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The Impact of Perinatal Stroke on Parents and Families

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The Impact of Perinatal Stroke on Parents and Families

by

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Abstract

In this dissertation, I examined the parental and familial impact of raising a child with perinatal stroke. This was accomplished through three carefully planned studies that used a population-based perinatal stroke research cohort and survey methodology.

In the first study, the APSP Parental Outcome Measure (POM) was developed to assess the psychosocial impact of raising a child with perinatal stroke, including quantifiable measures of guilt and blame. The results provided strong evidence for the POM's psychometric properties among a sample of parents of children with perinatal stroke. More specifically, evidence was gathered for the POM's internal consistency, test-retest reliability, concurrent validity, convergent validity, incremental validity, and factor structure.

In the second study, the psychosocial impact of raising a child with perinatal stroke was examined. Mothers of children with perinatal stroke were compared with mothers of children with typical development and fathers of children with perinatal stroke on measures of well-being. The results illustrated that the majority of mothers of children with perinatal stroke were indistinguishable from controls. However, mothers of children with moderate and severe conditions had worse outcomes on measures of depression, quality of life, marital satisfaction, and family functioning. Furthermore, mothers of children with perinatal stroke had similar or slightly worse outcomes than fathers with the most pronounced differences in their anxiety symptoms and feelings of guilt.

In the third study, predictors of parent and family outcomes were examined, along with mediators and moderators, in order to better understand the process of adaptation to raising a child with perinatal stroke. The results showed that child and psychosocial

variables predicted parent and family outcomes. Mores specifically, condition severity, social support, anxiety symptoms, and blame independently predicted caregiver depression, while condition severity, stress levels, and marital quality independently predicted family functioning. An evaluation of mediators and moderators yielded evidence that parental blame mediates the relationship between condition severity and caregiver depression.

Collectively, these findings demonstrate that raising a child with perinatal stroke increases parents' risk for psychosocial morbidity. However, a large portion of parents demonstrate resiliency, and a complex interplay of factors contribute to the condition's parental and familial impact.

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List of Abbreviations

APPIS = arterial presumed perinatal ischemic stroke

APSP = Alberta Perinatal Stroke Project

ANOVA = analysis of variance

CDN = Canadian

CPSP = Calgary Pediatric Stroke Project

DAS = Dyadic Adjustment Scale

HADS = Hospital Anxiety and Depression Scale (-A: -Anxiety; -D: Depression)

HRQL = Health-Related Quality of Life

KMO = Kaiser-Meyer-Olkin

KMSS: Kansas Marital Satisfaction Scale

M = mean

MADE = Making a Difference Every Day

Mdn = median

NAIS = neonatal arterial ischemic stroke

PECI = Parent Experience of Child Illness

PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module

POM = (Alberta Perinatal Stroke Project) Parental Outcome Measure

PSOM = Pediatric Stroke Outcome Measure

PSS = Perceived Stress Scale

PVI = periventricular venous infarction

SD = standard deviation

SPSS = Statistical Package for the Social Science

VIF = variance inflation factor

Epigraph

The scientist is not a person who gives the right answers, he is the one who asks the right questions.

Claude Levi-Strauss

Chapter One: Introduction

With an incidence of at least 1 in 2500 live births, perinatal stroke has emerged as a leading cause of lifelong neurological disability (Raju, Nelson, Ferriero, & Lynch, 2007). Unfortunately, there are no established treatments or prevention strategies for perinatal stroke. What is more unfortunate is that the consequences of perinatal stroke are often devastating and last a lifetime (Golomb, 2009). Such morbidities unquestionably impact the child, parents, and entire family across complex elements of life and evolve over decades. Despite this, no previous research studies have examined the parental and familial impact of raising a child with perinatal stroke. This research project involved the first known studies to empirically examine the consequences of caring for a child with perinatal stroke on parents' emotional well-being, family functioning, stress levels, and marital relationship.

The purpose of this chapter is to provide a broad introduction into the subsequent studies that focus on measuring the psychosocial impact of raising a child with perinatal stroke. The literature on raising children with related conditions (e.g., cerebral palsy, epilepsy, and developmental disabilities) is reviewed extensively at the onset of Chapters Three and Four. As such, this chapter serves to provide an overview of perinatal stroke, as well as a theoretical foundation from which to understand caregivers' experiences.

Perinatal Stroke

Ischemic perinatal stroke refers to a focal interruption of blood supply in the brain that is caused by the blockage of a blood vessel during the perinatal period, which has been defined as 20 weeks of fetal life to 28 days of life (Raju et al., 2007). Although a

perinatal stroke may be hemorrhagic in nature, meaning that it is characterized by a blood leakage rather than a blood blockage, the majority of perinatal strokes are believed to be ischemic (Heart and Stroke Foundation of Canada, no date). Ischemic perinatal strokes are commonly classified based on the timing of the diagnosis as well as the location of the injury (Kirton & deVeber, 2009). This classification system results in several stroke patterns, the main three types of which will be discussed in detail – neonatal arterial ischemic stroke (NAIS), arterial presumed perinatal ischemic stroke (APPIS), and periventricular venous infarction (PVI).

NAIS is the most common type of perinatal stroke and it is characterized by an occlusion of a cerebral artery, the majority affecting the middle cerebral artery (Kirton & deVeber, 2009). A blood clot often forms in an intracranial or extracranial vessel, the heart, or the placenta, and travels to the brain where it obstructs blood flow (Lynch & Nelson, 2001). As with all ischemic strokes, the blockage of blood flow causes cell death in two phases: primary cell death, which occurs when cells do not receive their vital energy resources (i.e., oxygen and glucose) that are normally transported through blood; and secondary cell death, which occurs when a cascade of detrimental biochemical reactions occurs in response to the blockage of blood flow (e.g., increases in excitotoxicity, free radical formation, nitric oxide production, etc.) that causes further energy failure (Perlman, 2006). These events result in well-circumscribed arterial infarcts commonly involving both cortical and subcortical structures with a slight predilection for the left hemisphere (Hunt & Inder, 2006). A hallmark feature of NAIS is that it is symptomatic at birth. Infants with NAIS typically present within the first days of life with focal or generalized seizures though other signs of neurological dysfunction may be

present (Raju et al., 2007). Neuroimaging, most often a very sensitive MRI scan (i.e., diffusion weighted imaging), then confirms the presence of an acute arterial infarct.

Many other children with perinatal stroke are asymptomatic at birth and are brought to medical attention four to eight months later when asymmetrical use of hands or legs is observed, developmental milestones are delayed, or seizures occur (Nelson, 2007). These stroke injuries are termed presumed perinatal ischemic stroke, since the timing of the injury can only be speculated based on the results of neuroimaging. Both arterial presumed perinatal ischemic stroke (APPIS) and periventricular venous infarction (PVI) are presumed perinatal strokes, but there are significant differences in their stroke patterns.

Much like NAIS, APPIS is characterized by a focal infarction in an arterial distribution and it likely occurs at term (Kirton, Shroff, & Pontigon, 2010). NAIS and APPIS may be capturing the same disease process that largely differs in the timing of clinical presentation. This notion is supported by magnetic resonance imaging of these stroke injuries (Kirton et al., 2010). Nonetheless, differences exist in the functional impairments associated with NAIS and APPIS, as the latter is associated with more seizures and non-motor delays. As Kirton and colleagues suggest, this difference may be due, at least in part, to a selection bias (i.e., only symptomatic 4- to 8-month-olds will undergo neuroimaging to detect the presence of a stroke).

In contrast to APPIS, PVI is characterized by a remote focal infarction in the subcortical white matter in the periventricular region, and it likely occurs in a developing brain prior to 34 weeks of gestation (Kirton & deVeber, 2009). During this developmental period, a collection of blood vessels exists below the lateral ventricles

called the germinal matrix. For unknown reasons, the germinal matrix occasionally bleeds which leads to a blockage of the medullary veins that drain blood from the periventricular region. A blood clot may also form in the medullary veins as a result, further blocking blood flow and ultimately leading to an infarct. Previous research has suggested that PVI is the second most common type of presumed perinatal ischemic stroke next to APPIS (Kirton et al., 2010).

Risk factors. There currently are no clear causes of perinatal stroke. Although over 100 potential risk factors have been identified, no known risk factors are present in up to one third of cases of perinatal stroke (Chalmers, 2005). The most common risk factors relate to maternal and fetal/neonatal disorders. These potential risk factors include placental disorders, cardiac disorders (especially congenital heart disease), blood-clotting disorders, infectious disorders, as well as complications during pregnancy and birth (see Table 1; Chalmers, 2005; Darmency-Stamboul et al., 2012; Nelson & Lynch, 2004; Raju et al., 2007). The risk factors also appear to differ slightly depending on the type of perinatal stroke (Kirton et al., 2010). For instance, children with APPIS are more likely to have had complications during their birth, as evident by increased rates of fetal distress, emergency caesarian sections, and neonatal resuscitation.

Because a definitive cause of perinatal stroke often cannot be determined, parents may experience distress. In the absence of an explanation for their child's condition, they may blame themselves or medical staff, which may cause them to feel guilty or angry (Bemister, Brooks, & Kirton, 2014). These feelings may be exacerbated by the chronic and devastating consequences of perinatal stroke.

Table 1

Examples of Commonly Reported Risk Factors for Ischemic Perinatal Stroke

Risk Factors for Ischemic Perinatal Stroke
Cardiac disorders
Congenital heart disease
Pulmonary valve atresia
Heart rate abnormalities
Blood clotting disorders
Protein-C deficiency
Lipoprotein a
Prothrombin mutation
Polycythemia
Infectious disorders
Bacterial meningitis
Sepsis
Disseminated intravascular coagulation
Disorders of the placenta
Placental infection
Placental abruption
Placental thrombosis
Maternal factors
Preeclampsia
Autoimmune disorders
Infertility
Cocaine use
Prothrombotic disorders
Intrauterine growth retardation
Diabetes
Smoking during pregnancy
Complications of pregnancy and delivery
Trauma
Emergency cesarean section
Forceps-assisted birth
Catheterization
Birth asphyxia
Miscellaneous factors
Dehydration
Sex
Race

Chalmers, 2005; Darmency-Stamboul et al., 2013; Nelson & Lynch, 2004; Raju et al., 2007

Outcome. Perinatal stroke is the number one cause of hemiparetic cerebral palsy, accounting for over 30% of all cases of cerebral palsy (Raju et al., 2007). Approximately 70-80% of children with perinatal stroke have these motor impairments (Golomb, 2009). Additionally, children with motor impairments after perinatal stroke are the most likely to have other disabilities (Golomb, Saha, Garg, Azzouz, & Williams, 2007). Other common disabilities are epilepsy, which occurs in approximately 40% of cases, and cognitive deficits, which occurs in approximately 40-60% of cases (Golomb, 2009; Sreenan, Bhargava, & Robertson, 2000). In addition, children with perinatal stroke often have language delays, behavioural problems, spatial impairments, and sensorimotor deficits (e.g., abnormal visual function; Kirton & Deveber, 2013; Murias, Brooks, Kirton, & Iaria, 2014). The vast majority endure life-long disabilities and a rare few do not survive after the stroke injury (less than 5%; Golomb, 2009). True estimates of the morbidity of perinatal stroke are difficult to determine because a child's brain is constantly developing and some difficulties are not detectable until later in development (Westmacott, MacGregor, Askalan, & deVeber, 2009), while others naturally resolve with seizures being the most common (Kirton & Deveber, 2013). This constantly creates new challenges for the parents and child as the child ages. Moreover, the outcomes may vary depending on the type of stroke syndrome. Motor impairments are common in all of the stroke syndromes previously reviewed, while non-motor outcomes (e.g., seizures, cognitive deficits, behavioural problems, etc.) are most common in arterial stroke injuries involving the cortex (i.e., NAIS and APPIS; Kirton, DeVeber, Pontigon, Macgregor, & Shroff, 2008).

