges quite early during the preschool years (Nelson and Fivush, 2004). Narrative skills continue to develop and become more complex through into middle childhood into adolescence. Based on the studies that have examined both episodic and semantic AM in childhood, research suggests that both components have different developmental trajectories (Nelson and Fivush, 2004).

Episodic AM and semantic AM are highly interconnected, especially during the early stages of retrieval when personal semantic knowledge can aid memory search and retrieval operations (Conway and Pleydell-Pearce, 2000). Typically, early investigations into the emergence of episodic AM relied on retrospective studies requiring adult to recall and date their earliest AMs. The results of these studies indicated that few AMs predated the age of 2 years with the majority of adults' earliest memories clustering around the ages of 3 or 4 years (Rubin, 2000). The apparent absence of episodic AM during the early years of life (i.e., the period reflecting infantile amnesia) is thought to be due to immature brain functioning, particularly poor encoding and storage of details associated with specific events (Rubin, 2000). However, during the period of infantile amnesia evidence suggests that infants develop early forms of semantic memory before they develop episodic AM. For instance, studies using deferred imitation (e.g. repeating a series of actions following a delay) have shown that infants as young as 6 months of age exhibit early forms of memory, as they are able to retain contextual information about object-action events after a delay (Meltzoff, 1995). Because infants often generalize this newly

learned information to other domains and do not appear to spontaneously re-experience the past learning episode (i.e. reflecting autonoetic consciousness) or integrate into the temporal continuity of their lives, this early form of memory maybe classified as being more semantic in nature rather than episodic (Bauer and Dow, 1994).

Other studies examining young children noted how children can remember specific facts about past events (e.g., a school trip) even after lengthy delays (Fivush & Hammond, 1990) however this event knowledge mostly included personal semantic details, fragmentary, and heavily dependent on the provision of retrieval cues or prompting questions by adults (Fivush & Hammond, 1990; Newcombe, Lloyd, & Ratcliff, 2007). Another recent study by Kian et a., (2021) examined 4-to 10-year olds' autobiographical event narratives to determine what types of event details and facts are recalled in narratives from a week-long experience at a local zoo. It was found that children included a relatively high number of fact-like details in their narratives, and consistent with prior findings there were age-related improvements in narrative length. The improvements in AM across development are thought to be due to maturation in the hippocampus (Bauer, 2006). The hippocampus is a medial temporal lobe structure that is known to play a crucial role in the formation, consolidation and retrieval of episodic AMs (Moscovitch, 2008). More specifically, the hippocampus binds patterns of neural activity present at the time of encoding into a memory trace that can be sustained and retained over time (Eichenbaum and Bunsey, 1995). Numerous lesion studies have shown that patients with hippocampal damage exhibit deficits in episodic AM, but not semantic AM, indicating that episodic AM is more critically dependent on the hippocampus than semantic AM (Addis, Moscovitch, & McAndrew, 2007). These findings also suggest that the development of episodic AM corresponds to the development of other cognitive abilities such as executive functioning modulated by the

prefrontal cortex (Picard et al., 2009). The prefrontal cortex has been identified as a critical region for AM retrieval because it controls self-referential processing (i.e., processing personal information), as well as memory search, retrieval, and evaluation processes, through its interactions with the hippocampus and medial temporal lobe (Buckner & Wheeler, 2001). Given that the hippocampus and prefrontal cortex both exhibit prolonged structural and functional maturation during childhood and adolescence, episodic AM continues to develop during adolescence due to improved neural connectivity between the hippocampus, prefrontal cortex, and other core regions of the AM neural network. Howe and Courage (1993) have demonstrated, using self-recognition mirror tests, that the emergence of episodic AM and the offset of infantile amnesia correspond with the development of the cognitive self. This knowledge structure enables children to recognize that the self is continuous over time, having a past and a future, which then allows them to organize and integrate personally experienced events within their self-concept (Howe, Courage & Edison, 2003). Without this form of self-awareness, children are unable to encode and store events as subjective experiences that are integrated within the personal self. Thus, a fully developed cognitive self seems to be an important prerequisite for the initial emergence of episodic AM, as children cannot encode, store, or retrieve events as personally relevant without this capacity (How et al., 2003). Despite an extensive literature on the emergence and development of episodic AM across early childhood, few studies have examined age-related changes in both episodic and semantic AM beyond the age of 5.

The first study to examine this by Piolino et al. (2007) used an adapted version of the Autobiographical Memory Interview (AMI; Kopelman, Wilson, & Baddeley, 1989) to investigate differences in episodic and semantic AM, as well as autonoetic consciousness in 42 children between the ages of 7 and 13 years. Significant age-related improvement were observed

in recollecting and re-experiencing specific childhood events, whereas semantic AM showed no significant change with age (Piolino et al., 2007). Importantly, this study was the first to demonstrate that episodic AM develops over a prolonged period into adolescence. In a second more refined study, Piolino and colleagues (2007) found significant improvements in both episodic and semantic AM across childhood in 6- to 11-year-olds. Furthermore, they found that age-related improvements in episodic AM across childhood were associated with age-related improvements in semantic AM, general episodic memory, and executive functioning (Picard et al., 2009). Thus, episodic AM has been associated with steeper developmental trajectory from childhood into adolescence relative to semantic AM (Picard et al, 2009).

Both studies provided novel data on episodic and semantic AM during childhood, however their assessment of episodic and semantic AM was based on separate tasks that were not matched for psychometric properties. For example, episodic AM was measured using the TEMPAu task, in which examiners provided subjective ratings (i.e. on a four-point scale) of the overall specificity of participant's recollection of childhood events (Piolino et al, 2007). In contrast, semantic AM was measured using a questionnaire requiring participants to list personal facts. (e.g., childhood heroes, home address, names of friends, and hobbies; Piolino et al.,2007). Thus, it may be difficult to make direct comparisons of age-related changes in episodic and semantic AM, due to possible task-related confounds (Levine, 2004). Given that episodic AMs are often embedded within semantic contexts that link episodic AM details with personal facts, it would be particularly informative to examine whether the number of episodic and semantic AM details recalled within a single autobiographical narrative change across childhood and adolescence. Thus, using an objective measure of AM that effectively dissociates episodic AM from semantic AM within a single task is warranted. Thus, a study by Willoughby et al., (2012)

was the first study to investigate age-related changes in episodic and semantic AM performance across both childhood and adolescence (i.e, beyond the age of 13), using the Children's Autobiographical Memory Interview (cAMI; Willoughby et al., 2012). The cAMI effectively dissociated episodic and semantic AM within a single autobiographical narrative, provided an objective and reliable measure of episodic AM (i.e., total number of details recalled), which was subdivided into specific subcategories of details (i.e., event, place, time, perceptual, and emotion/ thought details) and non-episodic details (i.e., semantic, repetitions, other metacognitive statements, and external events). It also incorporated a standardized qualitative rating system as an additional measure of episodic re-experiencing and allowed for the examination of different levels of retrieval support (Levine et al., 2002). It was found that episodic and non-episodic AM both improved between 8 and 16 years of age; however, age-related changes were larger for episodic AM than for non-episodic AM. In this same study, higher self-ratings of visual intensity and strength of episodic AMs were significantly related to the greater number of total episodic, time, and perceptual details. Furthermore, participants who indicated greater confidence in the accuracy of their recollections provided more perceptual and emotion/ thought details. Therefore, across development, episodic and semantic AM can be differentiated by their distinct properties, most notability their differences in their developmental trajectories and their underlying neural activations.

Autobiographical Memory in Older Adults

There is a wealth of research studying AM on the other side of the lifespan in older adults which document normal age-related deficits in episodic AM, with a relative sparing of general semantic knowledge (Levine et al., 2002; Tromp et al., 2015). Episodic details may become more difficult to retrieve with age as age-related changes to the brain may cause memory

retrieval to be compromised (Craik & Grady, 2002). A network approach to studying AM has become dominant over the past decade and has contributed to our understanding of how memory functions in the brain. With respect to structural connectivity, the fornix which is the main pathway from the hippocampus relates to the amount of episodic detail in AMs (Hodgetts et al., 2017; Memel et al., 2020; Rudebeck et al., 2009). The uncinate fasciculus, which connects the rostral (including medial temporal) lobes and the ventral, medial, and orbital prefrontal cortex (Schmahmann et al., 2007), is involved in self-referential processing of autobiographical information, along with a sense of phenomenological re-experiencing of AMs (Memel et al., 2020). The structural integrity of the inferior longitudinal fasciculus, connecting the anterior temporal lobe and the occipitotemporal fusiform gyrus, correlates with semantic AMs (Hodgetts et al., 2017; Memel et al., 2020). Neuroimaging studies in adults have also shown that episodic AM retrieval tends to activate the hippocampus and parahippocampal gyrus to a greater extent than semantic AM retrieval (Maguire, 2001). The pattern of reduced episodic AM specificity in normal aging corresponds with structural changes, including reduced medial temporal lobe volumes (Dickerson et al., 2009; Head et al., 2008), particularly in the hippocampus (Allen et al., 2005).

Substantial research has found age-related decline in both components of AM in the number of event-related details of episodic AM (Addis, Wong & Schacter, 2008; Levine et al., 2002; Piolino et al., 2003), and in changes in the specificity of AMs (Piolino et al., 2003). Episodic and semantic AM is typically examined using the Autobiographical Interview (AI; Levine et al. 2002). In the AI, participants are probed for memories pertaining to five time-periods (early childhood, adolescent–teenage years, early adulthood, middle age, and the previous year), and participants are typically requested to report just one memory for each

period. Each reported memory is then coded for the amount of episodic and non-episodic details generated (including personal semantic AM). AM studies of healthy older participants frequently reported fewer event-related details than younger subjects (e.g., Addis et al., 2004; Addis et al., 2008; Levine et al., 2002; Piolino et al., 2003) and AM in older adults appeared more generalized and less specific than AM reported by younger subjects (e.g., Piolino et al., 2003). The shift of specificity of event-related memories to more generic event memories in aging represents a process of generalization and is known as a semanticising in late adulthood. Regarding semantic AM, studies have shown that this part remains largely unaffected by age-related changes in normal aging (e.g., Levine et al., 2002; Piolino et al., 2003). However, a pronounced decrease of semantic personal facts is typically associated with the progression of Alzheimer's dementia (Berntsen, Kirk & Kopelman, 2022).

A recent study examining AM in older adults with Alzheimer's found that the temporal distribution for personal semantic information in Alzheimer's showed a time gradient steadily decreasing from middle childhood to present life (Berntsen, Kirk & Kopelman, 2022). In comparison, the temporal distribution of episodic memories produced by Alzheimer's patients in response to the memory interview showed a predominance of AMs from age 6 to 30, followed by a steep drop in memory referring to events that had occurred after age 30 (Berntsen, Kirk & Kopelman, 2022). Therefore, memory for autobiographical events in the aging population shows a more rapid decline in episodic AMs relative to semantic AMs in both the healthy aging population and Alzheimer's population.

Autobiographical Memory in Clinical Populations of Children and Youth

AM has been studied in various pediatric clinical populations, further adding to our knowledge of the neurological basis of memory systems. For example, hippocampal damage on AM performance has provided an important avenue for investigating the role of the hippocampus and associated regions in episodic and semantic AM. Vargha-Khadem and colleagues have examined episodic and semantic memory performance in children and adolescents with developmental amnesia, which is a condition characterized by selective bilateral damage to the hippocampus (i.e., a 20-50% reduction in hippocampal volume) due to a brief period of hypoxic ischemia (i.e., a lack of oxygen to the brain; Vargha-Khadem et al., 1997; 2003). These patients showed deficits in episodic AM, verbal episodic memory (i.e., story recall), delayed visuospatial memory, and everyday memory, but had preserved semantic memory (de Haan, Mishkin, Baldweg, & Vargha-Khadem, 2006; Maguire, Vargha-Khadem, & Mishkin, 2001; Vargha-Khadem et al., 1997; 2003). Interestingly, de Haan et al. (2006) noted that the episodic memory impairments exhibited by this group of patients were not apparent until late childhood, thus lending support to the hierarchical model of AM development because their impaired episodic AM appears to have developed later than their intact semantic memory. Studies of patients with developmental amnesia indicate that severe hippocampal damage results in impairments in episodic AM and delayed visuospatial memory and these impairments appear to be associated with significant alterations in patterns of hippocampal activation during episodic AM retrieval (Maguire et al., 2001; Vargha-Khadem et al., 1997). Vargha-Khadem et al.'s (1997) study was instrumental in showing that verbal episodic memory, delayed visuospatial memory, and everyday memory are critically dependent on the hippocampus, whereas semantic memory appears to be relatively unaffected by early hippocampal damage.

Similar outcomes of reduced hippocampal volume and blunted hippocampal neurogenesis has been observed in children and youth with brain tumours, more specifically medulloblastomas (Sekeres et al., 2018). Radiotherapy profoundly affects the developing brain and such hippocampal and extrahippocampal abnormalities affect AM in this population. Using the cAMI, episodic and non-episodic details for events that either preceded or followed treatment was observed. For post-treatment events, patients reported fewer episodic details compared with control participants. For pretreatment events, patients reported equivalent episodic details compared with control participants (Sekeres et al., 2018). Therefore, children and youth that had radiotherapy to treat brain tumours are also a population susceptible to AM deficits.

A study by Lah et al. (2018) investigated AM in children with severe closed traumatic brain injuries (TBI) and healthy controls of comparable age, sex, and socioeconomic status using the cAMI. It was found that children with TBI recalled significantly fewer episodic details relative to controls, but the between-group difference was eliminated when specific probes were provided. The groups did not differ in either recall of external details or in ratings of events' phenomenological qualities. The gap between the groups in recall of episodic details increased with age, as the greater number of episodic details was associated with older age in the control group, but not in the TBI group. Poorer verbal memory and lower IQ were related to recall of fewer episodic details in the TBI group (Lah et al., 2018). This study highlighted that severe child TBI is associated with a selective deficit in AM that involves episodic, but spares non-episodic details which include semantic AM, and identifies the risk factors for this impairment. These findings of deficits in episodic AM with relative sparing of semantic memory continue to be consistent across both normative and clinical populations of children and youth.