Thus, it is not surprising that perinatal stroke outcomes range vastly from neurological normalcy to severe quadriplegia. The ability to predict perinatal stroke outcomes at the time of diagnosis is unfortunately relatively limited (Kirton & Deveber, 2013), which likely exacerbates parents' reactions of stress and worry. However, some evidence exists that outcomes vary depending on lesion size and location (Kirton et al., 2008; Lee et al., 2005).

Impact on Parents and Families

Grief. During pregnancy, parents build up expectations of what their child will be like as they age, which are generally quite optimistic (Leerkes & Burney, 2007). Within the first year of life, parents of children with perinatal stroke are often confronted with the fact that their child will have lifelong disabilities. Consequently, these parents need to adjust their expectations and hopes for their child and manage their uncertainties about their child's future (Barnett et al., 2006). Hence, the mourning process following the diagnosis of a child with a disability is often described as "grieving the loss of the perfect child" (Marvin & Pianta, 1996).

Parental reactions to the diagnosis of a disabled child have been compared to the bereavement following the death of an infant (Solnit & Stark, 1961). The experiences of shock, denial, sadness, loss, resentment, and guilt are remarkably similar in both situations. Mothers of infants who have a stroke may have a similar experience and feel irrational guilt and aggression during the mourning process, despite the fact that their child's stroke was almost certainly unpreventable. These reactions have been reported in

parents of infants in neonatal intensive care units (Barr, 2012) and infants with sudden infant death syndrome (Hasui & Kitamura, 2004).

As mentioned previously, mothers of infants with perinatal stroke may be highly susceptible to experiencing intense guilt and blame because the causes of perinatal stroke are not well understood, and they may irrationally believe that something they did during their pregnancy, or the medical staff did during their child's birth, contributed to their child's stroke (Bemister et al., 2014). These feelings of guilt and blame may differentiate parents of children with perinatal stroke from other disabilities, and they may burden parents for many years, perhaps their entire life, if they are never addressed. Research has begun to show the detrimental effects of such feelings on parental well-being. For example, Barr (2012) found that parental guilt had detrimental effects on post-traumatic stress, anxiety, and depression among a group of parents of children in a neonatal intensive unit. However, the long-term effects on perinatal stroke populations are yet to be determined.

Even though there is consensus in the literature that parents experience grief following their infant's diagnosis of a disability, there is disagreement regarding what is a 'normal' grief process (Lowes & Lyne, 2000). Currently, there are two conflicting theories that dominate the literature on the normal grief process. The first is a time-bound theory, which is in line with conceptualizations of loss following death. Time-bound theories assume that parents will naturally come to terms with their infant's diagnosis as they progress through sequential stages of grief that accumulate towards resolution (Solnit & Stark, 1961). For instance, Fortier and Wanlass (1984) identify five stages of

parental responses to their child's diagnosis of a disability: impact, denial, grief, focusing outward, and closure. While some authors have found that parents of children with disabilities come to terms with their child's diagnosis (Rentinck et al., 2010; Schuengel et al., 2009), others have found disrupted grieving processes among these parents, which Solnit and Stark (1961) attribute to the overwhelming demands of adapting to the birth of a disabled child.

A competing and increasingly popular theory suggests that parental grief is an ongoing process. Feelings of grief and sorrow may co-exist with feelings of joy and happiness, fading and re-emerging throughout the child's life. This theory was coined chronic sorrow (Olshansky, 1962), and it was introduced to explain the experiences of parents of children with intellectual disabilities. Thus, this theory assumes that the grieving process due to death and disability are remarkably different. Eakes and colleagues suggest that the fundamental difference is the ongoing disparity parents feel between their child's current reality and idealized reality, which is brought to the forefront of parents' minds at critical times in their child's development, such as developmental milestones and events that serve as reminders (Eakes, Burke, & Hainsworth, 1998). As such, parents may continue to experience periodic feelings of grief, anger, helplessness, and guilt when they become acutely aware of the difference between their actual child and their hoped-for child. The chronic sorrow theory suggests that parents do not necessarily come to terms with their child's diagnosis regardless of successfully adapting their lives to accommodate for their child's condition. This theory has substantial support and has been applied to parents of children with a variety of neurodevelopmental conditions (e.g., epilepsy, cerebral palsy, intellectual disabilities, and

neural tube defects; Hobdell et al., 2007; Whittingham, Wee, Sanders, & Boyd, 2013; Brown, 2013; Hobdell, 2004), but it has never been studied in perinatal stroke.

In summary, Olshansky (1962) believes that chronic sorrow is a natural response to ongoing loss, while Solnit and Stark (1961) view it as a disruption in the time-bound grieving process. Regardless, there is evidence to suggest that parents of children with disabilities periodically experience grief and its accompanying feelings of anger, sadness, worry, and guilt throughout their child's life, which may affect the parents' emotional well-being.

Parent and family adaptation. Although theories of grief lay a strong foundation from which to understand parents' experiences, they do not address the long-term stressors that accompany raising a child with additional needs. A myriad of research supports that parents of children with disabilities experience higher caregiver stress than parents of children with typical development, even though a large portion of them adapt well (Miodrag & Hodapp, 2010). Several stress-process models have been developed to help explain differences in parental and family adaptation to raising a child with a disability.

The double ABCX model (McCubbin & Patterson, 1983) is currently one of the most influential stress-process models for understanding families of children with disabilities. The double ABCX model is an extension of Reuben Hill's ABCX model (1949), which was initially developed to guide a longitudinal study of families whose husbands/fathers were unaccounted for in the Vietnam War. Hill proposed that the adaptation to a crisis (X) is dependent on the stressors and hardships placed on the family

(A), as well as their available resources (B), and the meaning they give to the crisis (C). McCubbin and Patterson extended this model to account for the passing of time and the accumulation of stressors (aA) and resources (bB), as well as the meaning the family gives to the total crisis situation (cC). According to this model, family adaptation is based on the balance between the pile-up of stressors and the family's capabilities for meeting those demands. Minnes first applied the double ABCX model to caring for children with intellectual disabilities in 1988. Since then, the model has been examined and supported among parents of children with a wide range of disabilities, such as autism, Down syndrome, cerebral palsy, spina bifida, and sickle cell disease (Hall et al., 2012; Manning, Wainwright, & Bennett, 2011).

Lazarus and Folkman (1984) presented a similar stress-process model, but they elaborated on the cognitive attributions and incorporated a fourth variable, coping responses. Their model therefore suggests that family adaptation to raising a child with perinatal stroke may depend on the following: the stressful event, caregivers' appraisals of the event (primary and secondary), personal resources for coping, and coping responses (emotion-focused and problem-focused). According to Lazarus and Folkman, primary appraisals involve evaluating the significance of the stressful event whereas secondary appraisals involve evaluating the available resources to deal with the stressful event. These authors also differentiate between problem-focused coping and emotion-focused coping; the former entails managing the source of stress while the latter entails managing the distressing emotions. Coping responses are believed to be most effective if there is a match between the appraisals of the event and the coping strategy employed (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Nonetheless, problem-

focused coping has generally been associated with decreased distress among parents of children with disabilities (Bayrakli & Kaner, 2012; Woodman & Hauser-Cram, 2013). Emotion-focused coping strategies have also been found to benefit parents of children with disabilities, particularly when they involve positive interpretation (Cheshire, Barlow, & Powell, 2010; Trute, Benzies, Worthington, Reddon, & Moore, 2010). This stress-process model has been deemed effective for conceptualizing parents' and families' abilities to cope with pediatric disabilities (Beresford, 1994).

Other models concentrate on the various factors and their interactions that affect adaptation to raising a child with a disability. For instance, Raina and colleagues' multidimensional model (2004) summarizes the relationships between the child's chronic condition and behaviour, caregiver characteristics, social supports, family functioning, and the outcomes of caregivers' physical and psychological health. This model has been tested with parents of children with cerebral palsy (Raina et al., 2005), and it integrates the advantages of three different stress-process models that are largely based on parents of children with chronic conditions and neurodevelopmental disabilities (i.e., King, King, Rosenbaum, & Goffin, 1999; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Wallander et al., 1989).

More specifically, Raina's multidimensional model incorporates the risk-resilience model by Wallander and company (1989) and its extension by King and colleagues (1999). Briefly, Wallander and colleagues conceptualize parental adaptation as a process that is determined by risk factors (e.g., characteristics of the child's disability) and moderated by social-ecological factors and coping abilities. King and

colleagues expanded this model by incorporating parental perceptions of the quality of outside care as an additional moderator. In addition, Raina's multidimensional model incorporates aspects of a geriatric model of caregiving proposed by Pearlin and colleagues (1981). This geriatric stress-process model considers the primary stressors associated with caregiving (e.g., providing daily assistance with tasks) and the secondary stressors (e.g., economic strain). Hence, Raina's multidimensional model provides a comprehensive theoretical framework that considers background and context, child characteristics, caregiver strain, intrapsychic factors, and outcomes regarding coping, support, and health. This model has been influential in the pediatric disability literature, as it stresses the complex interplay of factors that affect parent outcomes, and it appears to be one of the most comprehensive models of its kind. However, it is scarcely identified as the theoretical framework for research studies, which may be due to its complexity.

Several additional theories have guided current knowledge on the adaptation of parents of children with disabilities (Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001). For instance, the social ecology theory (Bronfenbrenner, 1979) suggests that individual development occurs within multiple environments that range from the most proximal (i.e., the individual) to the most distal (i.e., the culture). This theory has guided researchers to examine the parents' functioning within the family context and within society by considering, for example, available support systems and marital relationships (Algood, Harris, & Hong, 2013). Other theories, such as the family systems theory (Minuchin, 1988), suggest that families are interactive systems in which changes in one member affects other members. Thus, a child's disability not only affects his or her

parents, but the parents' ability to adapt to the disability affects the child (Baker, Seltzer, & Greenberg, 2011).

Although nuances and notable differences exist between the reviewed stress-process models and theories, together they highlight the impetus to enhance knowledge of why some parents and families cope better than others. Striking similarities exist between these models and theories, particularly in their preponderance on stressors and resources that are personal and environmental in nature. For this reason, it is not surprising that the most parsimonious model, the double ABCX model, appears to be the most popular in the pediatric disabilities literature. However, as Turnbull and colleagues note, caregiver studies often fail to identify a theoretical framework (Turnbull, Summers, Lee, & Kyzar, 2007).

Parental and family well-being. Copious research studies exist on the parental and familial impact of raising a child with a pediatric disability, which are reviewed in subsequent chapters. Briefly, there is remarkable consistency across these studies regarding the negative impact on parents' physical and psychological health. Reviews and meta-analyses indicate that mothers of children with cerebral palsy, epilepsy, and developmental disabilities tend to have more psychological concerns (notably depression symptoms), increased stress levels, and poorer quality of life than mothers of children with typical development (Duffy, 2011; Ferro & Speechley, 2009; Pousada et al., 2013; Singer, 2006). Similarly, these mothers tend to report more marital distress and poorer family functioning, although discrepancies exist with respect to these findings (Reichman, Corman, & Noonan, 2008; Risdal & Singer, 2004). These discrepancies may

be due, at least in part, to the potential strain *and* strengthening of relationships that may follow from challenges within the family system. Furthermore, a variety of factors have been shown to contribute to variation in parent and family outcomes, such as condition severity, parent gender, and sociodemographic factors (Raina et al., 2004; Rentinck, Ketelaar, Jongmans, & Gorter, 2007). Despite the disheartening nature of these findings, it is universally accepted that several parents and families of children with disabilities demonstrate resiliency. The benefits of raising a child with a disability (e.g., increased compassion and personal growth) are also well acknowledged in the literature (Hastings, Beck, & Hill, 2005; Home, 2008).