Clinical populations such as children and youth with hypothyroidism displayed similar patterns of results in episodic and semantic aspects of AM. A study by Willoughby, McAndrews, & Rovet (2013) investigated AM in children aged 9 to 14 years, including those with early-treated congenital hypothyroidism and women with inadequately treated hypothyroidism (a critical substrate for hippocampal development) during pregnancy alongside typically developing controls. Results showed that relative to controls, patients in the hypothyroidism groups both exhibited weaknesses in episodic AM, but not non-episodic AM. In particular, the hypothyroidism groups showed difficulty in recalling event details (i.e., the main happenings) and visual details from past experiences. Overall, this study highlighted the importance of thyroid hormones for early neurodevelopment and long-term memory performance. Another study by the same authors (Willoughby, McAndrews, & Rovet, 2014) further assessed the accuracy of AM in typically developing youth and children and youth with hypothyroidism and those exposed to hypothyroidism in utero using a staged autobiographical event and the cAMI. It was found that children with hypothyroidism and early exposure to hypothyroidism in utero differed significantly in the number of accurate episodic details recalled and proportion accuracy scores, with controls having more accurate recollections of the staged event than the thyroid-deficient group (Willoughby et al., 2014). Total hippocampal volumes and anterior hippocampal volumes were positively correlated with proportion accuracy scores. Taken together, the results of both studies indicate that children and youth with early thyroid deficiency or early exposure to hypothyroidism had deficits in not only the recall of episodic AM but also the accuracy of their autobiographical events.

Studies of patients with temporal lobe epilepsy have shown that damage to the hippocampus is also associated with significant impairments in episodic AM, verbal episodic

memory (e.g., word list recall), and delayed visuospatial memory, but relatively intact non-episodic AM and general semantic memory (Noulhiane et al., 2007). Temporal lobe epilepsy has been linked to significant cellular damage in both the CA1 field and dentate gyrus, as severe seizures occurring early in life can significantly alter neural circuitry within the hippocampus (Velez-Pardo et al., 2004). A study by Gascoigne and colleagues (2013) was the first to systematically examine AM in children with temporal lobe epilepsy. Compared to controls, children with temporal lobe epilepsy recalled fewer episodic details, but only when no retrieval prompts were provided using the cAMI. There was no difference between the groups in number of non-episodic autobiographical details. Similar findings were discovered in a second study of children with idiopathic generalized epilepsy (Gascoigne et al., 2015). It was found that compared to controls, children with generalized epilepsy recalled significantly fewer episodic details, even when retrieval prompts were provided, but no differences were found again between non-episodic autobiographical details. It was also found that age at epilepsy diagnosis was related to episodic autobiographical memory, where children diagnosed later recalled more episodic details. Therefore, a range of pediatric conditions including developmental amnesia, brain tumours, traumatic brain injury, hypothyroidism, and temporal lobe epilepsy have patients who have displayed a loss of episodic details in comparison to semantic details for their AMs. Overall, converging evidence suggests that episodic AMs are a hallmark deficit in patients who sustained damage or injury to hippocampal and associated regions during development.

Summary

AM involves a widespread cerebral network operating as a multifaceted higher-order cognitive process that has been deemed a central element of human functioning (Nelson & Fivush, 2004; Fivush, 2019). The Social-Developmental model notes how AM is accounted for

within developmental, cognitive and cultural perspectives, and different social processes integrate to lead to the emergence of AM in the developing child. As a complex form of cognition, AM serves many purposes (Conway & Pleydall-Pearce, 2000). It provides a means through which one may access general knowledge, interpret behaviour in a social context, exchange experiences, and remain oriented in a shared social world (Nelson & Fivush, 2004). AM is found to play a very significant role in everyday life and adaptive functioning (Gascoigne et al., 2013), and contributes much to daily interactions with others as the retelling of personal events provides others with a sense of who we are and being able to recount these with good detail enhances the nature of our interpersonal communication.

Typically developing pediatric populations show age-related improvements particularly in episodic AM, and semantic AM may help to facilitate episodic AM recall. Across the aging population there is a pattern of preserved semantic AM in comparison to episodic AM. These trends are also reflective in atypically developing pediatric populations such as patients with developmental amnesia, TBI, tumours, and temporal lobe epilepsy where episodic AM deficits manifests themselves more profoundly than non-episodic AM, which included semantic AM. Youth patients with stroke are another particularly susceptible clinical population to AM deficits given that stroke has been associated with damage to the widespread cerebral networks involved in memory formation and retention.

No study to-date has investigated AM in paediatric stroke youth patients. Given the known memory and learning deficits in this population, the lack of research in this area represents a notable gap that needs to be addressed for several reasons. Potential AM impairments in children and youth with stroke may lead to difficulties in later adolescence and adulthood, thus examining the adolescent experience of AM is pivotal. Youth who have

experienced a stroke in childhood will have memories of pre-stroke normative functioning, which may create a heightened awareness of current difficulties. Similarly, parents of childhood stroke patients may also have to adapt to new neurological difficulties and problems in their youth 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 youth's perceived identity from early development and integrated into their self-concept. McAdams (2001) found that during late teens and mid-twenties individuals begin to organize their AMs in life narratives in order to achieve a sense of unity and purpose. Youth with stroke who have deficits in AM recall may have trouble achieving this critical milestone. This in turn may adversely impact social functioning or limit youth's independence and productivity during adulthood (Butler & Zeman, 2008). A comprehensive understanding of the memory experiences of paediatric stroke patients is essential, as it will facilitate opportunity for timely interventions that can improve outcome. Therefore, this research has implications for the adjustment of youth with histories of stroke and will lead to intervention programs to improve AM in this population.

Chapter 2: Clinical Study

Objectives and Hypotheses

This chapter consists of the clinical study aiming to examine AM in pediatric stroke. More specifically, the primary aim of this study was to examine AM in paediatric stroke patients recruited within the Children's Stroke Program at the Hospital for Sick Children and age- and sex-matched youth without stroke using the Children's Autobiographical Memory Interview (cAMI; Willoughby et al., 2012). The cAMI employs a standarized, reliable system by which to derive measures of episodic and non-episodic memory from participants' transcribed autobiographical protocols, and therefore allows for the direct comparison of episodic and non-episodic recall in patients and controls. Episodic details were assigned to episodic detail subcategories: (a) event, (b)place, (c) time, (d), perceptual, and (e) emotion/thought. The remaining details were considered non-episodic and were assigned to non-episodic detail sub-categories which included a) personal semantic facts b)external event, place, time, perceptual, and emotion/thought, c)unsolicited repetition of previously recalled details and d) other metacognitive statements. This analysis added to our understanding of the content and quality of the AM accounts in pediatric stroke patients. With regards to cognition, study measures focused on the assessment of intelligence, and overall memory functioning. In the interest of taking a developmentally oriented theoretical approach, we also looked at the effects of age at stroke and area of stroke on memory outcomes. Ultimately, this study aimed to utilize a comprehensive method in the investigation of AM in order to expand upon the current literature. The following hypotheses were put forth for the present study:

1. It was hypothesized that youth with a history of stroke and healthy controls would display significant group differences in neuropsychological tests of memory and intelligence.
    a. It was predicted that youth with a history of stroke would display poorer performance on both the CHAMP and the WASI, with lower scores on overall memory and intellectual functioning, respectively.

2. a. It was hypothesized that there would be significant group differences in AM recall on the cAMI between patients with stroke histories and healthy controls.
    i. It was predicted that patients with stroke would exhibit fewer episodic details on the cAMI compared to healthy controls. Furthermore, as an exploratory analysis, it was hypothesized there would be differences in the sub-categories (i.e. event, time, place, perceptual, thought/emotion) of episodic AM details between the group with those with stroke providing fewer details in each of these categories.

    b. It was predicted that there would be no significant differences in non-episodic AM recall between patients with stroke histories and healthy controls, as such no differences were expected in the sub-categories (i.e personal semantic facts, external event, place, time, perceptual, and emotion/thought, unsolicited repetition, and other metacognitive statements) of non-episodic AM details.

    c. It was hypothesized that there would be significant differences in the phenomenological ratings of the cAMI between the two groups.

    i. It was predicted that youth with stroke histories would report lower ratings across all questions in comparison to healthy controls.

3. It was hypothesized that there would be a relationship between stroke-related factors and AM recall.
    a. It was predicted that stroke factors such as age of stroke and area of stroke (i.e. both subcortical and cortical lesions) would be related to more deficits in AM episodic recall in comparison to non-episodic details in the stroke group.

Method

Participants

This study examined youth between the ages of 12 and 21 years with and without histories of stroke. The age range of participants was selected based by the measures that were administered in this study. A statistical power analysis was performed for sample size estimation. A power analysis using the G-Power computer program (Faul et al. 2007) indicated that a total sample of 56 participants would be needed to detect large effects (d=0.8) with 90% power using a t-test between means with a 1-tailed alpha at .05. Thus, a total of 60 youth were recruited for the present study. The stroke group comprised of 28 participants with a mean age of 14.86 years. Participants with stroke were recruited from the Children's Stroke Program at The Hospital for Sick Children who are also enrolled in the Canadian Pediatric Ischemic Stroke Registry (deVeber et al, 2017). Recruitment criteria for the group with stroke consisted of the following: (1) one or multiple ischemic strokes 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) moya moya disease; and (6) neurological disorders (e.g. head injury, malignancy).

The criteria did not exclude youth with learning disabilities or Attention-Deficit Hyperactivity Disorder (ADHD), as the literature has shown that attention and academic problems are common in the pediatric stroke population (Williams et al., 2017). Thirty-two sex-matched controls were recruited for the study, with a mean age of 15.75 years. Recruitment criteria for the control group was: (1) free of stroke and aged 12-21 years at the time of testing (2) fluency in English. Exclusion criteria for the control group included: (1) premature birth (less than 36 weeks' gestation); (2) hypoxic-ischemic encephalopathy; (3) sickle cell disease; (4) psychosis; (5) moya moya disease; (6) neurological disorders (e.g., head injury, malignancy, etc.) and/or (7) they had a condition that could impact neurodevelopment (e.g., epilepsy, diabetes, thyroid dysfunction etc.).

Stroke participants were stratified by age at stroke, which was defined as follows: 1) perinatal stroke (occurrence of stroke in the prenatal period or during the first 28 days of life); 2) stroke at 1 month to 5 years; and 3) 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, Isaacs, & Muter, 1994; Westmacott, et al., 2010). With regards to stroke participants' current age at the time of the study, we recruited participants in the following age categories: pre-teen and early adolescence (12-14 years), adolescence (15-18 years), and early adulthood (19-21 years). Stroke participants were also stratified according to the following lesion locations: 1) subcortical lesion: an infarct restricted to 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. A total of 10 participants with cortical lesions were recruited, 11 with subcortical lesions and 7 with combined subtype. With regards to gender as a variable, the sample comprised of slightly more males than females given that pediatric stroke is sex dimorphic. Previous studies indicated that males are clearly more vulnerable to suffering stroke and represent approximately 60% - 65% of the paediatric stroke population (Fuentes et al., 2016). Accordingly, we had no more than 65% of the sample as male, thus we had 15 males and 13 females in the stroke group.

Neuroimaging Data and Medical Records

As a component of patient care and assessment at the Hospital for Sick Children, 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 review MRIs and CT scans of stroke patients at hospital clinic visits and code lesion location according to subcortical, cortical, or combined lesion presentation, as described above. This information was used in the current study to examine the significance of lesion location as a predictor of AM. Medical records facilitated the stratification of patients according to age at stroke, as described within the above 'participants' section. Medical records were used to obtain recent information on neurological status of stroke patients.

Procedure

A telephone recruitment procedure was used to contact families who had indicated interest in research and had provided consent to be contacted including young adults who were previous patients of the Children's Stroke Program. Previous patients had their medical chart data reviewed only during the time that they were enrolled in the program. (i.e., up to the age of 18

years). If inclusion criteria were met, participants' caregivers provided written consent. All written consent was administered online using REDCap (Research Electronic Data Capture), a secure web application, and housed on a secure server (see Appendices A and B for patient and control consent forms, respectively). Participants accessed a unique survey link via email to electronically sign the written consent form and fill out the background demographic questionnaire.

Typically developing youth were recruited through online community advertisement such as Facebook or were siblings and friends of paediatric stroke patients if the youth indicate interest and consent to participation. Upon receiving an email from a control participant that was interested in the study, an email template outlining the details of the study was sent. Upon indicating interest, the study coordinator scheduled an appointment time for the Zoom Health video call via email. Before the call, the consent form was sent via REDCap giving the participant ample time to review and complete the form. At the beginning of the Zoom Health video call, the consent form was reviewed alongside participant eligibility. Eligibility was assessed by the study coordinator by asking the participant questions outlined in the eligibility screener. If inclusion criteria were met, the written consent was retained and the demographic questionnaire was completed by the study coordinator with the participant, followed by memory testing and interviewing. If the inclusion criteria were not met, the participant was notified that they are not eligible for the study, and their consent form was immediately and permanently deleted from REDCap.

All data collection took place online with data being secured on REDCap and the Hospital for Sick Children server. A complete description of the study and its objectives was provided to youth including a discussion regarding the consent document via Zoom Health

videoconferencing, a secure online video conferencing platform (https://zoom.us/healthcare) prior to commencing testing procedures. Before each session, youth received a meeting invitation link via email. This information was required to access the Zoom platform to participate in the video conference testing. Participants were not required to own a Zoom account or to provide identifying information to access Zoom. Zoom automatically adjusts for 3G, Wi-Fi, or wired modes of logging on, optimizing the best experience for each participant. The recommended minimum bandwidth for meetings is 600kbps for HQ video and 1.2MBps for HD video. In 2010, over 85% of Canadian households had access to high-speed internet which is sufficient to support online video conferencing (Satellite internet connections), which are often available in rural or remote areas, will support the Zoom platform (McConnaughey et al., 2013). Furthermore, recent validation studies have found there to be no significant difference in results obtained in in-person versus remote videoconference assessment sessions or change in performance across sessions for teleneuropsychologial assessments in a pediatric sample (Harder et al, 2020; Ransom et al., 2020). In total, the project took approximately 1-1.5 hours.