Summary and Overview of Dissertation Chapters

Similar to other types of pediatric disabilities, the consequences of raising a child with perinatal stroke have been long suspected to include psychological morbidity, increased stress levels, and pressure on marital relationships and family functioning, but they are yet to be examined. A strong theoretical basis exists for their exploration among parents, and mothers in particular, as indicated by existing grief theories, stress-process models, and caregiver research studies. This research project serves to address this gap in the literature by being the first empirical investigation of the familial and parental impact of raising a child with perinatal stroke. Using a population-based sample of symptomatic perinatal stroke syndromes in southern Alberta, this research project set out to answer the following questions: (1) How can we reliably measure the impact of raising a child with perinatal stroke, including guilt and blame outcomes?; (2) How are mothers impacted by raising a child with perinatal stroke in comparison to mothers of children with typical development? How are they impacted in comparison to fathers of children with perinatal

stroke?; and (3) What factors predict parent and family outcomes? What are the mechanisms (i.e., mediators and moderators) of these outcomes? This dissertation aims to address these questions in a systematic manner using questionnaire data collected from a population-based research cohort of families affected by perinatal stroke (i.e., Alberta Perinatal Stroke Project). Each of the following chapters is devoted to addressing one of the above questions with careful consideration of theory and statistics.

In Chapter Two, a 26-item questionnaire was developed to reliably assess the psychosocial impact of raising a child with perinatal stroke, including guilt and blame outcomes. This scale was named the Alberta Perinatal Stroke Program (APSP) Parental Outcome Measure (i.e., the POM) and it was validated on 110 parents of children with perinatal stroke. All questionnaire items were derived from expert opinion and scientific literature on issues salient to parents of children with perinatal stroke, which were not well captured in existing measures of family impact. The parents completed the POM and related questionnaires, and the data was analyzed to determine the POM's internal consistency, test-retest reliability, validity, and factor structure. The results revealed that the POM demonstrates three unique theoretical constructs: Psychosocial Impact, Guilt, and Blame. In addition, the results showed that the POM has excellent internal consistency and very good test-retest reliability over two to five weeks. Regarding validity, the POM was sensitive to condition severity, accounted for additional variance in parent outcomes, and strongly correlated with measures of anxiety, depression, stress, quality of life, family functioning, and parent adjustment. As such, this study supports the use of the POM as the first valid and reliable scale for parents of children with perinatal stroke that includes quantifiable measures of psychosocial impact, guilt, and blame.

In Chapter Three, the maternal impact of raising a child with perinatal stroke was examined using two comparison groups: mothers of children with typical development (Part I) and fathers of children with perinatal stroke (Part II). All of the participants completed validated measures of anxiety and depression, stress, quality of life and family functioning, marital satisfaction, and marital distress. Parents of children with perinatal stroke also completed the recently validated POM. In Part I, condition severity was categorized by parents, validated by the Pediatric Stroke Outcome Measure (PSOM), and compared across the above outcomes. The results revealed that parent assessment of condition severity was strongly correlated with PSOM scores and associated with parent outcomes. Mothers of children with mild conditions were indistinguishable from mothers of children with typical development on the outcome measures. However, mothers of children with moderate/severe conditions had poorer outcomes on measures of depression, marital satisfaction, quality of life, and family functioning. In Part II, mothers and fathers had similar outcomes except mothers demonstrated a greater burden of guilt and higher levels of anxiety. This chapter therefore demonstrates that, although most mothers of children with perinatal stroke adapt well, mothers of children with moderate and severe conditions appear to be at higher risk for psychological concerns.

Chapter Four builds on the findings in Chapter Three by investigating which factors predict parent and family outcomes. Child factors (e.g., condition severity and presence of behavioural problems), parent factors (e.g., gender and gross family income), and psychosocial factors (e.g., stress levels and social support) were examined as determinants of caregiver depression and family functioning. The results revealed that condition severity, anxiety symptoms, social support, and blame independently predicted

caregiver depression, while condition severity, stress levels, and marital quality independently predicted family functioning. An evaluation of the mediators and moderators of the relationship between condition severity and parent/family outcomes showed that parents' feelings of blame regarding the cause their child's condition was an independent mediator. Thus, this study sheds light on why some parents and families of children with perinatal stroke cope better than others while highlighting potential targets for intervention (e.g., stress management and psycho-education regarding the unpreventable nature of perinatal stroke).

In the fifth and final chapter, the full set of findings are reviewed, as well as each study's unique contribution to present knowledge of the impact of raising a child with perinatal stroke. In addition, the general limitations of this research project are reviewed and pertinent directions for future research studies are highlighted.

The following chapter is a reproduction of a published work. The publishing company, Elsevier, has granted permission for use of this publication in this dissertation (Appendix B). I was the primary investigator and main contributor for the publication entitled, *Development, Reliability, and Validity of the Alberta Perinatal Stroke Project (APSP) Parental Outcome Measure*. I was responsible for all aspects of the study, including its design, data collection, data analysis, interpretation, and write-up. Doctors Brooks and Kirton provided me with guidance, contributed to the study design, and extensively reviewed the manuscript.

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Chapter Two: Development, Reliability, and Validity of the Alberta Perinatal Stroke Project (APSP) Parental Outcome Measure

Perinatal stroke is a common but poorly understood focal cerebovascular brain injury occurring between 20 weeks gestation and 28 days of postnatal life (Raju, Nelson, Ferriero, & Lynch, 2007). With an incidence of more than 1 in 2500 live births, it remains a leading cause of pediatric neurological disability and the primary cause of hemiplegic cerebral palsy. While motor impairments are the most prevalent deficit (affecting 60-80%), other common outcomes include developmental delays, cognitive deficits, behavioural problems, and epilepsy (Golomb, 2009; Lynch, 2009). Such morbidities last decades with potentially severe and longstanding impacts on the child and family.

Parents of children with perinatal stroke not only need to adjust to their child's diagnosis, but also the additional caregiver demands that accompany raising a child with a disability. Although there are currently no published studies on the impact of raising a child with perinatal stoke, a myriad of research exists on the impact of raising a child with other neurological conditions, such as cerebral palsy (Pousada et al., 2013), epilepsy (Duffy, 2011), and developmental disabilities (Miodrag & Hodapp, 2010). These studies indicate that parents of children with neurological diagnoses tend to have poorer psychological well-being than parents of children with typical development, albeit the majority of these families adapt well. Recognizing the variation that exists in parent outcomes, researchers have begun to focus on why some parents and families cope better than others (Rentinck et al., 2010).

Many caregiver stress models help explain differences in the impact of caring for a child with a disability, the most influential in the literature being the Double ABCX

Model (McCubbin & Patterson, 1983). According to this model, parent adaptation is based on the balance between the pile-up of stressors and the parent's capabilities for meeting those demands. While the majority of research studies in this area fail to note a conceptual framework (as highlighted by Turnbull, Summers, Lee, and Kyzar, 2007), studies that assess the impact of pediatric disability on parents and families tend to measure stressors and resources that are interpersonal, emotional, and physical in nature.

Parents of children with perinatal stroke may share many of the same stressors as parents of children with other disabilities and medical conditions, which are captured in widely used questionnaires of family impact (e.g., Impact on Family Scale [Stein & Riessman, 1980], Child Health Questionnaire [Landgraf, Abetz, & Ware, 1996], Beach Centre Family Quality of Life Scale [Summers et al., 2005], and PedsQL Family Impact Module [Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004]). These questionnaires tend to measure family functioning, parent well-being (e.g., social, emotional, and physical), and resources (e.g., finances and time). However, they fail to directly assess guilt and blame, which has been noted as a salient concern among mothers of children with perinatal stroke (Kirton, Westmacott, & deVeber, 2007), but has received limited attention in the literature thus far.

Mothers of children with perinatal stroke may be highly susceptible to feelings of guilt and blame because the approximate timing of the stroke is known, but the causes are not well understood. Some mothers consequently turn to apparent perinatal events as possible explanations, such as personal actions during pregnancy or medical staff actions approximating delivery. Unaddressed, these feelings may exacerbate caregiver burden, depression, and anxiety, as evidenced by previous studies on caregiver guilt (Boye,

Bentsen, & Malt, 2002; Gonyea, Paris, & de Saxe Zerden, 2008; Spillers, Wellisch, Kim, Matthews, & Baker, 2008). Feelings of guilt and blame may also adversely affect parental adaptation to their child's condition (Gallagher, Phillips, Oliver, & Carroll, 2008; Hall & Marteau, 2003), which consequently can have detrimental effects on the child's well-being (Carona, Crespo, & Canavarro, 2013). Furthermore, our clinical experiences suggest that these feelings of guilt and blame are amendable to simple psycho-education interventions regarding the generally unpreventable nature of perinatal stroke.

At this time, there is no existing measure of the impact of raising a child with a disability or medical condition that quantifies parent guilt and blame. The Parent Experience of Childhood Illness (PECI; Bonner et al., 2006) scale is a family adaptation measure that examines a related but distinct construct of 'Guilt and Worry'. Thus, currently available family impact measures fail to assess all of the issues salient to families affected by perinatal stroke.

The purpose of this study was to develop and validate a family impact measure designed for parents affected by perinatal stroke. The questionnaire was constructed to quantify guilt and blame, as well as assess the general impact of perinatal stroke on parents' psychological well-being, personal activities, resources, and family functioning. We predicted that the questionnaire would strongly correlate with other measures of family impact and emotional well-being (stress, depression, and anxiety), while uniquely capturing parents' sense of guilt and blame.

Methods

Participants

Parents of children with perinatal stroke were identified through the Alberta Perinatal Stroke Project (APSP), a population-based research cohort of >180 perinatal stroke patients in southern Alberta. Inclusion criteria were biological parents of children 0-18 years with clinico-radiographically confirmed perinatal stroke according to validated criteria (i.e., neonatal arterial ischemic stroke, periventricular venous infarction, or arterial presumed perinatal stroke; Kirton & deVeber, 2009). Children with neurological conditions not attributable to stroke and parents with less than Grade 9 education or unable to read English (self-report) were excluded to ensure comprehensibility of the questionnaires.

Questionnaire Development

The APSP Parental Outcome Measure (POM) was developed by a multidisciplinary team with expertise in perinatal stroke. Team members included a pediatric stroke neurologist (AK), neuropsychologist (BB), doctoral clinical psychology student (TB), and stroke nurse (SR; see acknowledgements). This team reviewed the literature on caring for children with disabilities and, combined with their clinical experiences, created a list of 34 items relevant to parents of children with perinatal stroke. The list included both resources and stressors (e.g., adequate support caring for child and financial strain).

A draft of the POM was then distributed to 10 healthcare professionals familiar with the target population and six parents of children with perinatal stroke. Feedback was

obtained regarding the POM's item content, face validity, and wording. Recommendations included simplifying the wording (14 items), adding one item about family planning, and removing four items due to redundancy.

The resulting scale of 31 items was later revised to 26 items based on exploratory factor analysis (see Appendix A for the scale). Each item is scored on a 5-point Likert scale from 0 (Strongly Disagree) to 4 (Strongly Agree) with higher scores indicating poorer functioning. The final questionnaire takes approximately five minutes to complete and is at a Grade 7.6 reading level (Flesch-Kincaid Grade Level).

Data Collection

Approval was obtained from the Conjoint Health Research Ethics Board at the University of Calgary. APSP parents who previously consented to be contacted for research were approached via telephone or e-mail depending on their preference. The study was explained and informed consent was obtained. Participants were e-mailed a URL to a battery of questionnaires, including the POM, at Time Point 1 (closed survey design). They were able to save and alter their responses prior to submission. Two weeks after submission, participants were e-mailed a second URL to the POM (Time Point 2). Those failing to submit responses were e-mailed reminders after two weeks. Participants received a $10 eGift card in recognition of their contribution.

Questionnaires were administered between August 2012 and June 2013 with the online survey software, Qualtrics. Data were downloaded from Qualtrics and stored in a secure database at the Alberta Children's Hospital.

General Measures

Demographics. The Demographics Questionnaire is a 26-item scale created for this study to assess basic demographic information.

Anxiety and depression. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a 14-item scale that measures self-reported symptoms of anxiety (HADS-A) and depression (HADS-D) within the past week. Comprehensive reviews have indicated that the subscales have good reliability and validity (Bjelland, Dahl, Haug, & Neckelmann, 2002; Herrmann, 1997). Although the HADS was originally developed for medical patients in hospital settings, the scale has since been validated in community populations (Bjelland et al., 2002) and used among populations similar to the current study (Cheshire, Barlow, & Powell, 2010; Shariff et al., 2013).