During testing sessions, participants in both stroke and control groups were administered the following:

1. Children's Autobiographical Memory Interview (cAMI)
2. Child and Adolescent Memory Profile (ChAMP)
3. Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II)

Patients who have been administered intelligence tests within the past year as part of their Paediatric Stroke Program assessment did not receive the WASI-II. This reduced practice effects and ensured efficiency, as these youth already had valid and reliable scores for cognitive functioning. At the conclusion of testing, participants were provided with compensation, which

consisted of their selection of an Amazon or Indigo e-gift card and a certificate for community service volunteer hours. Compensation was emailed directly to the participant after the completion of the study.

Measures

Children's Autobiographical Memory Interview (cAMI; Willoughby et al., 2012). The Children's Autobiographical Interview was used to assess AM in participants. For the cAMI task, participants were required to recall two autobiographical memories that occurred more than one month ago (see Appendix C for cAMI instructions). All participants administered the cAMI were also provided with a sample list of life events, in order to help them identify appropriate events to describe in the assessment, although participants were free to recall any event, irrespective of the suggestions contained in the list (see Appendix D).

The cAMI has three distinct phases: free recall, general probe, and specific probe. In the Free Recall condition, participants describe the memory in as much detail as possible in a 5-minute time span. General probes were then provided in order to encourage the recall of additional details. In the event of a vague or non-specific memory being recalled, participants were asked to clarify the event during this condition. Finally, in the Specific Probing condition, specific questions were asked regarding the memory (e.g., "When did this event take place?") from a standardized series of questions about the event, pertaining to time, location, sensory/perceptual and emotional/cognitive details. On completion of all conditions of the cAMI, participants were asked to rate each memory on each of the following domains: ability to visualize the event (1=cannot see it at all, 7= really clear), change in emotions before to after the event (1= no change, 7=lots of change), current personal importance of the event (1=not important, 7=most important event), personal importance at time of event (1=not important,

7=most important event), frequency of memory rehearsal (1=once every few years, 7=everyday), confidence about the recollection (1=not sure, 7=really sure) and memory strength (1=not strong, 7=really strong) (see Appendix E).

The recall of both memories were recorded and transcribed. Each memory was scored according to the AI scoring manual (Levine et al., 2002). Two main types of details were identified within each memory: (i) episodic details, that pertain directly to the main episode and are placed in a particular spatio-temporal context, suggestive of the re-experiencing of the main event and (ii) non-episodic details, representing general autobiographical information that is not integral to the main event. Episodic details were then assigned to the episodic detail subcategories: a) event b) place c) time d) perceptual and e) emotion/thought. The non-episodic details were assigned the non-episodic detail subcategories: a) external events details unrelated to the main event recalled specific to event, place, time, perceptual, and emotion/thought b)personal semantic facts c)unsolicited repetitions of previously recalled details and d)other metacognitive statements. Details were summed to form a total episodic and non-episodic detail composite score across each phase of the cAMI. See Appendix F for a sample of scored memory. For each participant, the AM detail scores, and participant self-reports were averaged across their two memories. Appendix G provides a comprehensive list of descriptions and examples of each detail category. The cAMI interviews were audio-recorded during the Zoom Heath video conference and were transcribed. Each transcribed memory was initially scored by one experimenter (RS), who had previously completed training by scoring a practice set of memories provided with the AI scoring manual (Levine et al., 2002). Another trained research volunteer independently scored ten randomly selected memories. Intra-class inter-rater correlations for the composites obtained on the cAMI were (i) Free Recall: 0.90 and 0.91 for episodic and non-

episodic details, respectively; (ii) General Probe: 0.90 and 0.91 for episodic and non-episodic details, respectively; and (iii) Specific Probe: 0.91 and 0.90 for episodic and non-episodic details, respectively. Previous studies by Gascoigne et al. (2013 & 2015) using the cAMI, followed a similar method of inter-rater reliability check, with intra-class inter-rater correlations consistent with our results.

Child and Adolescent Memory Profile (ChAMP; Sherman, & Brooks, 2015). The Child and Adolescent Memory Profile was used as a measure of memory and learning. The ChAMP assesses both verbal and visual domains of memory and each subtest contains multiple learning trials designed to assess learning. ChAMP may be particularly useful for a stroke population with motor impairment, as there are no motor requirements to complete the test (Sherman &Brooks, 2015). Combinations of subtest scores generate index scores for verbal and visual memory, immediate memory, and delayed memory (Sherman & Brooks, 2015). Internal consistency reliability coefficients of all the index scores for the CHAMP were high ranging from 0.84 to above 0.90. Subtest reliabilities ranged from 0.81 to 0.92, indicating good internal reliability for CHAMP index scores and subtest scores. Furthermore, the CHAMP was designed to ensure strong content validity, and item development included reviewing the research literature abd consulting with experts in memory and learning (Sherman & Brooks, 2015). The CHAMP also demonstrated good concurrent validity with significant moderate relationships between verbal indexes and the California Verbal Learning Test- Children's Version (CVLT-C; Delis et al., 1994) with coefficients ranging from 0.57 to 0.68. Moreover, there were significant moderate relationships between the visual indexes and the Rey Complex Figure Test (RCFT; Meyers & Meyers, 1995), with coefficients ranging from 0.43 to 0.57. Therefore, intercorrelations between the CHAMP and other concurrent measures indicated that the CHAMP has good overlap with

established memory tests and that its verbal and visual components correlate well with other tests of]modality-specific memory.

Wechsler Abbreviated Scale of Intelligence- Second Edition (WASI-II; Wechsler, 1999). The WASI-II is an abbreviated intelligence test that consists of two to four subtests that have been taken from the Wechsler Intelligence Scales for Children - fourth edition (WISC-IV; 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 (Vocabulary subtest), Perceptual Reasoning (Matrix Reasoning subtest), and Full-Scale IQ scores (both subtests together). For the current study, administration of the two-subtest version of the WASI-II provided a quick and accurate estimate of Full-Scale IQ that is 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). In the Vocabulary subtest, participants were asked to describe the meaning of increasingly challenging words. In the Matrix Reasoning subtest, participants are asked to recognize, among an array of choices, the missing item in a series of patterned items. 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 (Garland, 2005).

Demographic questionnaire. All youth 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) (see Appendix H).

Results

All data was analyzed using IBM SPSS Statistics Software Version 26. Prior to inferential procedures, the data was analyzed to examine whether it met parametric test assumptions. Levene's test was used to assess homogeneity of variances between groups. The assumption of normality was examined through the Shapiro-Wilk test and by analyzing graphical representations of data distributions separated by group. An alpha significance level of .05 was adopted. This alpha level was selected because it has been suggested that it is more acceptable to be liberal in small sample-sized studies (Evans & Ildstad, 2001). In fact, Perneger (1998) suggests that adjusting statistical significance for the number of tests that have been performed on study data, the Bonferroni method, creates more problems than it solves, as the likelihood of type II errors is also increased. Patient and control group comparisons on demographic variables were conducted using chi-square tests for categorical variables (i.e. sex distribution), and effect sizes were calculated for differences that were significant using Cramer's V where 0.1 = weak association, 0.5 = medium association, >0.5 = strong association (Cramer, 1946). Potential group differences between the stroke and control groups on the cAMI, ChAMP, and WASI were tested using independent samples t-tests and effect sizes were calculated using Cohen's *d* where 0.20 = small effect, 0.50 = medium effect, 0.80 = large effect (Cohen, 1988) when normality

assumptions were met. When normality assumptions were not met, non-parametric tests such as the Mann Whitney U-tests and partial eta-squared values where 0.01 = small effect, 0.06 = medium effect, 0.14 = large effect were also computed on inferential test. Memory and intellectual scores were not used as covariates in any of the statistical models as Dennis et al. (2009) noted how the intellectual quotient (IQ) does not fulfill the methodological and statistical requirements of a covariate and the use of IQ as a covariate has produced anomalous, overcorrected, and counterintuitive findings about neurocognitive function. Relationships between stroke-related factors (i.e. age of stroke onset and year since stroke) and memory scores were investigated using Spearman's rho correlations. To further examine relationships between stroke-related factors (i.e. lesion lateralization, area of stroke, time of stroke) and memory recall scores, Kruskal Wallis one-way analysis of variance tests were conducted.

Group Differences on Demographic Variables and Cognitive Outcomes

The stroke and control groups did not differ significantly in gender distribution [$\chi^2(2) = 1.97$, $p = 0.37$], age [$U\,(32,28) = 363.00$, $z = -1.28$, $p = 0.20$], maternal education [$\chi^2(7) = 9.74$, $p = 0.20$] or household income [$\chi^2(7) = 7.09$, $p = 0.42$] (see Table 1). Significant differences were found between the groups in native languages spoken, with the control group having native languages other than English spoken in the home in comparison to the stroke group [$\chi^2(1) = 15.25$, $p<.01$, V=0.5)]. There were significant differences between the groups regarding the age at which English was learnt, with the control group learning English past the age of 5, in comparison to the stroke group where English was predominately learnt before the age of 5 years [$\chi^2(1) = 5.71$, $p = 0.02$, V=0.3)]. This means that in the control group there were more participants that were non-native English speakers or bilingual in comparison to the stroke group. In addition to the differences in language, there were significant differences in ethnicities between the

groups with the control group including participants from more racialized communities than the stroke group [$\chi_2(8) = 25.49$, ($p < .01$, V=0.8)]. The clinical characteristics of stroke participants are outlined in Table 2.

Table 1

Demographic Characteristics of Stroke and Control participants

	Stroke	Control
Number of participants	28	32
Males/Females	15/13	14/18
Age at assessment, mean (SD)	14.86 (2.24)	15.75 (2.00)
Maternal education, mean (SD)	6.08 (1.38)	7.00 (0.87)
Family Income, mean (SD)	4.43 (1.74)	5.19 (1.80)
Ethnicity		
Arab/West Asian	2	1
Asian American/Asian Pacific Islander	1	2
Bi-racial/Multi-racial	3	2
Black	2	5
European origin/White	14	5
Latino-a/Hispanic	1	0
South Asian	1	16
Other	4	1
English/Other Language	26/2	23/9

Note. Maternal education was rated on an eight-point scale and family income was rated on a seven-point scale (see methods section for details)

Table 2

Clinical Characteristics of Participants in the Stroke Group

Age at stroke, mean (SD)	5.65 years (5.20)
Years since stroke, mean (SD)	9.79 years (4.78)
Time of stroke	
Perinatal	5
1 month-5 years	11
6-14 years	12
Area of stroke	
Cortical	10
Subcortical	11
Combined	7
Left Lesion Lateralization/ Right Lesion Lateralization	14/14

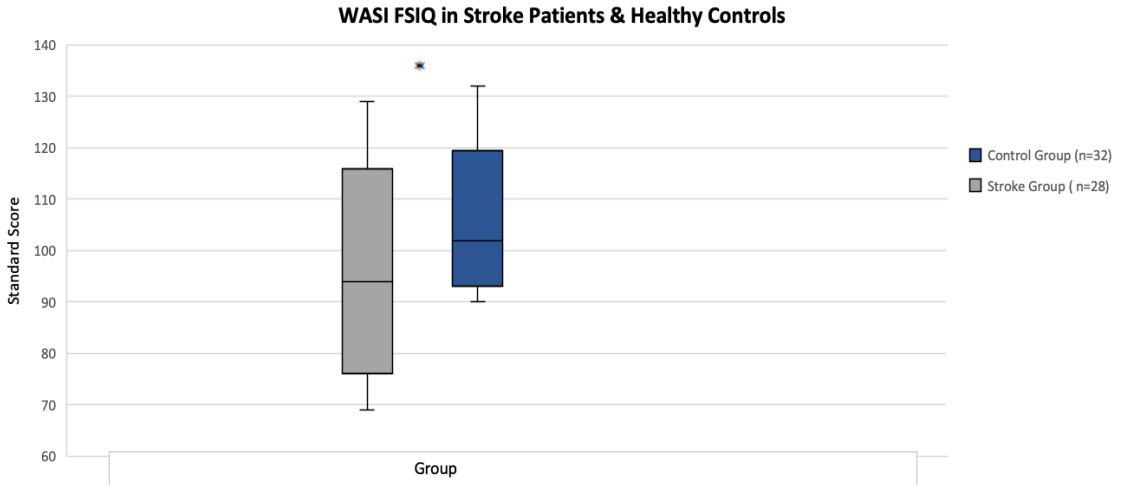
Compared to the control group, the stroke group was found to have lower FSIQ scores [$U(32,28) = 241.00$, z= -3.06, $p > .01$, $\eta^2 = 0.16$) (see Figure 2). Although the FSIQ of the stroke group was significantly lower than that of control group, lower FSIQ in the pediatric stroke population is commonly observed in this neurological condition. Moreover, compared to the control group, the stroke group was found to have significantly lower scores in all indices of the CHAMP which included the verbal memory index. [$t(58) = -2.28$, $p = 0.03$, $d = 0.58$], visual memory index [$t(58) = -2.17$, $p = 0.03$, $d = 0.56$], immediate memory index [$t(58) = -2.55$, $p = 0.01$, $d = 0.65$],delayed memory index [$t(58) = -2.27$, $p = 0.03$, $d = 0.58$], total memory index [$t(58) = -2.55$, $p = 0.01$, $d = 0.66$], and screening memory index [$t(58) = -2.16$, $p = 0.03$, $d = 0.55$], (see Figure 3). Taking a closer look, the stroke group had significantly lower scores in specific CHAMP subtests namely lists, where participants were asked to recall a list of words, [$t(58) = -2.37$, $p = 0.02$, $d = 0.61$], places, where participants were asked to remember a series of photographs of different locations, [$t(58) = -2.39$, $p = 0.02$, $d = 0.61$], and places delayed, where they were to recall these pictures after a delay period [$t(58) = -2.45$, $p = 0.02$, $d = 0.63$] (see Figure 4).

Group differences on Autobiographical Memory

Mann-Whitney U tests showed that the stroke group recalled significantly fewer episodic details than the control group in the Free Recall condition [$U(32,28) = 247.00$, z= 2.98, $p < .01$, $\eta^2 = 0.15$], and the general probe condition, [$U(32,28) = 254.00$, z= 2.88, $p < .01$ $\eta^2 = 0.14$], but not in the specific probe condition (see Figure 5).

Figure 2

Weschler Abbreviated Scale of Intelligence (WASI) Full Scale Intelligence Quotient (FSIQ) score in stroke patients and controls



Note. Boxes represent the Inter-Quartile Range, which contains data between the 25th and 75th percentiles. The median is represented by a horizontal line within each box. Whiskers represent minimum and maximum value. An asterisk denotes a statistically significant difference between the groups.

Figure 3

Child and Adolescent Memory Profile (CHAMP) index scores in stroke patients and controls

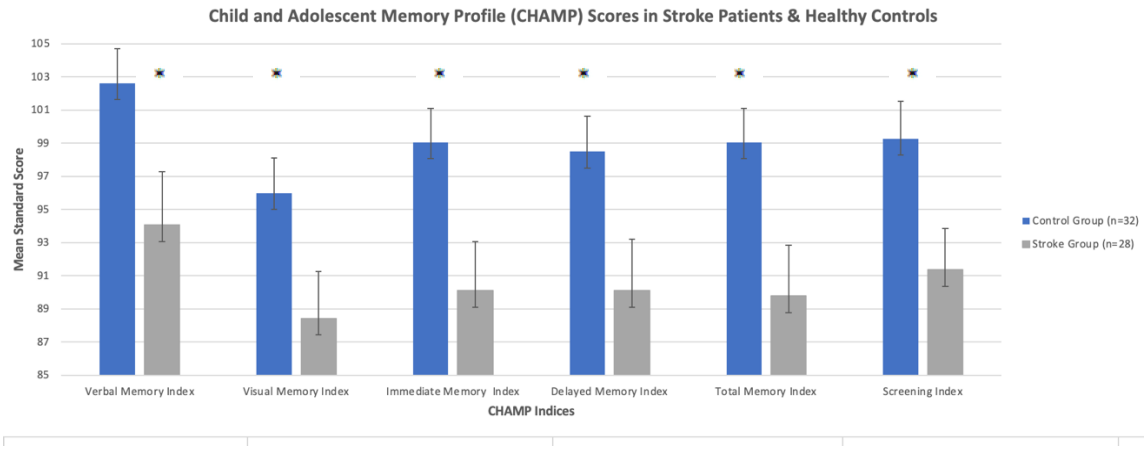
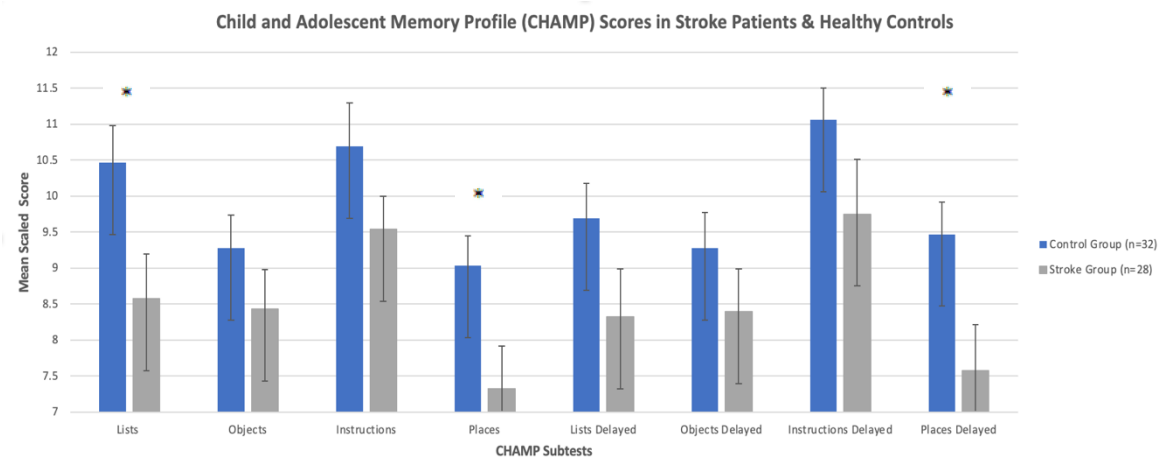


Figure 4

Child and Adolescent Memory Profile (CHAMP) subtests scores in stroke patients and controls



Taking a closer look into the sub-categories of the episodic details in the free recall condition, it was found that the stroke group recalled significantly fewer details in the event category [$U(32,28) = 230.50$, $z = 3.22$, $p < .01$, $\eta^2 = 0.17$], and time subcategory [$U(32,28) = 253.50$, $z = 2.90$, $p < .01$, $\eta^2 = 0.14$] (see Figure 6). In the general probe condition, there was significant differences in the event subcategory [$U\ (32,28) = 222.50$, $z = 3.35$, $p < .01$, $\eta^2 = 0.19$] (see Figure 7).

Figure 5

Children's Autobiographical Memory Interview (cAMI) episodic details in stroke patients and controls

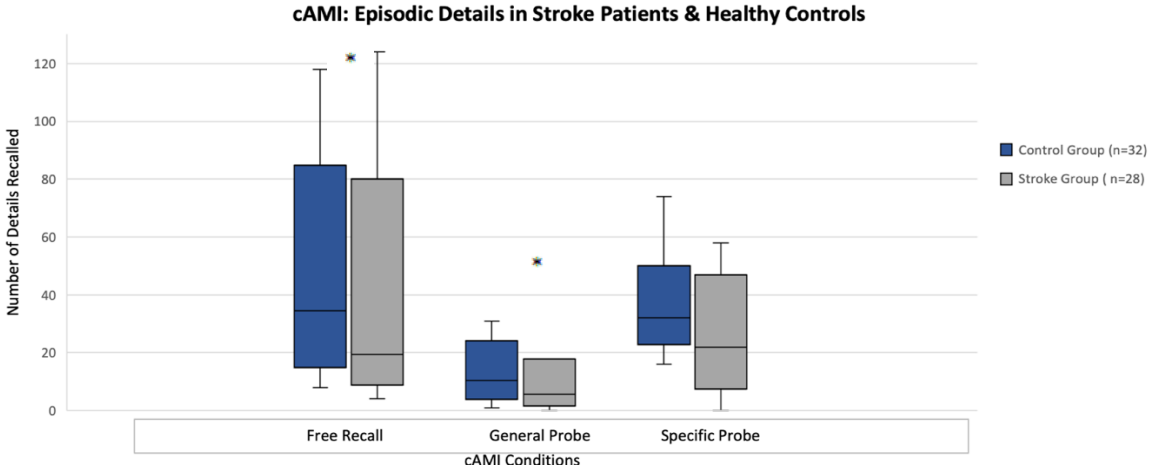
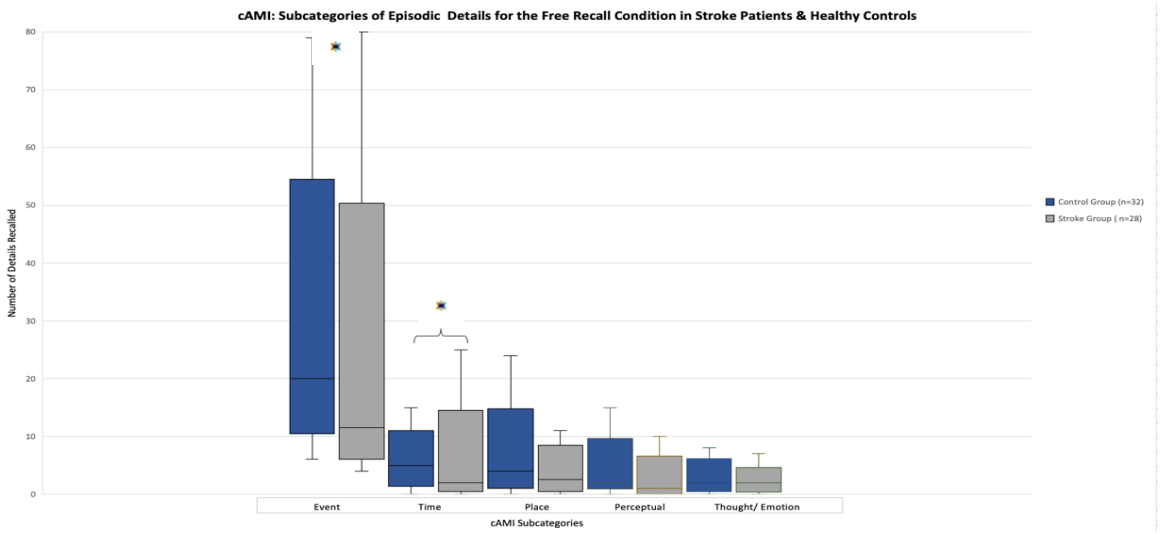


Figure 6

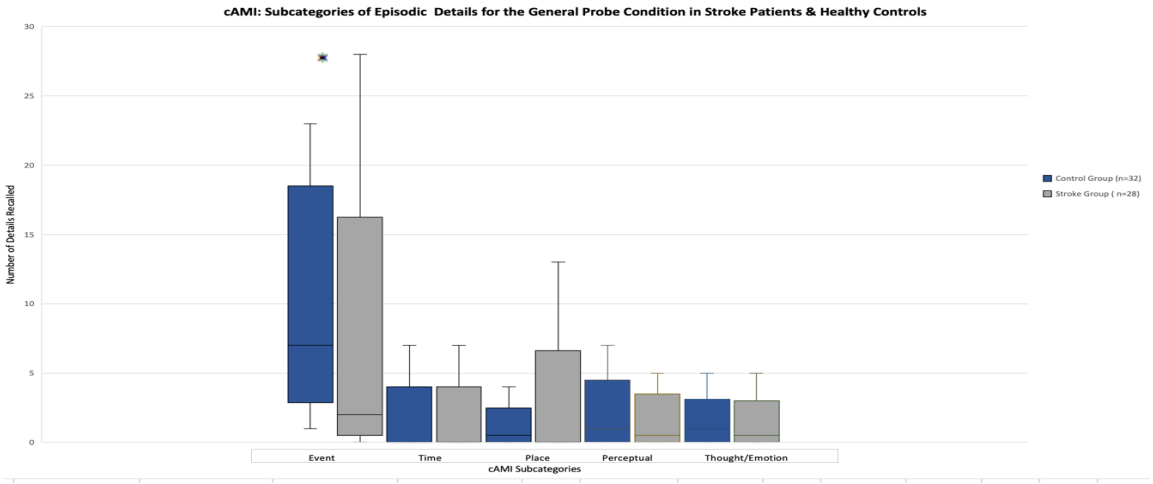
Children's Autobiographical Memory Interview (cAMI) episodic detail for the free recall condition in stroke patients and controls



Furthermore, the stroke group recalled significantly more non-episodic details than the control group in the Free Recall condition [U (32,28) = 227.50, z= -3.33, p<.01, η^2 = 0.18] and in the specific probe condition [U(32,28) = 269.50, z= -2.70, p<.01, η^2 = 0.12] (see Figure 8).

Figure 7

Children's Autobiographical Memory Interview (cAMI) episodic detail for the general probe condition in stroke patients and controls



Examining the sub-categories of the non-episodic details closer, in the free recall condition, it was found that the stroke group recalled significantly more details **of** external events [$U(32,28) = 300.00$, $z = -2.70$, $p < .01$, $\eta^2 = 0.08$], repetition [$U(32,28) = 300.00$, $z = -3.25$, $p < .01$, $\eta^2 = 0.08$], and other details [$U(32,28) = 299.00$, $z = -3.27$, $p < .01$, $\eta^2 = 0.08$] (see Figure 9). Similarly, in the specific probe condition, significant differences were found between the groups in repetition [$U(32,28) = 283.00$, $z = -3.50$, $p < .01$, $\eta^2 = 0.1$] and metacognitive statements [$U(32,28) = 298.00$, $z = -3.29$, $p < .01$, $\eta^2 = 0.08$] when recalling personal memories (see Figure 10).

Figure 8

Children's Autobiographical Memory Interview (cAMI) non-episodic details in stroke patients and controls

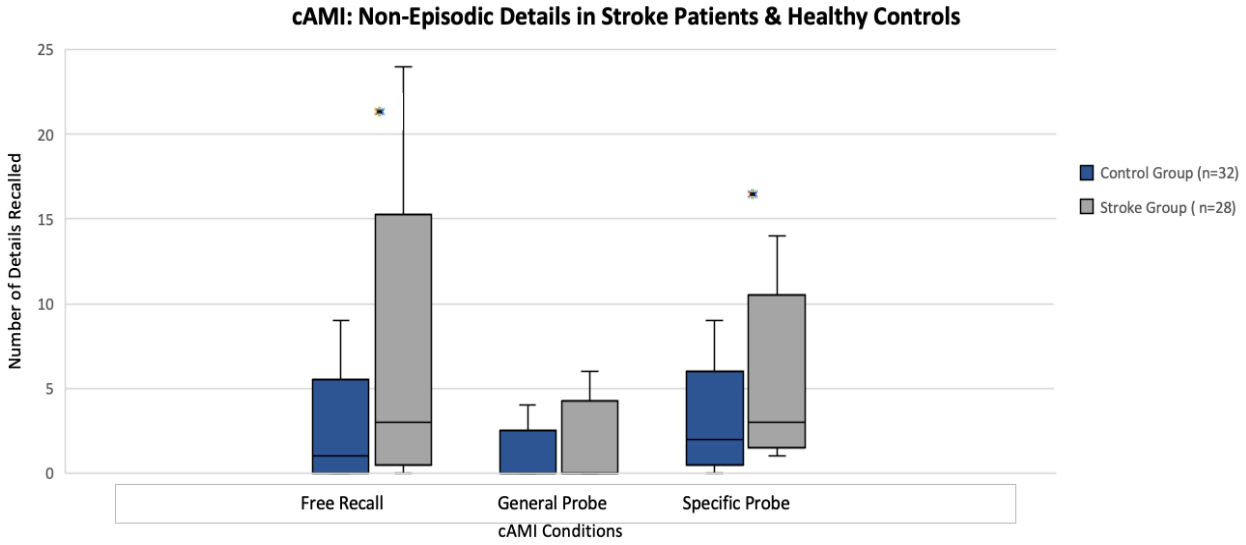


Figure 9

Children's Autobiographical Memory Interview (cAMI) non-episodic detail for the free recall condition in stroke patients and controls