Perceived stress. The Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) is a 14-item self-report measure that generates a total score reflecting the extent to which situations are judged as being stressful. The PSS is considered an effective tool for evaluating stress in parents of children with disabilities (Lessenberry & Rehfeldt, 2004), and the authors have demonstrated the scale's reliability and validity among two college samples and one community sample.

Family Impact Measures for Pediatric Health Conditions

Quality of life and family functioning. The Pediatric Quality of Life Inventory-Family Impact Module (PedsQL-FIM; Varni et al., 2004) measures the impact of pediatric chronic health conditions on parent quality of life and family functioning. The scale consists of 36 self-report items, which generate two summary scores (Family

Functioning and Health-Related Quality of Life) and a total score. The PedsQL-FIM has been validated in parents of children with and without chronic conditions, demonstrating excellent internal consistency and convergent validity in both populations (Mano, Khan, Ladwig, & Weisman, 2011; Medrano, Berlin, & Davies, 2013).

Psychosocial impact, guilt and blame. The APSP Parental Outcome Measure (POM) is a scale designed for parents of children with perinatal stroke to examine the impact of their child's condition on the family. The final scale consists of 26 items that examine psychosocial impact, guilt, and blame. Evidence for the scale's psychometric properties is gathered in this study (see results).

Emotional adjustment to illness. The Parent Experience of Child Illness (PECI; Bonner et al., 2006) is a measure of parent adjustment to caring for a child with a chronic illness. The scale consists of 25 self-report items measuring four domains: 1) guilt and worry; 2) emotional resources; 3) unresolved anger and sorrow; and 4) long-term uncertainty. The PECI was originally validated with parents of children with brain tumors and cancer and has since been applied to parents of children with other chronic conditions (Storch et al., 2009). This questionnaire was chosen for comparison purposes because it most closely resembles the POM in that it measures parent guilt and worry. To make it applicable to this study's population, the wording of the PECI was modified slightly to align with parenting a child with a chronic condition.

Statistical Analyses

Parents who did and did not participate in the study were compared on basic demographic variables using chi-square analyses for categorical data and *t*-tests for

continuous data. These analyses were repeated for both time points. Basic demographic information was available for the parents who participated in the study and was approximated for those who did not using Postal Code Conversion Files (Statistics Canada, 2011).

Shapiro-Wilk Test of Normality indicated that the POM data did not violate the assumption of normality, therefore parametric analyses were used. Item analysis and tests of the data's amenability to factoring were conducted (KMO test and Bartlett's test of sphericity) followed by assessments of the POM's factor structure, reliability, and validity.

To evaluate the POM's factor structure, principal axis factoring with promax rotation was used (Gorsuch, 1990). Pearson-product moment correlations were employed to evaluate the POM's internal consistency, test-retest reliability, convergent validity, and concurrent validity. Concurrent validity was further assessed by examining whether the POM could differentiate between parents of children with mild, moderate, and severe outcomes using a one-way analysis of variance (ANOVA) and planned comparisons. An auxiliary analysis used a paired *t*-test to examine whether the POM could differentiate between mother-father pairs. Hierarchical multiple regression analyses were conducted to evaluate the POM's incremental validity over other family impact measures (PedsQL-FIM and PECI). Separate analyses were conducted for the parent outcomes of anxiety (HADS-A), depression (HADS-D), and stress (PSS). For all of the analyses, SPSS Version 19.0 was used and Bonferroni corrections were applied as needed.

Results

Sample

A total of 110 parents of children with perinatal stroke participated in this study (Figure 1). The majority of the parents were female (74.5%) and Caucasian (91.8%; Table 1). Condition severity was classified as mild (63.1%), moderate (31.0%), or severe (6.0%) according to parents' ratings, which were in strong agreement with the results of the standardized Pediatric Stroke Outcome Measure (PSOM; deVeber, MacGregor, Curtis, & Mayank, 2000), Goodman and Krusk's gamma correlation (γ) = 0.64, $p < .001$. PSOM data was accessed from the APSP database for the children in which the data was available and consent was obtained (n = 76).

There were no significant differences between those who did and did not complete the questionnaire battery at Time Point 1 in terms of the child's sex and type of stroke. However, differences emerged when evaluating parent sex ($\chi^2(1, 110) = 26.51$, $p < .001$), ethnicity ($\chi^2(1,110) = 10.20$, $p = .001$), gross family income ($\chi^2(2,110) = 9.23$, $p = .01$), and level of education ($\chi^2(4,110) = 33.73$, $p < .001$) suggesting that fathers, ethnic minorities, and those with lower incomes and levels of education were less likely to participate in this study. No differences existed among parents who participated and did or did not complete the POM at Time Point 2.

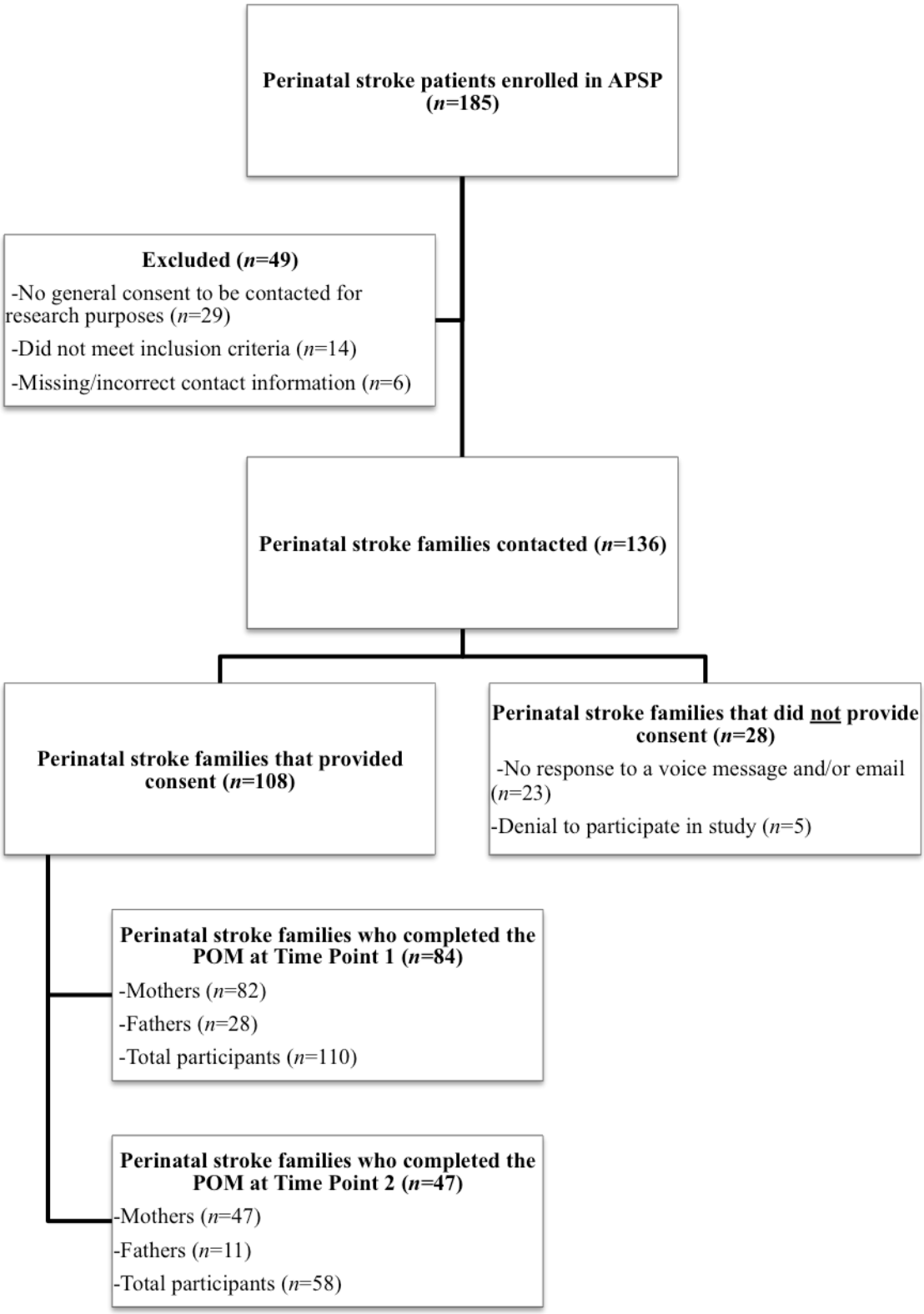
Perinatal stroke patients enrolled in APSP (n=185)
Excluded (n=49)
-No general consent to be contacted for research purposes (n=29)
-Did not meet inclusion criteria (n=14)
-Missing/incorrect contact information (n=6)
Perinatal stroke families contacted (n=136)
Perinatal stroke families that provided consent (n=108)
Perinatal stroke families that did not provide consent (n=28)
-No response to a voice message and/or email (n=23)
-Denial to participate in study (n=5)
Perinatal stroke families who completed the POM at Time Point 1 (n=84)
-Mothers (n=82)
-Fathers (n=28)
-Total participants (n=110)
Perinatal stroke families who completed the POM at Time Point 2 (n=47)
-Mothers (n=47)
-Fathers (n=11)
-Total participants (n=58)

Figure 1. Response rate throughout the recruitment process. Both parents completed the POM in 26 cases at Time Point 1 and 11 cases at Time Point 2. APSP = Alberta Perinatal Stroke Project; POM = APSP Parental Outcome Measure.

Table 1

Parent and Child Demographics as a Percentage of the Sample

	Parent (*n* = 110)	Child (*n* = 84)
	n (%)	*n* (%)
Sex		
Male	28 (25.5%)	37 (44.0%)
Female	82 (74.5%)	47 (56.0%)
Ethnicity		
Caucasian/White	101 (91.8%)	72 (85.7%)
Southeast Asian	3 (2.7%)	2 (2.4%)
Hispanic/Latino	2 (1.8%)	2 (2.4%)
First Nations/Aboriginal	1 (0.9%)	1 (1.2 %)
Other (mixed ethnicity)	3 (2.7%)	7 (8.3%)
Type of perinatal stroke		
nAIS		28 (33.3%)
APPIS		21 (25.0%)
PVI		22 (26.2%)
Unclassified		13 (15.5%)
Severity of perinatal stroke[a]		
Mild		53 (63.1%)
Moderate		26 (31.0%)
Severe		5 (6.0%)
Total gross household income		
< $30,000	7 (6.4%)	
$30,000-70,000	29 (26.4%)	

$71,000-110,000	27 (24.5%)	
$111,000-150,000	24 (21.8%)	
>$151,000	23 (20.9%)	
Hours spent caregiving		
<10	26 (23.6%)	
10-20	12 (10.9%)	
21-30	3 (2.7%)	
31-40	4 (3.6%)	
>40	65 (59.1%)	
Education level		
Grade school certificate	4 (3.6%)	
High school certificate	20 (18.2%)	
College certificate or diploma	39 (35.5%)	
Bachelor's degree	30 (27.3%)	
Master's, doctorate, or professional degree	17 (15.5%)	
	Mean (*SD*), Range	Mean (*SD*), Range
Age (years)	39.5 (7.4), 26-59	7.4 (5.3), 0.5-18
Years since perinatal stroke diagnosis[b]		5.4 (4.4), 0.0-18
Years since first clinical presentation[b]		6.7 (5.0), 0.0-18
Motor impairments[c]		1.81 (1.09), 0-4
Cognitive impairments[c]		0.89 (1.18), 0-4
Language impairments[c]		0.91 (1.20), 0-4
Behavioural impairments[c]		0.77 (1.22), 0-4
Visual impairments[c]		0.57 (1.06), 0-4
Seizures[c]		0.55 (1.06), 0-4
PSOM total[d]		1.85 (1.87), 0-9

Note. nAIS = neonatal arterial ischemic stroke; APPIS = arterial presumed perinatal ischemic stroke; PVI = periventricular venous infarction; PSOM = Pediatric Stroke Outcome Measure.

[a]Rating is based on parents' self-reported perceptions of the severity of their child's condition. [b]*n* = 71. [c]Participants rated their child's symptoms on a scale of 0 (non-existent) to 4 (severe). [d]*n* = 76.