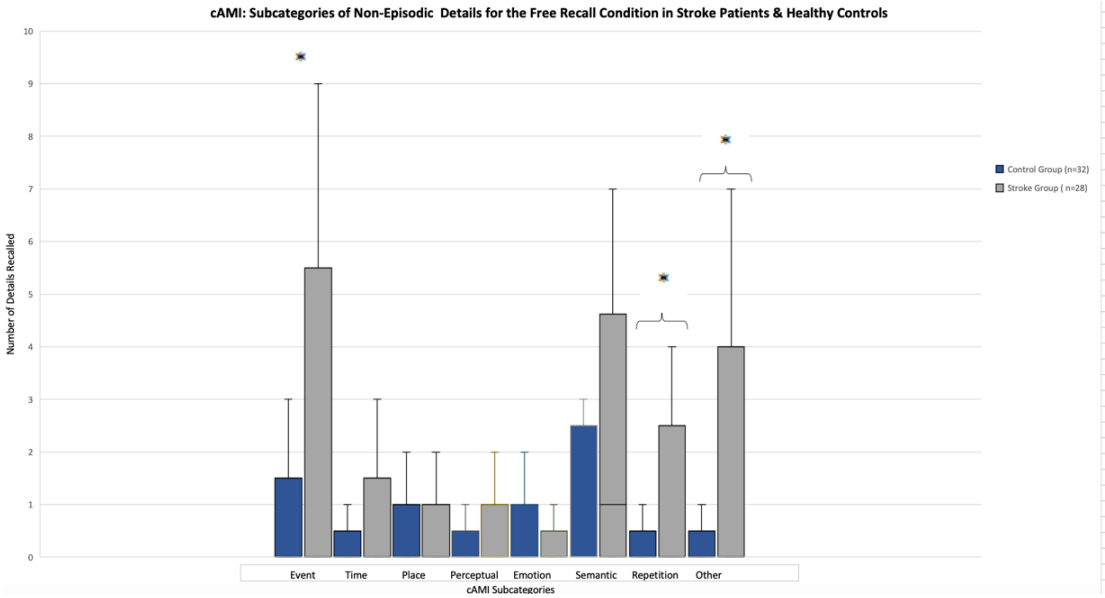
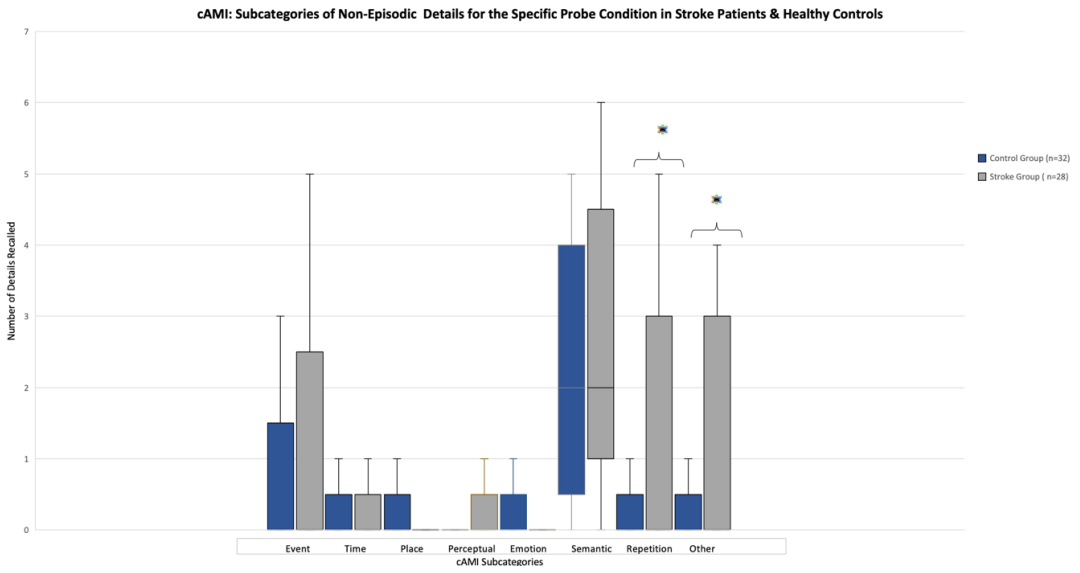


Figure 10

Children's Autobiographical Memory Interview (cAMI) non-episodic detail for the specific probe condition in stroke patients and controls



Further analysis of total word count of AMs revealed no significant differences between the control group (M = 592.59, SD = 396.04), and the stroke group (M = 377.71, SD = 324.38) in the Free Recall condition of the cAMI [$t(58) = 2.27$ $p = 0.07$] . Similarly, in the General Probe condition healthy controls (M = 192.56, SD = 145.22), and the stroke patients (M = 123.61, SD = 144.49), displayed no significant differences in the word count of personal memories [$t(58) = 1.83$ $p = 0.07$] . Finally, no significant differences [t (58) = 1.84 $p = 0.07$] in word count were found between the healthy controls (M = 522.88, SD = 264.80), and youth with stroke (M = 394.50, SD = 274.12) in the Specific Probe condition of the cAMI.

Participants' self-ratings.

Significant differences between the stroke and control groups were found on the participants' ratings of the phenomenological qualities of recalled events. Stroke participants had lower ratings in their memory on how sure of what they remember [$U(32,28)$ =303.00, z= 2.16,

p=0.03, η^2 = 0.08], how many times they thought of the past event [U(32,28) =264.00, z= 2.75, p<.01, η^2 = 0.08], how clearly they can imagine the memory in their mind [U(32,28) =315.00, z= 1.99, p=0.04, η^2=0.07], the importance of these memories in the past [U(32,28) =319.50, z= 1.92, p=0.05, η^2=0.12] and present [U(32,28) =301.00, z= 2.21, p=0.02, η^2=0.08] and how much their feelings/emotions changes after the reported events [U(32,28) =301.00, z= 2.20, p=0.02, η^2=0.08] (see Figure 11).

Stroke-related Factors and Memory Scores

Across the stroke group, Spearman's correlations were undertaken to examine relations between the recall of episodic and non-episodic total details on the cAMI and CHAMP scores with stroke-related factors which included years since stroke and age of stroke onset. No significant correlations were found between the memory measures and these stroke-related factors as displayed in Table 3.

Figure 11

Children's Autobiographical Memory Interview (cAMI) perceptual rating scale for stroke patients and controls

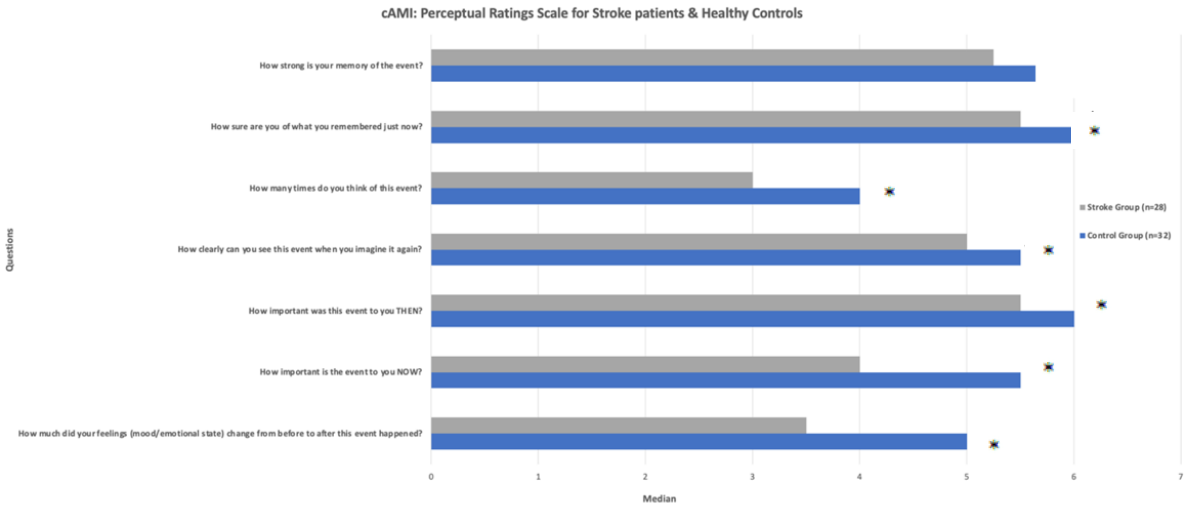


Table 3

Spearman's Correlations between Stroke-related Factors and Memory Scores in the Stroke Group

Memory Measure	Years since Stroke	Age of Stroke Onset
Children's Autobiographical Memory Interview (cAMI)		
Free Recall Total Internal	.108	.015
Free Recall Total External	.011	.101
General Probe Total Internal	.121	.136
General Probe Total External	.052	.104
Specific Probe Total Internal	-.153	-.349
Specific Probe Total External	-.096	.230
Child and Adolescent Memory Profile (CHAMP)		
Total Memory Index	.118	-.093
Memory Screening Index	.183	-.206
Verbal Memory Index	.139	-.098
Visual Memory Index	.008	.023
Immediate Memory Index	.109	-.105
Delayed Memory Index	.098	-.087

Furthermore, Kruskal-Wallis tests were conducted to evaluate differences among the stroke factors of area of stroke, lesion laterization and time since stroke on cAMI and CHAMP memory scores. Area of stroke was categorized into cortical, subcortical or combined types, lesion laterization was categorized into left and right lesions, and time of stroke was categorized into neonatal (birth to 1month of age), early childhood (1 month to 5 years), and middle to late childhood (6 to 18 years). Significant differences were found between area of stroke and the cAMI free recall internal time details [H (2) =9.46, $p=0.01$]. Post-hoc tests to test pairwise comparisons revealed significant differences between subcortical and combined cortical-subcortical areas of stroke on free recall episodic details [H (2) =11.85, $p<.01$, $\eta^2 = 0.07$]. Furthermore, significant differences were found between area of stroke and the cAMI specific probe internal emotion details [H (2)=6.28, $p=0.04$] with pairwise comparisons revealing significant differences between combined cortical-subcortical and cortical areas of stroke

[*H* (2)=8.02, *p=0.05,* $\eta^2 = 0.47$], and subcortical and combined cortical-subcortical areas of stroke [*H* (2)=9.43, *p=0.02,* $\eta^2 = 0.53$] on specific probe internal details. Finally, significant differences were observed between area of stroke on the CHAMP instructions subtest [*H* (2) =6.40, *p=0.04],* with pairwise comparisons displaying significant differences between subcortical and combined cortical-subcortical areas of stroke [*H* (2)=9.92 *p=0.01,* $\eta^2 = 0.56$] on CHAMP scores. (see Figure 12).Significant differences were also found between time of stroke and cAMI general probe internal perceptual details [*H* (2)=7.01, *p=0.03*], with pairwise comparisons revealing significant differences between neonatal stroke and middle to late childhood stroke [*H* (2)=-8.51, *p=0.03,* $\eta^2 = 0.63$] as well as differences between early childhood stroke and middle to late childhood stroke [*H* (2)=-7.37, *p=0.02,* $\eta^2 = 0.30$] on episodic details. (see Figure 13).

Figure 12

Area of stroke and memory details in stroke participants

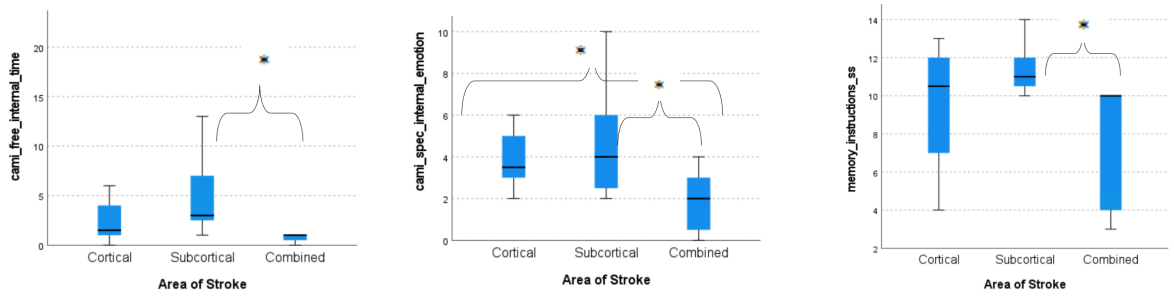
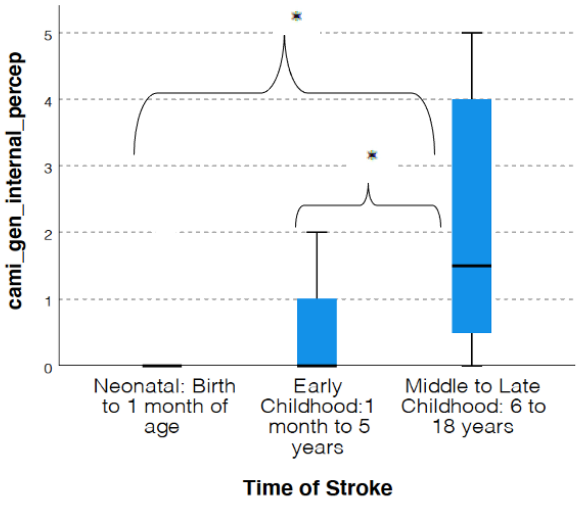


Figure 13

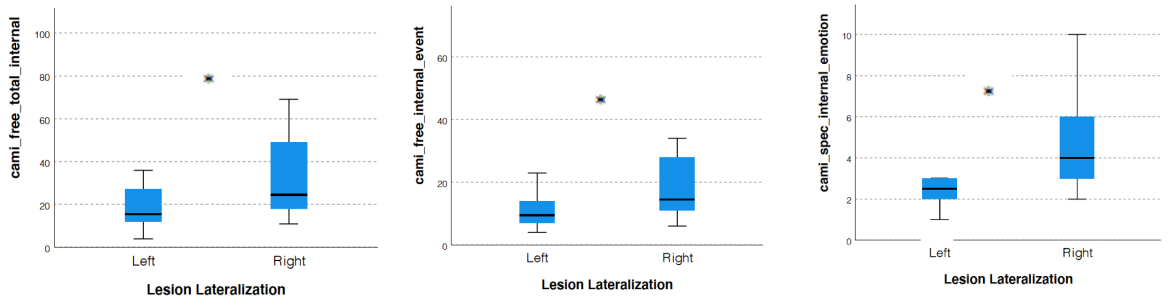
Time of stroke and memory details in stroke participants



Significant findings were observed between lesion laterization and the cAMI free recall total internal details [H (1) =5.08, p=0.02, η^2 = 0.12], free internal event details [H (1) =5.21, p=0.02, η^2 = 0.12], and specific probe internal emotion details [H (1) =5.21, p=0.02, η^2 = 0.12] with patients with right sided lesions recalling more details than patients with left sided lesions (see Figure 14).

Figure 14

Lesion laterization and memory details in stroke participants



Discussion

To our knowledge, this is the first study to examine the recall of AMs in youth with a history of stoke, and to compare their performance to age-and sex-matched youth without stroke. The study yielded several interesting findings. First, in line with our hypotheses we found significant differences between overall memory scores and intellectual functioning between the two groups. As predicted, youth with stroke showed deficits in the recall of episodic, but not non-episodic including semantic AM in comparison to controls, specifically in event and time details in the Free Recall and General Probe conditions the cAMI. Contrary to our hypotheses, youth with stroke recalled more non-episodic details, than healthy controls in the Free Recall and Specific Probe conditions. These details include more details pertaining to external events, repetitive and metacognitive statements. Moreover, significant differences were found in nearly all the phenomenological qualities of recalled events between the groups. Finally, confirming our hypotheses, stroke-related factors such as area of stroke, lesion lateralization, and time since stroke were related to AM and memory outcomes. However, no significant relationships were found between memory measures and age of stroke onset or time since stroke.

Group Differences on Demographic Variables and Cognitive Outcomes

The stroke and control groups were comparable on age, gender, maternal education, and household income. However, there was more racial and linguistic diversity in the control group than in the stroke group. Despite these differences, it is well documented that there are strong links specifically between socioeconomic status (SES) and cognitive performance in many racialized communities. A cross-cultural review has found that socioeconomic status strongly related to cognitive development from infancy to adolescence (Bradley, Corwyn, Whiteside-

Mansell,1996). There were no differences between the groups on SES as denoted by household income and parent education status, suggesting that the cognitive outcomes of each group are comparable.

When comparing the groups on neuropsychological scores, the patients with stroke had lower scores in FSIQ. Our findings are consistent with prior literature that has found that overall full-scale IQ is often significantly lower than normative population means in pediatric stroke (Hajek et al., 2014; O'Keeffe et al., 2014; Westmacott et al., 2009, 2018). Studies focused on general intellect have documented that children with stroke often perform at the lower end of the average range between scaled scores of 90 to 95 (Everts et al., 2008; Max et al., 2002; O'Keeffe et al., 2012). Our findings were consistent with previous literature as we reported an average scaled score of 94 for general intellect in the stroke group. Furthermore, compared to the control group, the stroke group was found to have significantly lower scores in all indices of the CHAMP. A recent study by Virani et al., (2022) similarly found that participants with a history of perinatal stroke performed significantly worse on all scales scores of CHAMP. Our study found specific deficits in subtests where participants were asked to recall a list of words, remember a series of photographs of different locations, and recalling these pictures after a delay period. The worse performance on tasks of both verbal and visual learning and memory have been documented in the literature with a study by Lansing et al., (2004) finding that children with histories of stroke have impaired verbal memory, and weaknesses in visual memory recall were also found in a separate study by Allman & Scott (2013). Thus, the neuropsychological profile of the stroke group of our study is consistent with prior literature.

Group differences on Autobiographical Memory

The most striking finding of the current study is of deficits in the recall of episodic, but not non-episodic autobiographical details in youth with stroke. This is consistent with studies of other clinical pediatric populations that found between-group differences in the recall of episodic autobiographical details, but not non-episodic details compared to healthy controls (Lah et al., 2019; Sekeres et al., 2018; Willoughby et al., 2013; Gascoigne et al., 2013 & 2015). More specifically, these findings are consistent with populations with hippocampal dysfunction, such as children with thyroid hormone deficiency and developmental amnesia; relative to controls these patients' exhibited weaknesses in episodic, but not non-episodic AM details (Willoughby et al., 2013; Vargha-Khadem et al., 1997). Similar findings were also observed in patients with traumatic brain injury, brain tumours, and temporal lobe epilepsy where patient groups displayed deficiencies in episodic AM in comparison to healthy controls (Lah et al., 2019; Sekeres et al., 2018; Willoughby et al., 2013). When looking closer at the nature of these episodic AM deficits between patients with stroke and controls, between-group differences in the recall of autobiographical events were not present when youth were asked specific questions. These findings have also been observed in pediatric TBI (Lah et al., 2019;) and temporal lobe epilepsy (Gascoigne et al., 2013 & 2015) where no significant differences were found between patient groups and controls in the specific probe condition. The lack of between-group differences in recall of autobiographical event details suggests that providing specific probes is likely to alleviate difficulties with recall of autobiographical events, which is important for development of interventions. Such interventions could utilize findings of developmental literature which has shown that children of mothers who use elaborative styles when talking with children and youth about past experiences are likely to be elaborative in remembering their past experiences, even at

an early age (Wareham & Salmon, 2006). Youth with stroke showed impairments when recalling personal events without cues during the Free Recall stage of the interview, and with general retrieval support in the General probe condition. This may suggest that within the stroke group, impairments in episodic recall were largely due to retrieval difficulties, rather than memory storage. In youth with stroke, subcortical and cortical structures, including the thalamus, the prefrontal cortex and posterior cortical regions maintain dense connections with the hippocampus and other medial temporal lobe structures. These regions mediate specific memory retrieval processes, which if affected by vascular damage in stroke then present with memory impairments (Maguire, 2001). Stroke participants had particular difficulties in recalling episodic details related to both event and time. Vascular damage may lead to difficulties with the establishment of connections between various brain regions that may be required to form a gestalt of an autobiographical episode.

Contrary to our predictions, the stroke group recalled significantly more non-episodic details than the control group in both the Free Recall and Specific Probe conditions. Examining these details more closely, it was found that the stroke group reported more details related to external events, repeated details several times, and used more metacognitive statements when recalling memories. These findings suggest that youth with stroke may have greater vulnerability of episodic memory disruption which may lead to providing other external details and frequently repeating details of personally experienced episodes. It has been hypothesized that episodic memories are experienced only once, meaning that the record of the memory is unique and cannot be re-established when disrupted during vascular damage, thus leading to a heavier reliance on non-episodic external details to recall events. Youth with stroke recalled more non-episodic details in both the Free Recall and Specific Probe stage suggesting that recalling non-

episodic details did not heavily depend on retrieval supports. These results are also consistent with findings with adult patients with hippocampal damage that failed to find any beneficial effect of retrieval support on non-episodic recall (Rosenbaum et al., 2011; St. Laurent et al., 2009). Therefore, these findings suggest that the vascular damage caused by stroke may affect the retrieval of episodic details, but not non-episodic details when compared to healthy controls. These findings may potentially have significant implications for the way autobiographical memory deficits manifest in pediatric stroke.

Participants' self-ratings.

In line with our hypotheses, there were significant between-group differences between patients with stroke and controls in their self-ratings of their memories for personally experienced events. Patients with stroke had lower ratings in their memory of the event, how sure of what they remember, how clearly, they can imagine the memory in their mind and the importance of these memories in the past and present. These findings are consistent with results by Gascoigne et al., (2015) who found that children and youth with pediatric epilepsy rated their memories as being weaker. This suggests that youth with stroke may be aware of their memory recall difficulties, as they are self-reporting lower confidence in their ability to recall specific memories related to prior life experiences. It is also of interest to comment on the way in which stroke patients described their memories. When youth with stroked recalled their memories, their narratives were far less detailed (in spite of a similar word count), unorganized and scattered in comparison to healthy age and sex-matched controls. Their narratives were not as rich and full of perceptual details in contrast to those that did not have stroke. The way in which memories are described gives us insight into how autobiographical events are being structured in youth with stroke and how they are organizing these experiences in their minds.

Stroke-related Factors and Memory Scores

Consistent with our hypothesis, there were relationships between stroke-related factors and memory recall. Relationships between area of stroke, time since stroke and lesion lateralization were found with cAMI episodic and non-episodic details and CHAMP scores. When examining these relationships closer, it was found that patients with combined cortical and subcortical stroke had poorer episodic recall in the free recall and specific probe condition and memory recall on the CHAMP compared to patients with subcortical or cortical strokes alone. This is in line with prior literature that found that combined cortical-subcortical subtype stroke had poorer outcomes due to the widespread neuronal damage. It is likely that those patients with either cortical or subcortical stroke types may have better memory recall as localized vascular damage is not as widespread, and this may in turn preserve the functioning of cortical areas needed for AM recall and other forms of cognitive functioning. Furthermore, it was found that those participants that had neonatal stroke and early childhood stroke recalled fewer episodic details in the general probe condition in comparison to middle to late childhood stroke. This is consistent with prior literature that suggested that earlier time of stroke may be predictive of worse cognitive outcomes as younger brains may be more vulnerable to trauma (Westmacott et al., 2009). Early injury is thought to disrupt the course of myelination thereby rendering the developing brain less capable of supporting higher-level cognitive skills, such as episodic AM. This interpretation is also supported by the Socio-Cultural Developmental Model that notes how higher-level cognitive skills and social processes follow a developmental sequence allowing for the emergent capacities of AM (Nelson & Fivush, 2004).

Significant findings were observed between lesion laterization and the cAMI free recall and specific probe episodic details with patients with right sided lesions recalling more details

than patients with left sided lesions. Considering that memory interviewing is quite dependent on verbal language and recall, it is not surprising that left perinatal stroke patients performed worse as there is left hemispheric specialization of language. Functional neuroimaging findings have also indicated the reorganization of language areas to the right hemisphere following left perinatal stroke (Tillema et al., 2008). We did not find relationships between age at stroke and years since stroke with memory recall. To-date the literature has been quite mixed with reported significant and non-significant findings regarding age of stroke onset with cognitive outcomes. Nevertheless, this analysis added to our understanding of the cognitive mechanisms that may play an important role in the retrieval of episodic autobiographical events in patients with pediatric stroke.

Chapter 3: Future Directions and Clinical Implications

Limitations and Future Directions

This chapter delves into implications for future research and clinical implications for youth who have had strokes and suffer from AM challenges. Firstly, it is important to note that our study is not without limitations. An issue plaguing research involving uncommon conditions is the low sample size, which translates to low statistical power and limited analyses. Hence, our clinical sample was too small to undertake statistical analyses such as regression that would allow us to concurrently examine contribution of different variables on episodic AM; for example, factors such as age of stroke onset and years since stroke and their effect on autobiographical memory recall. Although our study did not find a relationship with these factors and memory recall, it is possibly they may have had a moderating effect on AM. Thus, future research should use analytic techniques that combine multiple variables, which would allow for the control for such potential confounders. In terms of recruitment, there may be a biased representation towards individuals who were seeking a cognitive evaluation perhaps due to self-perceived cognitive complaints and as a result were more inclined to participate. Also, despite recent research on the validity of online testing, standardized testing norms still reference in person assessment. Thus, the online modality may not be sensitive into tapping into memory skills, particularly visual memory. Therefore, further online studies should be used in the future to explore relationships with autobiographical memory recall in this pediatric population through a virtual platform. Despite these limitations, our findings are consistent with the limited research that has been done thus far in understanding autobiographical memory in pediatric stroke.

Clinical implications

Our findings confirm the possibility that youth with stroke are at a greater risk for developing episodic autobiographical memory deficits in comparison to healthy controls. We found that certain stroke characteristics such as area of stroke, time of stroke and lesion laterality may further impact autobiographical recall. The implications of these findings are that clinicians should assess AM in this neurological population as a routine part of a post-stroke neuropsychological assessment, and follow-up, particularly when memory complaints are referred. This is to ensure that subtle higher-level deficits such as episodic recall are not missed, particularly in youth with little or very mild evidence of neurological residual disabilities. Clinicians should also assess AM via other means independent of verbal memory and language, such as visual memory considering the apparent verbal and language deficits in this pediatric population. For example, youth may sequence and draw illustrations of their autobiographical memory events that do not rely so heavily on verbal skills. Through these means, clinicians can better understand how to assess and identify AM deficits.

Conclusion

Pediatric stroke is a rare but potentially devastating occurrence. Our study had several notable strengths that were of significance. Our findings provided confirmation that youth with stroke may be at-risk of episodic AM deficits. We also explicitly examined the relationship between stroke related factors and autobiographical memory. To-date, there are no specific intervention programs or training for impaired AM in youth with stroke. Intervention strategies must be applied to the pediatric stroke population given the growing evidence of apparent memory concerns. Thus, the current study highlights not only the need for earlier diagnosis, but

future research should be directed at creating intervention program and cognitive rehabilitation that enhance retrieval of AMs spsecifically in youth with stroke.

Ultimately identifying the risks of AM deficits is particularly important since autobiographical memory is a central element of human functioning (Conway & Pleydell-Pearce, 2000). AM plays a significant role in everyday adaptive functioning and deficits in this form of memory in these youth may lead to poorer outcomes in adulthood. As a result, future research should also aim at examining the longitudinal effects of AM deficits in this population. Overall, this study serves to increase awareness about the effects of stroke on AM so that earlier diagnosis and intervention programs may one day attenuate the memory weaknesses that this pediatric population faces and maximize youth's potential.

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Appendix A

Research Consent Form for Youth Patient Participant

Study Title: Autobiographical Memory in Youth with Stroke

Principal Investigator(s):
Dr. Robyn Westmacott, Division of Psychology

Co-Investigator(s):
Raman Sehra, York University, Division of Psychology
Dr. Mary Desrocher, York University, Division of Psychology

Conflict of Interest:
The research team members have no conflict of interest to declare.

Introduction
We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. This consent form may have words that you do not understand. Please ask the study staff to explain anything that you do not understand during the Zoom Health videoconference call. Please take as much time as you need to think about your decision to participate or not and ask any questions you have. If it is helpful to you, you are encouraged to discuss the study with family, friends, your personal physician, other health professionals, or any members of your community that you trust. All participation is voluntary, and you are not under any obligation to participate.

Please learn enough about this research study and its risks and benefits to decide whether you agree to participate. We must explain the study to you, and give you a chance to ask questions about anything you do not understand. This process is called "informed consent". It is up to you to choose if you want to be in this study. You may refuse to be in this study or quit this study at any time, and standard medical care will still be available here or at a doctor of your choice without a penalty or loss of benefits to you. It is important to understand that there may not be any benefit from being in this study, but we may learn something that could help others.