Item Analysis

To examine the effectiveness of the POM's items, inter-item correlations, corrected item-total correlations, and Cronbach's α values following the deletion of items were examined. The results revealed one problematic item ("Having a family member with a medical condition positively impacts my other family members") that was removed from the scale. This item demonstrated a relatively low corrected item-total correlation and inter-item correlations (<.30), and its removal improved the internal consistency of the scale based on changes to Cronbach's α (from .91 to .92).

Factor Structure

Initial analyses revealed that the data were suitable for factor analysis (KMO = .85; Bartlett's test of sphericity, $p < .001$). In order to determine the number of factors, the scree test (Cattell, 1966), parallel analysis (Horn, 1965), and minimum average partial test (Velicer, 1976) were conducted according to O'Connor's recommendations (O'Connor, 2000). The results of all three analyses indicated the presence of three factors. The percentage of variance explained for the first three factors were as follows: 30.60%, 9.76%, and 6.47%. Thus, the model accounted for a total of 46.83% of the variance.

The factor structure was then rotated using a promax rotation and factor loadings of .32 or higher in the pattern matrix were considered substantial (Tabachnick, Fidell, & Osterlind, 2001). The results revealed that two items about parent education and two items about the benefit of raising a child with a medical condition failed to adequately load on any of the factors. As a result, these items were dropped. An additional two items

cross-loaded on multiple factors, all of which were theoretically related. These items were assigned to a single factor based on their highest loading and theoretical relevance. See Table 2 for a summary of the rotated factor structure based on the pattern matrix.

Table 2

Factor Pattern for the POM after Promax Rotation

POM Items	Factor 1	Factor 2	Factor 3
7. My child's condition limits my personal activities	.82		
8. I feel overwhelmed caring for my child	.81		
16. My child's condition does not restrict our family activities	-.76		
3. I feel isolated when caring for my child	.72		
12. My family is not significantly impacted by my child's condition	-.71		
6. I feel like I have adequate support caring for my child	-.70		
4. I have more negative than positive experiences parenting a child with a medical condition	.69		
15. My child's condition places financial strain on my family	.69		
9. I feel a sense of loss when I think about my child's future	.64		
11. I feel guilt for spending more time with my child with a medical condition than my other family members	.59		
13. Parenting a child with a medical condition places strain on marriages and common-law relationships	.58		
14. Family members resent the time I spend with my child	.57		
2. I feel intense emotions when I think of my child's condition	.52		
5. I worry about my child's future more than other parents because of his/her medical condition	.45		
1. I have come to terms with my child's condition	-.41		
10. My child's condition has brought my family closer together	-.36		

17. Having a child with a medical condition makes the decision to have more children difficult	.34		
21. I worry that something I did or my partner did during pregnancy caused my child's condition		.75	
20. I feel guilt about the potential cause(s) of my child's condition		.74	
19. I am focused on finding a specific reason for why this happened to my child		.67	
18. I worry that something related to my body or my partner's body caused my child's condition (e.g., a pre-existing medical condition)		.51	
23. No one is to blame for my child's condition			.69
25. My child's condition could not have been prevented			.64
26. I worry that medical mismanagement caused my child's condition			-.55
22. I accept that I may never understand the cause of my child's condition			.35
24. I feel anger when I think about the potential cause(s) of my child's condition			-.35

A total of 17 items loaded on the first factor, making it the largest component of the scale. These items capture the psychosocial impact of raising a child with a neurological condition on parents and families, including the impact on their personal activities, family functioning, and psychosocial well-being (*Psychosocial Impact*). The remaining two factors capture parents' guilt (*Guilt*) and blame (*Blame*) regarding the cause of their child's condition.

Normality and Descriptive Statistics

The data from the revised POM did not deviate from normality (Shapiro-Wilk's $W = 0.98$, $p = 0.07$) nor did it demonstrate ceiling or floor effects for the total score. Low ceiling/floor effects were observed for the subscales (<20% of the respondents). Table 3 summarizes the descriptive statistics of the POM.

Internal Consistency

The results demonstrated that the POM exceeds the minimum reliability standard for Chronbach's α (0.70). The POM has excellent internal consistency (Cronbach's α = 0.91) while its subscales have acceptable to excellent internal consistency (Chronbach's α ranged from 0.77 to 0.92; Table 3).

Test-Retest Reliability

The POM total score demonstrated very good reliability (r = .87) across two to five weeks (Days: M = 19.09, SD = 6.27, range = 12-37), while the subscale scores demonstrated good to very good reliability (r ranged from .80 to .87; Table 3).

Table 3

Internal Consistency, Test-Retest Reliability, and Descriptive Statistics of the POM

Subscale	# of Items	α	Test-Retest *r*	Min. Score	Max. Score	Mean Score	*SD*
Psychosocial Impact	17	0.92	0.87	0.00	63.00	24.44	15.22
Guilt	4	0.80	0.87	0.00	16.00	5.60	4.46
Blame	5	0.77	0.80	0.00	19.00	7.16	4.76
Total	26	0.91	0.87	1.00	86.00	37.20	19.96

Note. Every item is rated on a scale from 0 to 4. The minimum possible score on all of the subscales is 0 while the maximum possible score on the Psychosocial Impact subscale is 68, Guilt subscale is 16, Blame subscale is 20, and Total is 104. Test-retest *r* was calculated over 2-5 weeks. All reported statistics are based on the POM at Time Point 1, except the test-retest reliability.

Concurrent Validity

Comparisons between the POM and other family impact measures (PedsQL-FIM and PECI) supported the POM's concurrent validity. The results revealed that the POM total score and Psychosocial Impact subscale score had strong and significant correlations with these measures. The Guilt and Blame subscale scores, however, generally demonstrated weaker correlations suggestive of possible discriminant validity (Table 4).

In addition, the POM was able to differentiate between parents of children with different condition severities ($F(2,107) = 13.22$, $p < .001$), providing further support for the scale's concurrent validity. Parents of children with mild conditions tended to have lower scores on the POM ($M = 30.51$, $SD = 16.81$) compared to parents of children with moderate conditions ($M = 48.97$, $SD = 19.37$) and severe conditions ($M = 48.50$, $SD = 24.32$). However, only the finding comparing the mild and moderate conditions reached statistical significance after controlling for family-wise error ($t(102) = -4.99$, $p < .001$). This is likely due to limited sample size in the severe condition ($n = 6$).

An auxiliary analysis was conducted to compare POM scores of mother-father pairs who live in the same household. The results revealed that the POM was unable to differentiate between the mothers and fathers, $t(25) = 2.00$, $p = .06$.

Convergent Validity

Correlations between the POM and theoretically related measures are summarized in Table 4. Results from these analyses revealed significant correlations between the POM and all of the aforementioned measures.

Table 4

Summary of Pearson Correlations Between the POM and the PedsQL-FIM, PECI, HADS, and PSS

Measures	POM			
	Total	Psychosocial Impact	Guilt	Blame
PedsQL-FIM				
Total	-0.78**	-0.82**	-0.38**	-0.29*
Family Functioning	-0.74**	-0.78**	-0.31**	-0.32**
Parent HRQL	-0.70**	-0.74**	-0.36**	-0.23
PECI				
Guilt and Worry	0.72**	0.66**	0.64**	0.33**
Sorrow and Anger	0.79**	0.80**	0.42**	0.36**
Uncertainty	0.75**	0.76**	0.45**	0.31**
Emotional Resources	-0.65**	-0.69**	-0.27	-0.25
HADS				
Anxiety	0.60**	0.63**	0.36**	0.18
Depression	0.71**	0.73**	0.33**	0.35**
PSS				
Total	0.64**	0.67**	0.34**	0.21

Note. For all of the scales, except PedsQL-FIM and the PECI Emotional Resources subscale, higher scores indicate poorer functioning with respect to the construct being assessed. Adjusted *p*-value for multiple comparisons = 0.00125. HADS = Hospital Anxiety and Depression Scale; PSS = Perceived Stress Scale; PedsQL-FIM = Pediatric

Quality of Life Inventory - Family Impact Module; HRQL = Health-Related Quality of Life; PECI = Parent Experience of Child Illness.

*p-value < 0.00125. ** p-value < 0.001.

Incremental Validity

Box-and-whisker plots of the criterion and predictor variables revealed that three outliers were present in the HADS-A, HADS-D, and PSS data. The multiple regression results did not differ when the outliers were excluded, so they were retained in the analyses.

The results from the multiple regression analyses illustrate that the POM accounted for shared and additional variance in parent outcomes when combined with other family impact measures (Table 5). The PedsQL-FIM on its own, and in combination with the POM, accounted for a significant portion of variance in all of the parent outcomes examined. Importantly, the POM accounted for additional variance, above and beyond that captured in the PedsQL-FIM, in measures of parent anxiety (HADS-A; $\Delta R^2 = .05$, $F(1,107) = 8.39$, $p = .005$) and depression (HADS-D; $\Delta R^2 = .06$, $F(1,107) = 12.93$, $p < .001$). The incremental validity of the POM for predicting these outcomes was not only statistically significant, but also substantial (Hunsley & Meyer, 2003; semipartial $r = .22$ for HADS-A and .23 for HADS-D).

Similar results were found when controlling for outcomes on a measure of parent adjustment, the PECI (Table 5). The POM, however, only accounted for additional and substantial variance, above and beyond the PECI, in parent depression (HADS-D; $\Delta R^2 = .08$, $F(1, 104) = 16.26$, $p < .001$; semipartial $r = .28$).

Table 5

Hierarchical Regression Analyses Predicting Anxiety, Depression, and Stress based on Measures of Parental Impact and Adjustment

Criterion Variable	Order	Predictor Variable	Adj. R^2	*F*	*p*-value	ΔR^2	ΔF	*p*-value
HADS-A	1	PedsQL-FIM Total	.33	53.40	<.001**			
	2	PedsQL-FIM Total	.38	32.78	<.001**	.05	8.39	.005*
		POM Total						
	1	PECI Scales	.40	18.62	<.001**			
	2	PECI Scales	.41	15.65	<.001**	.02	2.60	.11
		POM Total						
HADS-D	1	PedsQL-FIM Total	.50	107.35	<.001**			
	2	PedsQL-FIM Total	.55	66.24	<.001**	.06	12.93	<.001**
		POM Total						
	1	PECI Scales	.42	20.07	<.001**			
	2	PECI Scales	.49	21.71	<.001**	.08	16.26	<.001**
		POM Total						
PSS	1	PedsQL-FIM Total	.49	101.86	<.001**			
	2	PedsQL-FIM Total	.50	53.84	<.001**	.02	3.45	.07
		POM Total						
	1	PECI Scales	.52	29.63	<.001**			
	2	PECI Scales	.52	23.90	<.001**	.005	1.00	.32

	POM Total

Note. n = 107. HADS-A = Hospital Anxiety and Depression Scale – Anxiety; PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module; POM = (Alberta Perinatal Stroke Project) Parent Outcome Measure; PECI = Parent Experience of Child Illness; HADS-D = Hospital Anxiety and Depression Scale – Depression; PSS = Perceived Stress Scale. PECI Scales included the following: 1) Guilt and Worry, 2) Unresolved Anger and Sorrow, 3) Long-term Uncertainty, and 4) Emotional Resources. $^{*}p < .017$. $^{**}p < .001$.

Discussion

The purpose of this study was to develop and validate a family impact scale for parents affected by perinatal stroke that includes a quantifiable measure of guilt and blame. The POM consists of 26 items and three subscales derived from an exploratory factor analysis: Psychosocial Impact, Guilt, and Blame. Preliminary evidence for the POM's reliability and validity was obtained from 110 parents of children with perinatal stroke. The results indicate that the POM has excellent internal reliability and very good test-retest reliability over two to five weeks. In addition, this study provides evidence for the POM's convergent, concurrent, and incremental validity. The results revealed strong correlations between the POM and measures of anxiety, depression, stress, quality of life, family functioning, and parent adjustment. The results also illustrated that scores on the POM varied depending on the child's condition severity. Lastly, the results revealed that the POM was able to predict parent outcomes of emotional well-being (anxiety and depression) above and beyond that of related measures (PedsQL-FIM and PECI).

The POM is comprehensive with the bulk of the items focusing on the parent and family impact of raising a child with a neurological condition. Not surprisingly, the POM demonstrated criterion validity through its strong correlations with the family impact measures, PedsQL-FIM and PECI. Dramatic decreases in the magnitude of the correlations between the POM and these scales were observed when the Guilt and Blame subscales were specifically evaluated. These results emphasize that the Guilt and Blame subscales are relatively novel contributions of the POM. Furthermore, these constructs appear to be relevant to the vast majority of the parents who participated in this study, as highlighted by the subscales' low floor effects.

The PECI appears to be the only other family impact measure that resembles the POM in that it measures 'Guilt and Worry'. However, the magnitude of the correlation between the POM and PECI's guilt-related subscales suggests that they are not measuring the same construct. An evaluation of the items sheds light on this observation: the PECI's Guilt and Worry subscale places a strong emphasis on acute anxiety and worry whereas the POM's Guilt subscale focuses exclusively on the construct of guilt. Thus, the PECI and the POM appear to be complimentary measures of family and parent impact.

The POM further augments the current literature by adding to efforts to improve family-centered care for those affected by perinatal stroke. The results of this study highlight the clinical utility of the scale in predicting common outcomes among parents of children with neurological conditions, such as depression and anxiety. This study's findings support the use of the POM, along with other measures, to elucidate which parents are at greater risk for psychological health concerns. In addition, the POM may prove to be useful for identifying targets for intervention (based on subscale scores and items endorsed), as well as monitoring outcomes of interventions and services. The POM therefore has many potential applications to clinicians, researchers and policymakers who provide support to families affected by perinatal stroke.

Limitations

The results of this study should be interpreted within the scope of its limitations. First, the generalizability of the findings is limited by the study's sample. Fathers, ethnic minorities, and families with low socioeconomic status appeared to be underrepresented. In addition, parents of children with severe conditions may have been underrepresented

given that they only consisted of 5.6% of the sample. Future research is needed to validate the POM in these diverse populations, as well as beyond the southern Alberta region. Whether the POM is suitable for other pediatric health populations also remains to be determined. It is anticipated that the POM may be useful for measuring parent impact in a variety of neurological conditions, which the authors are beginning to test with parents of children with epilepsy.

This study is also limited by its relatively small sample size. Sample sizes present an ongoing challenge when working with populations affected by specific and understudied neurological conditions such as perinatal stroke. In order to help mitigate this limitation, we recruited participants from one of the largest population-based perinatal stroke cohorts in Canada (APSP). As a result, this study includes the largest population of parents affected by perinatal stroke published to date. Nonetheless, this study fails to satisfy the commonly accepted sample size criteria of five participants per variable for exploratory factor analysis (Gorsuch, 1990). However, Guadagnoli and Velicer (1988) argue that factor loadings, along with total sample size and number of items per factor, determine the stability of factor solutions. According to Guadognoli and Velicer, "If components possess four or more variables with loadings above .60, the pattern may be interpreted whatever sample size is used" (Guadagnoli & Velicer, 1988; p 274). When using principal components analysis (as Guadagnoli and Velicer did in their study), the Psychosocial Impact and Guilt factors exceed this criteria while the Blame factor has three variables loading above .60. Thus, there is reason to believe that our current factor structure may be stable, but further research is warranted.

Conclusions

This study provides preliminary evidence that the POM is a reliable, valid, and useful tool for quantifying psychosocial functioning, guilt, and blame among parents of children with perinatal stroke. The scale takes approximately five minutes to complete and appears to adequately measure the impact of perinatal stroke on parents and families. The POM may serve to identify families who are adapting well and those who may benefit from additional psychosocial, educational, and health services. Furthermore, the scale may propel research on the family impact of raising a child with perinatal stroke, a topic not yet explored in the published literature. Such research is necessary in order to improve services and resources available to this underserved population.

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Appendix A

APSP Parental Outcome Measure
Bemister T., Brooks B., Rothenmund S., & Kirton A., 2013

This questionnaire asks you about your thoughts and feelings parenting a child with a medical condition within the **PAST 3 MONTHS**. Please indicate how much you agree with each statement by checking the appropriate box.

	Strongly Agree	**Slightly Agree**	**Neither Agree nor Disagree**	**Slightly Disagree**	**Strongly Disagree**
1. I have come to terms with my child's condition*					
2. I feel intense emotions when I think of my child's condition					
3. I feel isolated when caring for my child					
4. I have more negative than positive experiences parenting a child with a medical condition					
5. I worry about my child's future more than other parents because of his/her medical condition					
6. I feel like I have adequate support caring for my child*					
7. My child's condition limits my personal activities					
8. I feel overwhelmed caring for my child					
9. I feel a sense of loss when I think about my child's future					

	Strongly Agree	Slightly Agree	Neither Agree nor Disagree	Slightly Disagree	Strongly Disagree
10. My child's condition has brought my family closer together*					
11. I feel guilt for spending more time with my child with a medical condition than my other family members					
12. My family is not significantly impacted by my child's condition*					
13. Parenting a child with a medical condition places strain on marriages and common-law relationships					
14. Family members resent the time I spend with my child					
15. My child's condition places financial strain on my family					
16. My child's condition does not restrict our family activities*					
17. Having a child with a medical condition makes the decision to have more children difficult					
18. I worry that something related to my body or my partner's body caused my child's condition (e.g., a pre-existing medical condition)					
19. I am focused on finding a specific reason for why this happened to my child					
20. I feel guilt about the potential cause(s) of my child's condition					

	Strongly Agree	Slightly Agree	Neither Agree nor Disagree	Slightly Disagree	Strongly Disagree
21. I worry that something I did or my partner did during pregnancy caused my child's condition					
If you agreed with the previous item, please check any that apply: □ Diet □ Exercise □ Medications or vitamins □ Drugs or alcohol □ Other _____					
22. I accept that I may never understand the cause of my child's condition*					
23. No one is to blame for my child's condition*					
24. I feel anger when I think about the potential cause(s) of my child's condition					
25. My child's condition could not have been prevented*					
26. I worry that medical mismanagement caused my child's condition					
If you agreed with the previous item, please check any that apply: □ Neonatologist (newborn specialist) □ Family doctor □ Obstetrician (childbirth and labor specialist) □ Nurse(s) (present at birth) □ Nurse(s) (other) □ Neurologist (brain specialist) □ Other _____ □ Pediatrician (child specialist)					

*Reverse-score.

Scoring of the APSP Parental Outcome Measure

Score each regularly scored item from 0 (Strongly Disagree) to 4 (Strongly Agree). Subscale and total scores are calculated by summing the items listed below with special attention paid to the eight items that require reverse scoring.

POM Total and Subscale Scores

	Items	Reverse Score Items
Psychosocial Impact	1-17 (17 items)	1, 6, 10, 12, 16
Guilt	18-21 (4 items)	None
Blame	22-26 (5 items)	22, 23, 25
Total	1-26 (26 items)	1, 6, 10, 12, 16, 22, 23, 25

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Bemister, T. B., Brooks, B., Dyck, H. & Kirton A. (2014). Parent and family impact of raising a child with perinatal stroke. *BMC Pediatrics, 14*(182). Published online. doi:10.1186/1471-2431-14-182

Chapter Three: Parent and Family Impact of Raising a Child with Perinatal Stroke

Ischemic perinatal stroke is a focal interruption of blood supply in the brain that is caused by the blockage of a blood vessel between 20 weeks of fetal life to 28 days of life (Raju, Nelson, Ferriero, & Lynch, 2007). This cardiovascular event occurs in at least 1 in 2500 live births and is a leading cause of lifelong neurological disability. The majority of perinatal stroke survivors experience chronic motor impairments, while other typical outcomes include seizures, cognitive deficits, sensorimotor deficits, and behaviour problems (Golomb, 2009; Lynch, 2009). This condition impacts the child, parents, and family across complex aspects of life and over the child's lifespan. Despite this, no study to date has examined the well-being of parents of children with perinatal stroke.

Several studies have examined the well-being of mothers of children with chronic neurological conditions, such as cerebral palsy, epilepsy, and developmental disabilities. These studies suggest that, although many mothers of children with perinatal stroke will adapt well, they may be at elevated risk for psychological concerns. Heightened rates of stress and depression have consistently been found among parents of children with cerebral palsy, while heightened rates of anxiety have been found in response to acute stressors (e.g., child's diagnosis; Guyard, Fauconnier, Mermet, & Cans, 2011; Pousada et al., 2013). Similar findings have emerged in the epilepsy and developmental disability literature with meta-analyses and reviews supporting affected mothers' increased susceptibility to stress, depression, and other mental health concerns (Duffy, 2011; Ferro & Speechley, 2009; Singer, 2006). Even though these mothers tend to have an increased risk for psychological concerns, it is important to note that a large portion of them demonstrate resiliency (Heiman, 2002).

Caregivers' quality of life is influenced by their psychological functioning as well as other aspects of well-being (health, independence, relationships, beliefs, and environment; Terra et al., 2011). In line with previous research, mothers of children with cerebral palsy and other neurological disabilities tend to report poorer quality of life than mothers of typically developing children (Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Pousada et al., 2013; Terra et al., 2011). An extensive review of 46 studies on mothers of children with cerebral palsy highlights the consistency of this finding within the literature (Pousada et al., 2013) with only two studies failing to find such an effect (Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001; Terra et al., 2011). Nonetheless, many of these mothers continue to report quality of life within the normal range.

Fewer studies have focused on the paternal impact of raising a child with a neurological disability (Pelchat, Lefebvre, & Levert, 2007). The studies that have included fathers have generally found them to have similar or better psychological outcomes than mothers (Ha, Hong, Seltzer, & Greenberg, 2008; Pelchat et al., 2007). A meta-analysis of 229 adult caregiver studies found that male caregivers tend to report lower levels of stress and depression in conjunction with higher levels of well-being and physical health than female caregivers, although the effects were small to very small (Pinquart & Sörensen, 2006). The authors note that these gender differences may stem from females' increased caregiver responsibilities and stressors. Furthermore, other studies have observed gender differences in the ways that parents perceive and cope with stress (Matud, 2004).

Although there is an emphasis on primary caregivers in pediatric disability research, a family systems perspective is increasingly being employed with an emphasis on parental, marital, and family functioning. In terms of marital functioning, research indicates that there is an elevated risk of divorce and separation among parents of children with disabilities, albeit the effect is smaller than previously believed (i.e., 3-7% increased risk; Risdal & Singer, 2004). Hence, many parents of children with disabilities have marriages within the normal range of function and dysfunction (Sobsey, 2004). Some authors still insist that parents of children with disabilities have lower marriage quality and lower marital satisfaction (Florian & Findler, 2001; Parker, Mandleco, Olsen Roper, Freeborn, & Dyches, 2011). Alternatively, some authors argue that the challenge of coping with a child's disability can strengthen and enrich an already satisfying marriage (Havens, 2005).

With respect to family functioning, the results in the literature have largely been mixed. More problematic family functioning has been observed in families with children with disabilities (Cuzzocrea, Larcan, & Westh, 2013; Lach et al., 2009), while other studies have failed to find such an effect (Magill-Evans et al. 2001; Povee, Roberts, Bourke, & Leonard, 2012). In light of these findings, Coffey suggests that caring for a child with a disability may strain the family system by restricting family activities, but it also may strengthen the family system by bonding family members (Coffey, 2006). Regardless, there is widespread recognition of the value of family functioning and its effect on individual family members.