Why am I being asked to participate?
You are being asked to consider participating in this research study because you were diagnosed with a stroke sometime during your infancy or childhood. We are interested in better understanding how youth with and without histories of stroke perform on memory tasks. More specifically, we are interested in understanding autobiographical memory, or memory for events in our lives.

Why is this study being done?
Each of the skills we are interested in testing have an impact of how we get through our daily lives, interacting with others, and creating a sense of who we are as person. We are interested in exploring how youth with stroke do on these tests, as a first step to designing intervention programs that can build skills in each of these areas.

What will happen if I join this study?
We want to invite you to take part in the study. The study will take place completely online on a date and time that is convenient for you. We plan to have 56 children and youth involved in the study.

As a participant, you will:

- Fill out a demographic questionnaire about your history that will take about 10-15 minutes. This questionnaire asks questions about you (using an online survey tool REDCap). You are encouraged to answer all the questions, but you can refuse to answer any of them. RedCap is a secure web-based survey tool that ensures the information is recorded in such a way that only authorized individuals can read or view it. All questionnaires will remain confidential and provided with a study ID.
- Complete a semi-structured memory interview online. It will be delivered over the internet using a web-based video communication program (e.g., Zoom Health). This means that you can participate remotely without leaving home, as long as you have a computer with a secured Internet connection. This portion of the video conferencing session will be audio taped in order to transcribe the details of your interview for research purposes. The audio recording will be stored in a password protected, secure and confidential location that only the research study team will have access to. The audio recorded sessions will be transcribed by a study team member. Your name or any other identifying information will not be included in the transcription of the audio recording. The audio recording will be destroyed immediately after it has been transcribed.
- Complete some game-like tasks that involve remembering numbers, naming colours, and other similar things online via Zoom Health. These tasks will not be audio or video recorded.
- As part of this study we would like to review your health chart. Your medical records at SickKids will be obtained from the Canadian Pediatric Ischemic Stroke Registry (CPISR). Specifically, we will gather information about the type and location of the stroke in your brain, details about your development, results from previous neuropsychological assessments, and referrals for rehabilitation therapy. This will include information gathered from when you were baby until now. This information will be used to understand how your stroke relates to how your brain is working now. We will also be looking at the test results from any earlier neuropsychological assessments you may have had at The Hospital for Sick Children.
-

In total, the study will take about 1-1.5 hours. We will take a break mid-way into the study as needed.

Initials: **I consent to be audio recorded.**

- The memory interview will be audio recorded. The audio recording will be transcribed after the interview and will be analyzed by the research team. The transcription will be done by a member of the study team. Your name or any other identifying information will not be included during

the recording, except your voice. The audio recording will be destroyed after it has been transcribed and checked for accuracy.

What are the risks, harms or discomforts of the study?
We know of no harm that taking part in this study could cause you.

You may find some of the tasks difficult. If you find something uncomfortable, we can stop. During the interview, you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions (e.g., it may be difficult to remember things or talk about your emotions). You can skip questions, take a break or stop answering at any time. If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

Audio and Video Recording:
There is a potential risk of loss of your confidentiality because even though your name will not be part of the audio or video recording, nor the transcription, your voice may still be identifiable as yours. If anyone mentions identifiers (e.g., your name), during the recording, this may identify you.

Confidentiality risk:
Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?
If you are experiencing memory difficulties, we can provide you with a list of resources and recommendations to direct you towards helpful services. Additionally, because the study aims to improve our understanding of childhood stroke outcomes, future clinical practice may be improved and you may benefit indirectly from participation.

By studying the memory needs of children and youth with stroke and comparing findings to healthy children, results from this study may be used to improve memory outcomes in this group and identify individuals who are in need of help and services.

Can I choose to leave the study?
It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at SickKids/on your employment/training at SickKids. If you decide to leave the study, you can contact the Principal Investigators or a member of the study team to let them know.

Will I be paid and/or reimbursed if I join this study?
You will be given a $25 e-giftcard for Amazon or Indigo as a token for your participation. You will also receive community service hours if needed. If you decide to stop participating, you will still receive the gift card and completed community service hours.

How will my privacy be protected?
The Hospital for Sick Children is committed to respecting your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this. For instance, the study investigators will be required to break confidentiality if you provide information that causes us to be concerned for your safety (e.g., self-harm or suicide risk) or the safety of other individuals, if there are indications of a child-abuse situation, if we learn that a regulated health professional has committed an act of abuse or malpractice, or if our records are subpoenaed (required by a judge in a court case).

The SickKids study investigators will collect personal health information about you. This includes things learned from the study procedures described in this consent form and/or information from your medical records. They will only collect the information they need for the study.

All personal health information or personal information collected about you will be "de-identified" by replacing your identifiable information (i.e., name, MRN) with a "study number". The SickKids study staff are in control of the study code key, which is needed to connect your personal health information/personal information. The link between the study number and your identity will be safeguarded by the study staff and will not be available to the Hospital for Sick Children. SickKids guidelines include the following:

- All information that identifies you, both paper copy and electronic information, will be kept confidential and stored and locked in a secure place that only the study staff will be able to access.
- Electronic files will be stored securely on hospital or institutional networks or securely on any portable electronic devices.
- No information identifying you will be allowed off site in any form without your consent. Examples include your hospital or clinic charts, copies of any part of your charts, or notes made from your charts.

The study investigators listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

Following completion of the research study the data will be kept as long as required then destroyed as required by SickKids policy. Published study results will not reveal your identity. The results of the tests we describe in this form will be used only for this study. If another health care professional caring for you needs to see these results, you will have to give us your permission. We will ask you to sign a form saying that you agree that this person can see your results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

What if I am injured during/in this study?
If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s), sponsors or involved institutions from their legal and professional responsibilities.

If you require treatment for any injuries or illness related to your participation in the study, you should contact the study doctor immediately.

How will I be informed about new information?
We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?
You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor, sponsor or involved institutions for compensation, nor does this form relieve the study doctor, sponsor or their agents of their legal and professional responsibilities.

Will I receive study results?
Research results will be shared through journal publications, academic conferences, and any other means of disseminating information. When the results of this study are shared, your identity will not be disclosed. You have the right to be informed of the results of this study once the entire study is complete.

If you would like to be informed of the results of this study, please let the study doctor know. You will only be provided with overall study results (aggregate results from all participants). This means you will not know the results as they relate to you specifically.

Who can I call if I have questions about the study?
If you have any questions during your participation in this research study you can contact the Principal Investigator Dr. Robyn Westmacott.

Research Ethics Board Contact Information
The study protocol and consent form have been reviewed by the SickKids Research Ethics Board (REB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Research Ethics Board during business hours.

Consent to Participate in a Research Study

Study Title: Autobiographical Memory in Youth with Stroke

By signing this research consent form, I understand and confirm that:

1) All of my questions have been answered
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my medical records will be kept private except as described to me.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Appendix B

Research Consent Form for Youth Control Participant

Study Title: Autobiographical Memory in Youth with Stroke

Principal Investigator(s):
Dr. Robyn Westmacott, Division of Psychology

Co-Investigator(s):
Raman Sehra, York University, Division of Psychology
Dr. Mary Desrocher, York University, Division of Psychology

Conflict of Interest:
The research team members have no conflict of interest to declare.

Introduction
We would like to invite you to take part in our research study. This consent form describes the research study and what it means to participate. This consent form may have words that you do not understand. Please ask the study staff to explain anything that you do not understand during the Zoom Health videoconference call. Please take as much time as you need to think about your decision to participate or not and ask any questions you have. If it is helpful to you, you are encouraged to discuss the study with family, friends, your personal physician, other health professionals, or any members of your community that you trust. All participation is voluntary, and you are not under any obligation to participate.

Please learn enough about this research study and its risks and benefits to decide whether you agree to participate. We must explain the study to you, and give you a chance to ask questions about anything you do not understand. This process is called "informed consent". It is up to you to choose if you want to be in this study. You may refuse to be in this study or quit this study at any time, and standard medical care will still be available here or at a doctor of your choice without a penalty or loss of benefits to you. It is important to understand that there may not be any benefit from being in this study, but we may learn something that could help others.

Why am I being asked to participate?
You are being asked to consent or agree to be part of a research study because you have volunteered to be a healthy control participant .We are interested in better understanding how youth with and without histories of stroke perform on memory tasks. More specifically, we are interested in understanding autobiographical memory, or memory for events in our lives.

Why is this study being done?
Each of the skills we are interested in testing have an impact of how we get through our daily lives, interacting with others, and creating a sense of who we are as person. We are interested in exploring how youth with stroke do on these tests, as a first step to designing intervention programs that can build skills in each of these areas.

What will happen if I join this study?
We want to invite you to take part in the study. The study will take place completely online on a date and time that is convenient for you. We plan to have 56 children and youth involved in the study.

As a participant, you will:

- Fill out a demographic questionnaire about your history that will take about 10-15 minutes. This questionnaire ask questions about you (using an online survey tool REDCap). You are encouraged to answer all the questions, but you can refuse to answer any of them. RedCap is a secure web-based survey tool that ensures the information is recorded in such a way that only authorized individuals can read or view it. All questionnaires will remain confidential and provided with a study ID.
- Complete a semi-structured memory interview online. It will be delivered over the internet using a web-based video communication program (e.g., Zoom Health). This means that you can participate remotely without leaving home, as long as you have a computer with a secured Internet connection. This portion of the video conferencing session will be audio taped in order to transcribe the details of your interview for research purposes. The audio recording will be stored in a password protected, secure and confidential location that only the research study team will have access to. The audio recorded sessions will be transcribed by a study team member. Your name or any other identifying information will not be included in the transcription of the audio recording. The audio recording will be destroyed immediately after it has been transcribed.
- Complete some game-like tasks that involve remembering numbers, naming colours, and other similar things online via Zoom Health. These tasks will not be audio or video recorded.

In total, the study will take about 1-1.5 hours. We will take a break mid-way into the study as needed.

Initials: **I consent to be audio recorded.**

- The memory interview will be audio recorded. The audio recording will be transcribed after the interview and will be analyzed by the research team. The transcription will be done by a member of the study team. Your name or any other identifying information will not be included during the recording, except your voice. The audio recording will be destroyed after it has been transcribed and checked for accuracy.

What are the risks, harms or discomforts of the study?
We know of no harm that taking part in this study could cause you.

You may find some of the tasks difficult. If you find something uncomfortable, we can stop. During the interview, you may experience some anxiety, emotional and/or psychological distress due to the nature of the questions (e.g., it may be difficult to remember things or talk about your emotions). You can skip questions, take a break or stop answering at any time. If your responses indicate that there is a serious risk of harm to yourself or others, confidentiality will be broken in order to protect you or another person. If we feel that you need urgent care as result of participating in this research study we will intervene according to routine clinical care practices.

Audio and Video Recording:
There is a potential risk of loss of your confidentiality because even though your name will not be part of the audio or video recording, nor the transcription, your voice may still be identifiable as yours. If anyone mentions identifiers (e.g., your name), during the recording, this may identify you.

Confidentiality risk:
Despite protections being in place, there is a risk of unintentional release of information.

Are there benefits from being in the study?
If you are experiencing memory difficulties, we can provide you with a list of resources and recommendations to direct you towards helpful services.

By studying the memory needs of children and youth with stroke and comparing findings to healthy children, results from this study may be used to improve memory outcomes in this group and identify individuals who are in need of help and services.

Can I choose to leave the study?
It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to. Withdrawal from the study will not have any effect on the care you or your family will receive at SickKids/on your employment/training at SickKids. If you decide to leave the study, you can contact the Principal Investigators or a member of the study team to let them know.

Will I be paid and/or reimbursed if I join this study?
You will be given a $25 e-giftcard for Amazon or Indigo as a token for your participation. You will also receive community service hours if needed. If you decide to stop participating, you will still receive the gift card and completed community service hours.

How will my privacy be protected?
The Hospital for Sick Children is committed to respecting your privacy. No information about you will be given to anyone or be published without your permission, unless the law requires us to do this. For instance, the study investigators will be required to break confidentiality if you provide information that causes us to be concerned for your safety (e.g., self-harm or suicide risk) or the safety of other individuals, if there are indications of a child-abuse situation, if we learn that a regulated health professional has committed an act of abuse or malpractice, or if our records are subpoenaed (required by a judge in a court case).

The SickKids study investigators will collect personal health information about you. This includes things learned from the study procedures described in this consent form and/or information from your medical records. They will only collect the information they need for the study.

All personal information collected about you will be "de-identified" by replacing your identifiable information (i.e., name, birth date) with a "study number". The study staff are in control of the study code key, which is needed to connect your personal information. The link between the study number and your identity will be safeguarded by the study staff and will not be available to the Hospital for Sick Children or York University. SickKids guidelines include the following:

- All information that identifies you, both paper copy and electronic information, will be kept confidential and stored and locked in a secure place that only the study staff will be able to access.
- Electronic files will be stored securely on hospital or institutional networks or securely on any portable electronic devices.
- No information identifying you will be allowed off site in any form without your consent.

The study investigators listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

Following completion of the research study the data will be kept as long as required then destroyed as required by SickKids policy. Published study results will not reveal your identity. The results of the tests we describe in this form will be used only for this study. If another health care professional caring for you needs to see these results, you will have to give us your permission. We will ask you to sign a form saying that you agree that this person can see your results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

What if I am injured during/in this study?

If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s), sponsors or involved institutions from their legal and professional responsibilities.

If you require treatment for any injuries or illness related to your participation in the study, you should contact the study doctor immediately.

How will I be informed about new information?

We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?
You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor, sponsor or involved institutions for compensation, nor does this form relieve the study doctor, sponsor or their agents of their legal and professional responsibilities.

Will I receive study results?
Research results will be shared through journal publications, academic conferences, and any other means of disseminating information. When the results of this study are shared, your identity will not be disclosed. You have the right to be informed of the results of this study once the entire study is complete.

If you would like to be informed of the results of this study, please let the study doctor know. You will only be provided with overall study results (aggregate results from all participants). This means you will not know the results as they relate to you specifically.

Who can I call if I have questions about the study?
If you have any questions during your participation in this research study you can contact the Principal Investigator Dr. Robyn Westmacott.