Despite the overall impact of pediatric disabilities on parents' well-being, variation in outcomes exists depending on the type and severity of the child's condition (Raina et al., 2004). For instance, condition-specific effects have been observed for epilepsy, cerebral palsy, and pervasive developmental disorder (Eker & Tüzün, 2004; Mugno et al., 2007; Tzoufi et al., 2005). The differences in outcomes have been attributed to the conditions' unique presentations and associated challenges and strengths. Because no studies to date have evaluated the well-being of parents of children with perinatal stroke, the specific impact of this condition is yet to be determined. As noted by Bemister and colleagues (Bemister, Brooks, & Kirton, 2014), these parents may present with elevated levels of guilt and blame compared to other neurological disabilities. This may occur because parents are aware of the timing of their child's stroke, but they are unaware of a definitive cause; as a result, they may make causal attributions involving apparent events around the time of the stroke (e.g., their actions during the last trimester and/or medical staff actions during delivery).

In addition, differences in caregiver well-being have emerged within specific conditions dependent on child, parent, and environmental factors (e.g., child behaviour problems, parent self-esteem, and socioeconomic status; Raina et al., 2004). One commonly researched determinant is condition severity. Even though there are inconsistent findings on this topic, milder conditions have been associated with better outcomes for parents of children with cerebral palsy (Eker & Tüzün, 2004; Raina et al., 2004). These results may be due to the relative reduction of caregiver demands.

The existing literature highlights the importance of examining the maternal, parental, and familial impact of raising a child with perinatal stroke. Many families affected by perinatal stroke remain underserved in our clinical experience, which may be partially due to the paucity of research on this population. Family-based research studies on perinatal stroke may augment the existing literature, as well as enhance existing resources, supports, and services available to affected families. Furthermore, such research is consistent with family-centered care, an increasingly revered service delivery approach for pediatric neurological conditions (King, Teplicky, King, & Rosenbaum, 2004).

The primary aim of this study is to examine the impact of raising a child with perinatal stroke on mothers' well-being, as evident by measures of their depression symptoms, anxiety symptoms, stress levels, quality of life, marital distress, marital satisfaction, and family functioning. A secondary aim is to examine how caring for a child with perinatal stroke differentially affects mothers and fathers. Based on previous literature, it was hypothesized that mothers would have worse outcomes in all domains measured relative to mothers of children with typical development and fathers of children with perinatal stroke.

Methods

Participants

Mothers of children with typical development and mothers and fathers of children with perinatal stroke were identified through the Alberta Perinatal Stroke Project (APSP). APSP is a population-based research cohort of >180 perinatal stroke patients and >50

healthy controls in southern Alberta. Mothers of children with typical development were additionally recruited through a research participation system at the University of Calgary and community advertisements (printed and online). The biological parents of children 0-18 years with a clinico-radiographically confirmed perinatal stroke syndrome (neonatal arterial ischemic stroke, periventricular venous infarction, or arterial presumed perinatal stroke; Kirton & deVeber, 2009) and the biological mothers of typically developing children 0-18 years (no known neurological or developmental conditions) were included in this study. Participants were excluded if they had less than nine years of formal education (excluding schooling prior to four years of age) or were unable to fluently read English (based on self-report).

Procedure

Study I and II were conducted concurrently between August 2012 and June 2013 as part of an ongoing research project, and ethics approval was obtained from the Conjoint Health Research Ethics Board at the University of Calgary. Parents were explained the study via telephone or email (depending on their preference), and consent was obtained prior to sending them a link to the questionnaire battery. Individual links were sent to the parents using the online survey software, Qualtrics, which enabled participants to save and alter their responses prior to submission. All participants were given the option to complete paper versions of the questionnaires. The vast majority of the participants received a $10 eGift card in recognition of their contribution, while the participants recruited through the university received one bonus credit toward a course. The data were downloaded from Qualtrics and stored in a secure database at the Alberta Children's Hospital.

Measures

Demographics. The Demographics Questionnaire is a 26-item scale created for an ongoing research project (Bemister et al., 2014) to assess relevant background information about the participants, including their age, income, education, and ethnicity. This questionnaire has not yet been validated.

Anxiety and depression. The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale that measures self-reported symptoms of anxiety (HADS-A) and depression (HADS-D) within the past week (Zigmond & Snaith, 1983). Comprehensive reviews of the HADS suggest it has good reliability and validity in hospital and community populations (Bjelland, Dahl, Haug, & Neckelmann, 2002). Furthermore, the scale is commonly used among parents of children with and without chronic conditions.

Perceived stress. The Perceived Stress Scale (PSS) is a 14-item scale that measures the extent to which situations are judged as being stressful, uncontrollable, unpredictable, and overloading (Cohen, Kamarck, & Mermelstein, 1983). The PSS has good to very good reliability and validity, and it has been deemed an effective tool for evaluating stress in parents of children with disabilities (Lessenberry & Rehfeldt, 2004).

Family functioning and quality of life. The Pediatric Quality of Life Inventory – Family Impact Module (PedsQL-FIM) is a 36-item scale that measures the impact of pediatric health conditions on parent quality of life and family functioning (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). The PedsQL-FIM generates three scores – Parents' Health-Related Quality of Life (HRQL), Family Functioning, and Total Score – all of which have demonstrated internal consistency and construct validity

(Panepinto, Hoffmann, & Pajewski, 2009). The PedsQL-FIM has been widely used among parents of children with chronic conditions, but it is also suitable for healthy controls.

Family impact. The APSP Parental Outcome Measure (POM) is a 26-item scale that measures the impact of perinatal stroke on parents and families (Bemister et al., 2014). As such, this scale was not administered to parents of children with typical development. The POM has three subscales that measure parents' psychosocial impact, guilt, and blame. Evidence for the POM's reliability and validity was gathered in its original validation study with parents of children with perinatal stroke.

Marital strain and satisfaction. Only participants in marital or common-law relationships completed the following scales:

The Dyadic Adjustment Scale (DAS) is a 32-item scale assessing distresss in marital or common-law relationships (Spanier, 1976). The DAS is one of the most established questionnaires of its kind, and it has been shown to be theoretically-based, valid, and reliable (Graham, Liu, & Jeziorski, 2006; Spanier, 1976).

The Kansas Marital Satisfaction Scale (KMSS) is a global measure of marital satisfaction that was administered to complement the DAS (Schumm, 1983; Schumm et al., 1986). The KMSS is psychometrically sound and consists of three items that assess satisfaction with one's partner, marriage, and relationship (Sabatelli, 1988).

Study Part I: Perinatal Stroke vs. Typical Development

Statistical Analyses

Descriptive statistics for demographic variables were calculated and comparisons were made between the mothers of children with perinatal stroke and the mothers of children with typical development using chi-square analyses for categorical data and *t*-tests for continuous data. A preliminary examination of the data was conducted using scatterplots and the results revealed substantial variation in the outcome measures among the mothers of children with perinatal stroke. As a result, the mothers were grouped according to the severity of their child's condition: mild and moderate/severe (moderate and severe conditions were collapsed together due to the small sample size of severe cases; see Results for details of this process). Nonparametric statistics were conducted for the rest of the analyses due to the unequal sample sizes and heterogeneity of variance among the outcome measures. Specifically, Kruskal-Wallis H tests were used to compare the groups on the outcome measures, followed up with Mann-Whitney *U* tests. Bonferroni adjustments were applied to correct for family-wise error rates, and all statistics were conducted with IBM SPSS Statistics for Windows Version 20.0.

Results

Sample

A total of 82 mothers of children with perinatal stroke met the study's inclusion criteria and were recruited as part of a larger ongoing research study (Bemister et al., 2014). A total of 62 mothers of children with typical development met the study's inclusion criteria and were recruited from community advertisements (n = 34), the

university (n = 15), and the APSP control database (n = 13). Among them, 56 were successfully matched to mothers of children with perinatal stroke based on their child's sex, age (± 2 years), and total gross family income (± 1 category). As highlighted in Table 1, the mothers of children with perinatal stroke were comparable to the mothers of children with typical development on all of the demographic variables examined.

Mothers of children with perinatal stroke were divided into mild (n = 29) and moderate/severe (n = 27) conditions based on parent classifications. These classifications were in very strong agreement with the results of the standardized Pediatric Stroke Outcome Measure (PSOM; deVeber, MacGregor, Curtis, & Mayank, 2000), which was available for 49 of the 56 cases (Goodman and Krusk's gamma correlation (γ) = 0.75, p < .001). These groups did not differ on any of the demographic variables described in Table 1 (data not shown).

The mild, moderate/severe, and typical development conditions were compared on the outcome variables, the results of which are summarized in Table 2. Pairwise comparisons with Bonferroni corrections were conducted on all significant findings and are listed in Table 3. The mothers of children with typical development recruited from different sources were also compared on the outcome variables, but no statistically significant differences emerged (data not shown).

Table 1

Demographics as a Percentage of the Sample: Perinatal Stroke vs. Typical Development

	Perinatal stroke	Typical development	Statistical value
Child demographics	*n* (%)	*n* (%)	(*p*-value)
Age of child (years)	Mean=7.34 (SD=5.20), Range=0.75-18	Mean=7.49 (SD=5.15), Range=0.50-18	-0.15 (.88)[a]
Child's sex			
Male	29 (51.79%)	29 (51.79%)	
Female	27 (48.21%)	27 (48.21%)	
Ethnicity			1.46 (.23)
Caucasian/White	48 (85.71%)	43 (76.79%)	
Other	8 (14.29%)	13 (23.21%)	
PSOM total[b]	2.28 (2.43), 0-10	--	--
Severity of condition[c]			--
Mild	29 (51.8%)	--	
Moderate	19 (34.0%)	--	
Severe	8 (14.2%)	--	
Parents demographics			
Age of parents (years)	Mean=38.05 (SD=6.64), Range=27-55	Mean=37.82 (SD=7.23), Range=22-51	.18 (.86)[a]
Caregiver status			2.05 (.36)
Lone caregiver	8 (14.29%)	11 (19.64%)	
Co-caregiver	48 (85.71%)	45 (80.36%)	
Mental health concerns			.73 (.39)

prior to child's birth			
Yes	13 (23.21%)	17 (30.36%)	
No	43 (76.79%)	39 (69.64%)	
Total gross household income (CDN)			2.02 (.37)
< $70,000	19 (33.93%)	25 (44.64%)	
$71,000-110,000	18 (32.14%)	12 (21.43%)	
>$111,000	19 (33.93%)	19 (33.93%)	
Hours spent working outside of the home			3.07 (.55)
<10	25 (44.64%)	18 (32.14%)	
10-30	14 (25.0%)	15 (26.79%)	
>30	17 (30.36%)	23 (41.07%)	
Education level			4.41 (.35)
≤ High school certificate	15 (26.79%)	10 (17.86%)	
College certificate or diploma	20 (35.71%)	14 (25.0%)	
Bachelor's degree	14 (25.0%)	21 (37.5%)	
Master's, doctorate or professional degree	7 (12.5%)	11 (19.64%)	

Note. $n = 56$ for both groups. All statistical values are X^2 unless otherwise specified. [a]Statistical value is a *t*-value. [b]$n = 49$. [c]Rating is based on parents' self-reported perceptions of the severity of their child's condition. PSOM = Pediatric Stroke Outcome Measure; CDN = Canadian.

Table 2

Comparison of Mothers of Children with Typical Development, Mild Conditions, and Moderate/Severe Conditions on Outcome Variables

	Median [95% CI]				
	Typical dev. condition	Mild condition	Moderate/ severe condition	X^2 (p-value)	Effect size (η^2)
Anxiety & depression					
HADS-A	7.00 [5.50-8.00]	7.00 [4.00-8.00]	8.00 [5.00-10.00]	2.11 (.35)	.02
HADS-D	3.00 [2.00-4.00]	2.00 [1.00-3.00]	5.00 [4.00-9.00]	12.43 (.002)*	.11
Perceived stress					
PSS	22.50 [19.00-25.00]	21.00 [15.51-24.00]	26.00 [20.00-30.00]	4.93 (.08)	.04
Marital strain & satisfaction					
KMSS[a,b]	18.00 [17.00-18.00]	18.00 [17.00-21.00]	15.00 [12.00-18.00]	8.12 (.017)*	.09
DAS[a,b]	115.00 [106.01-120.00]	113.00 [105.00-122.00]	105.00 [88.00-116.00]	2.76 (.25)	.05
Parent & family adaptation					
PedsQL-FIM[a]					
Total[a]	78.13 [70.83-85.42]	79.86 [71.53-88.19]	53.47 [38.89-58.33]	24.38 (<.001)*	.22
Parent	72.50	81.25	60.00	12.08	.11

HRQL[a]	[67.50-80.00]	[72.50-90.00]	[49.37-65.00]	(.002)*	
Family Functioning[a]	84.38 [70.31-90.63]	87.50 [65.63-100.00]	46.87 [34.38-62.42]	25.77 (<.001)*	.23

Note. $n = 56$ for typical development, $n = 29$ for mild condition, and $n = 27$ for moderate/severe condition. Higher scores indicate poorer functioning unless specified otherwise. A η^2 of .01 is a small effect, .06 is a medium effect, and .14 is a large effect (Cohen, 1988). HADS = Hospital Anxiety and Depression Scale (-A = - Anxiety; -D = - Depression); PSS = Perceived Stress Scale; KMSS = Kansas Marital Satisfaction Scale; DAS = Dyadic Adjustment Scale; PedsQL FIM = Pediatric Quality of Life Inventory Family Impact Module; HRQL = Health-Related Quality of Life.