Research Ethics Board Contact Information
The study protocol and consent form have been reviewed by the SickKids Research Ethics Board (REB). If you have any questions regarding your rights as a research participant, you may contact the Office of the Research Ethics Board during business hours.

Consent to Participate in a Research Study

Study Title: Autobiographical Memory in Youth with Stroke

By signing this research consent form, I understand and confirm that:

1) All of my questions have been answered
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my health care at Sick Kids.
4) I am free now, and in the future, to ask questions about the study.
6) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
7) I agree, or consent, to take part in this study.

I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Appendix C

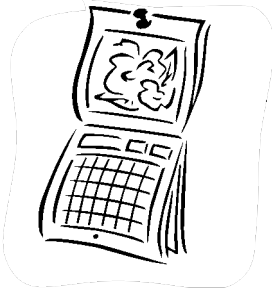
Instructions for the Autobiographical Interview

I am going to ask you to tell me about two things that have happened to you; we call these things events. I will give you a list of some events that might be of help. You can choose two events from this list or you can choose a different event, one that is not on the list. The event you choose can be from any time in your life, as long as it happened at least one month ago. I will ask you to describe one event first, then the other one. Then I will ask you some questions about the events. To help me remember what you said, I will be audiotaping your description of the event and your answers to the questions.

The event has to be one where you were personally there and you took part in what happened. Do not pick events that you have heard about from your parents, family, or friends. They must have happened to you. Also, the event should be from a specific time and place. For example, describing a 3-week vacation would not be enough; that is too general. However, something that happened on one day during your vacation would be great. I would like you to give me as much detail on what happened as you can. It is like telling me a story, for example in a book or a TV show. Stories have a beginning, a middle, and an end.

I am not interested in which events you choose, but I am interested in how you tell the event to me. Pick any event that you like from the list *[point to list]*. I want to remind you that I will be asking you to give some details for these events later. So, pick events that you feel comfortable describing to me in detail.

Do you have any questions?



Appendix D

Autobiographical Event List

Choose events that happened to you in a specific time and place more than one month ago. For example, you could choose…

- **Your last birthday**
- **A school trip**
- **A play, circus, or concert**
- **Winning an award or a prize**
- **Your first time riding a bike, skateboarding, or rollerblading**
- **A school party or dance**
- **A boat ride**
- **A train ride**
- **A trip on a plane**
- **A wedding**
- **Halloween**
- **Moving to a new home**
- **Something that happened on vacation**
- **Your first sleepover**
- **Getting your first pet**
- **A holiday party**
- **Your performance in a play, recital, or band**
- **Your graduation**

Or, you can choose something else (another event not on this list)!

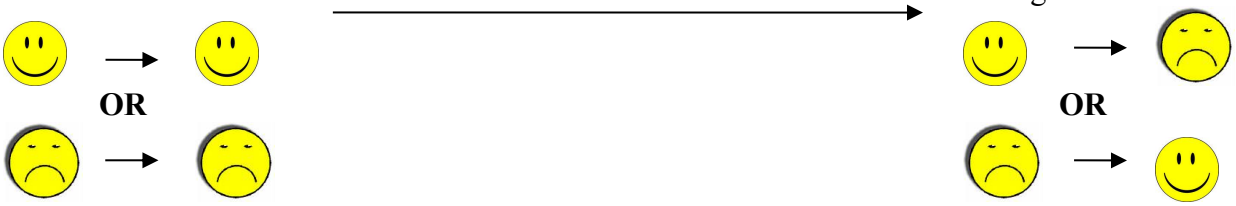
Appendix E

Participant Rating Scales

How much did your feelings (mood/emotional state) change from before to after this event happened?

1 **2** **3** **4** **5** **6** **7**

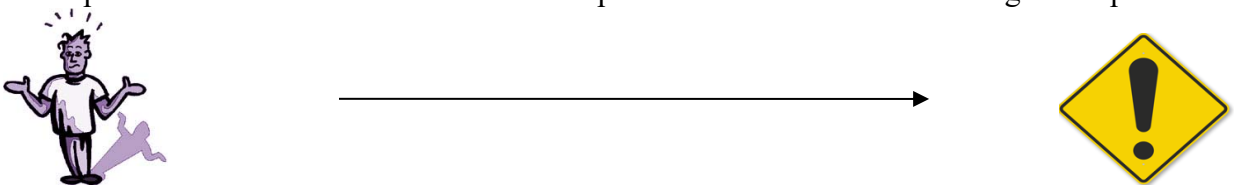
No change in how I felt — Some change — Tremendous emotional Change



How important is the event to you NOW?

1 **2** **3** **4** **5** **6** **7**

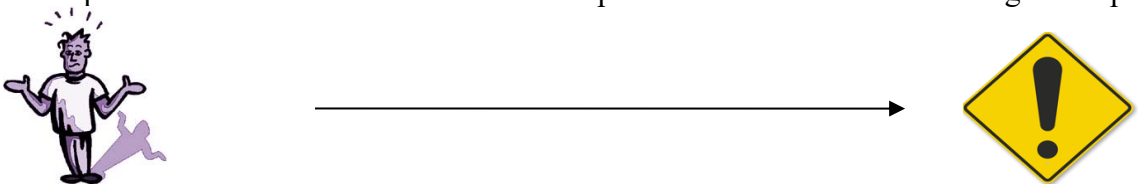
No importance — Some importance — Of great importance



How important was this event to you THEN?

1 **2** **3** **4** **5** **6** **7**

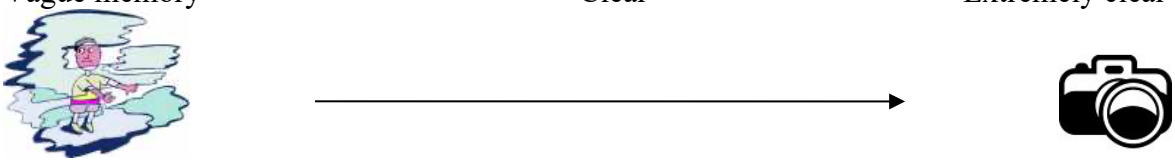
No importance — Some importance — Of great importance



How clearly can you see this event when you imagine it again?

1 **2** **3** **4** **5** **6** **7**

Vague memory — Clear — Extremely clear



How many times do you think of this event?

1	2	3	4	5	6	7
Rarely			Sometimes			Very often

How sure are you of what you remembered just now?

1	2	3	4	5	6	7
Not too sure, not confident			Somewhat confident		Very confident	

How strong is your memory of the event?

1	2	3	4	5	6	7
Not very strong				Fairly strong		Very strong

Appendix F

Sample Scored Autobiographical Memory Protocol

"Ok so ummm...well I woke up **(Event-Internal),** I remember waking up really early **(Time-Internal**) , and I woke up my entire family **(Event-Internal)** , because I was excited **(Emotion-Internal).** This was the most, the most recent Christmas, 2020 **(Time-Internal),** and umm, and we ate breakfast **(Event-Internal).** And then we went to open our gifts, and ummm some gifts I got where AirPods, clothes, like T-shirts and pajama pants, and umm I then **(Event-Internal).** Since it is Covid **(Semantic)** we had to spend it at home without family **(Event-Internal)** Some families dropped some stuff off, but ah, they couldn't stay or we couldn't spend time with them **(Event-Internal).** Umm... and that's like... and I remember like I got posters and stuff **(Event-Internal)** and I set it up in my room **(Place-Internal**). I got some video games, and I played for a bit, **(Event-Internal)** but it's pretty, not very exciting **(Emotion-Internal)** because we are in quarantine.**(Semantic)"**

Appendix G

Description of Scoring Categories

Category	Description	Example
Episodic (Internal)	Details related to an event that occurred within one day	
Event	Happenings, people involved the actions and reactions of others, the weather, buying objects or food	- 'I fell asleep' - '3 friends' -'she was smiling' - 'my mom drove' - 'it was sunny' - 'I bought a burger'
Time	Year, season, month, date, day of week, time of day	-'1 year ago' - '2010' - 'it was summer' - '2 months ago' - 'it was May' - 'it was the day before my birthday' - 'afternoon'
Place	Country, province, city, street, building, room, part of room	- 'my house' - 'I was in the kitchen' - 'I was in the 3rd row'
Perceptual	Sounds, smell, tastes, physical sensations, visual details, body position, duration of event	- 'it was loud' - 'it smelled like wood chips' - 'the apple was sweet' - 'I had a headache' - 'she was short' - 'I was standing' - 'I was there for 3 hours'
Thought/ emotion	Feelings, thoughts, opinions related to event, expectations	- 'I was so excited' - 'I didn't know what to do' - 'the worst part about the trip was…' - 'I expected a lot of people to come'
Non- Episodic (External)	Details not related to event that occurred within one day	
External	Event, time, place, perceptual, or thought/ emotion details that pertain to other events not identified as the main event in the recollection and factual information.	
Semantic	General knowledge or facts, personal knowledge or facts ongoing events, extended states of being	-Paris is the capital of France -Scott also lives in Toronto
Repetition	Unsolicited repetition of details	
Other	Metacognitive statements, editorializing inferences	- 'standing, yeah I was standing' - 'I'm not sure if I'm remembering this right - 'it was a fairly good day' - 'I must have been wearing my coat because it was winter'

Appendix H

DEMOGRAPHICS AND HISTORY QUESTIONNAIRE

Participant's Name: _____ Gender: Male Female Non-Binary Prefer Not to Answer

Date of Birth(MM/YYYY)_____ Age: _____

Participant's Cell Number: _____

SECTION 1: GENERAL INFORMATION

In your own words, describe any concerns that you might have pertaining to your physical or cognitive development, academic achievement, behaviour, or social/emotional development. If you do not know please indicate and proceed to next question.

a._____
_____

b.
_____
_____

c.
_____
_____

d.
_____
_____

SECTION 2: DEVELOPMENTAL HISTORY

1. What is your handedness?: LEFT RIGHT BOTH
2. Have you ever had or been diagnosed with (if yes, please provide further information):

   ADHD [ ] no [ ] yes –

		explain:_____
Anxiety	[ ] no	[ ] yes – explain:_____
Autism Spectrum Disorder	[ ] no	[ ] yes – explain:_____
Depression	[ ] no	[ ] yes – explain:_____
Diabetes	[ ] no	[ ] yes – explain:_____
Epilepsy	[ ] no	[ ] yes – explain:_____
Febrile Convulsion	[ ] no	[ ] yes – explain:_____
Gifted and Talented	[ ] no	[ ] yes – explain:_____
Head Injury	[ ] no	[ ] yes – explain:_____
Hearing Problems	[ ] no	[ ] yes – explain:_____
Hospitalization	[ ] no	[ ] yes – explain:_____
Language Difficulties / Disorder	[ ] no	[ ] yes – explain:_____
Learning Disability	[ ] no	[ ] yes – explain:_____
Operations	[ ] no	[ ] yes – explain:_____
Other Chronic Illness	[ ] no	[ ] yes – explain:_____
Other Psychiatric Illness	[ ] no	[ ] yes – explain:_____
Premature Birth	[ ] no	[ ] yes – explain:_____
Sensory Difficulties	[ ] no	[ ] yes – explain:_____
Thyroid Dysfunction	[ ] no	[ ] yes – explain:_____
Vision Problems	[ ] no	[ ] yes – explain:_____
Other	[ ] no	[ ] yes – explain:_____
I do not know		

3. Do you have difficulty with any of the following? (Please circle all that apply and indicate if problems are still ongoing):

	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		
I do not know		

If yes, please explain:

_____

_____

_____

_____

_____

4. Have you, either currently or in the past, received some form of professional psychological support or therapy? If yes, please describe the type of therapy, when it was received, and for how long. If you do not know please indicate and proceed to next question.

_____

_____

_____

_____

_____

_____

SECTION 3: SCHOOL HISTORY

1. Current Grade: _____ Placement: Regular___ Resource: __ Special Ed.:____ I DO NOT KNOW

2. Any difficulties at school with the following?

	Problem in the past that has resolved	**Ongoing problem currently**
Attention		
Hyperactivity		
Math		
Reading		
Spelling		
Expressing ideas when speaking (e.g. finding words, organizing thoughts)		
Printing / Handwriting		
Following instructions		
Remembering information on tests		
Reasoning / Problem solving		
Getting along with others		
Following classroom rules and routines		
I do not know		

3. Have you ever had an Individual Education Plan (IEP) at school? YES NO I DO NOT KNOW

SECTION 4: FAMILY HISTORY

1. What is your ethnicity? (please circle):
   Aboriginal (Inuit, Métis, North American Indian)
   Arab/West Asian (e.g., Armenian, Egyptian, Iranian, Lebanese, Moroccan)
   Asian American / Asian Pacific Islander
   Black (e.g., African, Haitian, Jamaican, Somali)
   Latino-a/Hispanic
   South Asian
   European Origin / White
   Bi-racial/Multi-racial
   Other: _____
   Prefer Not to Answer

2. Parents' Marital Status:
   Single _____
   Married/Common-Law _____
   Separated _____
   Divorced _____

Widowed _____
Prefer Not to Answer
I do not know

3. Does any member of the family (or extended family) have a history of **intellectual, academic, learning, or attention difficulties**? If yes, please indicate who and the nature of the difficulties. If you do not know please indicate and proceed to next question.

_____
_____

_____
_____

_____
_____

4. Does anyone in the family (or extended family) have a history of **emotional or psychiatric illnesses** (e.g., depression, anxiety, schizophrenia)? If yes, please indicate who and the nature of the difficulties. If you do not know please indicate and proceed to next question.

_____
_____

_____
_____

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

6. If not English, at what age did you start speaking English? If you do not know please indicate and proceed to next question._____

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
   Prefer Not to Answer
   I do not know

9. What is the mother's occupation? _____
   Currently employed? Yes/No
   Full-time or Part-time?
   Prefer Not to Answer
   I do not know

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
    Prefer Not to Answer
    I do not know

11. What is the father's occupation? _____
    Currently employed? Yes/No
    Full-time or Part-time?
    Prefer Not to Answer
    I do not know

12. Do you have a job? Yes/No
    If yes, what is the job? _____
    How many hours per week on average? _____
    Prefer Not to Answer

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
    - Prefer Not to Answer
    - I do not know