*p-value is significant correcting for family-wise error rate ($p < .025$ for HADS, $p < .025$ for measures of marital strain and satisfaction, and $p < .017$ for PedsQL-FIM).

[a]Higher scores indicate better functioning. [b]$n = 45$ for typical development, $n = 27$ for mild, and $n = 24$ for moderate/severe.

Table 3

Pairwise Comparisons on Outcome Variables

	Mann-Whitney *U* (*p*-value)	Effect size (*r*)
HADS-D		
Typical dev. vs. mild	644.50 (.12)	-.17
Typical dev. vs. moderate/severe	500.50 (.01)*	-.27
Mild vs. moderate/severe	183.50 (.001)*	-.46
PedsQL-FIM Total		
Typical dev. vs. mild	784.50 (.80)	-.03
Typical dev. vs. moderate/severe	283.50 (<.001)*	-.50
Mild vs. moderate/severe	139.00 (<.001)*	-.55
PedsQL Parent HRQL		
Typical dev. vs. mild	748.50 (.56)	-.06
Typical dev. vs. moderate/severe	459.00 (.004)*	-.32
Mild vs. moderate/severe	188.00 (.001)*	-.45
PedsQL Family Functioning		
Typical dev. vs. mild	727.50 (.43)	.08
Typical dev. vs. moderate/severe	305.50 (<.001)*	-.23
Mild vs. moderate/severe	111.50 (<.001)*	-.62
KMSS[a]		
Typical dev. vs. mild	544.50 (.45)	-.09
Typical dev. vs. moderate/severe	377.00 (.04)	-.25
Mild vs. moderate/severe	171.00 (.003)*	-.41

Note. $n = 56$ for typical development, $n = 29$ for mild condition, and $n = 27$ for moderate/severe condition. A r of |.1| is a small effect, |.3| is a medium effect, and |.5| is a large effect (Cohen, 1992). HADS-D = Hospital Anxiety and Depression Scale – Depression; PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module; HRQL = Health-Related Quality of Life; KMSS = Kansas Marital Satisfaction Scale.

*p-value (one-way) < .017.

[a]$n = 45$ for typical development, $n = 27$ for mild, and $n = 24$ for moderate/severe.

Anxiety and Depression

Although no statistical difference was found in symptoms of anxiety among the conditions (HADS-A; $p = .35$), a statistically significant difference emerged when examining symptoms of depression (HADS-D; $p = .002$). Pairwise comparisons revealed that the moderate/severe condition (*Mdn* = 5) had significantly more symptoms of depression than the mild condition (*Mdn* = 2, $p = .001$) and typical development condition (*Mdn* = 3, $p = .01$). However, no statistical difference was found between the mild and typical development conditions ($p = .12$).

Perceived Stress

A similar pattern was observed in perceived stress among the three conditions, but the results did not reach statistical significance (PSS; $p = .08$).

Family Functioning and Quality of Life

Significant differences were found among the groups in the PedsQL-FIM Total score ($p < .001$), Family Functioning score ($p < .001$), and Parent Health-Related Quality of Life score (HRQL; $p = .002$). Pairwise comparisons showed that the moderate/severe condition (Total *Mdn* = 53.47; Family Functioning *Mdn* = 46.87; HRQL *Mdn* = 60.00) had significantly lower scores (worse functioning) than the mild condition (Total *Mdn* = 79.86, $p < .001$; Family Functioning *Mdn* = 87.50, $p < .001$; Parent HRQL *Mdn* = 81.25, $p < .001$) and the typical development condition (Total *Mdn* = 78.13, $p < .001$; Family Functioning *Mdn* = 84.38, $p < .001$; Parent HRQL *Mdn* = 72.50, $p = .004$) on all three outcomes. No statistical differences existed between the mild and typical development conditions on the outcomes ($p = .80$ for Total; $p = .43$ for Family Functioning; and $p =$

.56 for HRQL).

Marital Distress and Satisfaction

For both measures of marital distress (DAS) and satisfaction (KMSS), the moderate/severe condition tended to have worse outcomes. However, a statistically significant difference was only present for KMSS (p = .017; DAS: p = .25). Pairwise comparisons confirmed that the moderate/severe condition (*Mdn* = 15.00) had significantly less marital satisfaction than the mild condition (*Mdn* = 18.00; p = .003). No statistical differences were found between the typical development condition (*Mdn* = 18.00) and the mild condition (p = .45) or the moderate/severe condition (p = .04) after correcting the p-value for family-wise error rates (p < .017).

Study Part II: Mothers vs. Fathers

Statistical Analyses

Mothers and fathers of children with perinatal stroke were compared on demographic variables using chi-square analyses for categorical data and paired samples t-tests for continuous data. For the primary outcome variables, the data were not normally distributed, so Wilcoxon matched pairs signed-rank tests were used throughout.

Results

Sample

A total of 56 parents (28 mother-father couples) of children with perinatal stroke participated in this study. The vast majority of the sample was Caucasian (92.86%) and caring for a child with a mild condition (75%). No statistical differences were found

between the mothers and fathers on the demographic variables examined with the exception that fathers spent more hours working outside the home compared to mothers ($\chi^2(4,56) = 24.83$, $p < .001$; Table 4).

Table 4

Demographics as a Percentage of the Sample: Mothers vs. Fathers

Child demographics	Mothers *n* (%)	Fathers *n* (%)	Statistical value (*p*-value)
Child's age (years)	Mean=8.25 (SD=5.82), Range=0.5-17	Mean=8.25 (SD=5.82), Range=0.5-17	--
Child's sex			--
Male	15 (53.57%)	15 (53.57%)	
Female	13 (46.43%)	13 (46.43%)	
Ethnicity			--
Caucasian/White	26 (92.86%)	26 (92.86%)	
Other	2 (7.14%)	2 (7.14%)	
PSOM total[a]	Mean=1.46 (SD=1.35), Range=0-5	Mean=1.46 (SD=1.35), Range=0-5	--
Severity of condition[b]			
Mild	21 (75.00%)	20 (71.43%)	.10 (.75)
Moderate	7 (25.00%)	8 (28.57%)	
Severe	0 (0%)	0 (0%)	
Parent demographics			
Age (years)	Mean=40.57 (SD=7.87), Range=29-57	Mean=42.32 (SD=7.47), Range=31-59	-.06 (.95)[c]
Ethnicity			--
Caucasian/White	26 (92.86%)	26 (92.86%)	

Other	2 (7.14%)	2 (7.14%)	
Mental health concerns prior to child's birth			1.02 (.50)
Yes	7 (25.00%)	4 (14.29%)	
No	21 (75.00%)	24 (85.71%)	
Total gross household income (CDN)[d]			2.00 (.37)
< $70,000	7 (25.00%)	6 (21.43%)	
$71,000-110,000	10 (35.71%)	6 (21.43%)	
>$111,000	11 (39.29%)	16 (57.14%)	
Hours spent working outside of the home			24.83 (<.001)*
<10	13 (46.43%)	2 (7.14%)	
10-30	6 (21.43%)	2 (7.14%)	
>30	9 (32.14%)	24 (85.72%)	
Education level			3.71 (.45)
≤ High school certificate	4 (14.29%)	6 (21.43%)	
College certificate or diploma	7 (25.00%)	7 (25.00%)	
Bachelor's degree	14 (50.00%)	8 (28.57%)	
Master's, doctorate, or professional degree	3 (10.71%)	7 (25.00%)	

Note. $n = 28$ for both groups. All statistical values are X^2 unless otherwise specified. [a]$n = 27$. [b]Rating is based on parents' self-reported perceptions of the severity of their child's condition. [c]Statistical value is a *t*-value. [d]The mothers and fathers are from the same household, and therefore the differences reported in gross family income reflect

differences in perception or understanding. PSOM = Pediatric Stroke Outcome Measure; CDN = Canadian.

*p-value < .05.

Psychosocial Outcomes

A series of Wilcoxon matched pairs signed-rank tests revealed that the mothers and fathers did not differ significantly on the majority of the outcome measures after controlling for family-wise error rates (Table 5). The only statistically significant differences were on the measures of anxiety and guilt. The results suggest that mothers have higher levels of anxiety (HADS-A: mother *Mdn* = 7.00, father *Mdn* = 5.00; Z = -1.99, *p* = .023), as well as higher levels of guilt regarding the cause of their child's condition (POM Guilt: mother *Mdn* = 7.00, father *Mdn* = 4.00; Z = -2.33, *p* = .01) in comparison to fathers.

Although no significant findings emerged for the remaining outcome variables, an examination of the effect sizes suggests that mothers may have slightly worse functioning than fathers on measures of depression, stress, quality of life, parent impact, and psychosocial functioning (Table 5). However, no differences were observed between mothers and fathers' reports of marital distress and satisfaction.

Table 5

Comparison of Mothers and Fathers of Children with Perinatal Stroke on Outcome Variables

	Median [95% CI]			
	Mothers	Fathers	*Z* (*p*-value)	Effect size (*r*)
Anxiety & depression				
HADS-A	7.00 [6.00-8.00]	5.00 [3.50-8.00]	-1.99 (.023)*	-.27
HADS-D	2.00 [2.00-4.49]	2.00 [1.00-5.00]	-1.14 (.13)	-.15
Perceived stress				
PSS	22.50 [18.00-24.00]	20.00 [16.00-26.50]	-1.11 (.45)	-.15
Marital strain and satisfaction				
KMSS[a]	18.00 [17.00-19.00]	18.00 [16.00-19.00]	-0.75 (.23)	-.10
DAS[a]	112.50 [105.00-121.00]	112.00 [104.00-127.00]	-0.20 (.42)	-.03
Parent & family adaptation				
PedsQL-FIM[a]				
Total[a]	71.87 [59.37-84.72]	79.86 [70.84-86.11]	-.80 (.21)	-.11
Parent HRQL[a]	70.00 [60.00-90.00]	81.25 [74.00-90.00]	-1.09 (.14)	-.15
Family Functioning[a]	71.88 [56.25-89.06]	75.00 [65.62-90.63]	-0.16 (.44)	-.02

POM				
Total	34.50 [27.50-47.00]	28.00 [19.00-36.49]	-1.59 (.06)	-.21
Psychosocial Impact	20.50 [16.50-29.50]	18.50 [13.00-24.00]	-1.17 (.12)	-.16
Guilt	7.00 [4.00-9.00]	4.00 [1.50-5.00]	-2.33 (.01)*	-.31
Blame	5.50 [4.00-7.50]	6.00 [4.00-8.49]	-0.37 (.36)	-.05

n = 28 for each group. Higher scores indicate poorer functioning unless specified otherwise. A *r* of |.1| is a small effect, |.3| is a medium effect, and |.5| is a large effect (Cohen, 1992). HADS = Hospital Anxiety and Depression Scale (-A = - Anxiety; -D = - Depression); PSS = Perceived Stress Scale; KMSS = Kansas Marital Satisfaction Scale; DAS = Dyadic Adjustment Scale; PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module; HRQL = Health-Related Quality of Life; POM = Parental Outcome Measure.

**p*-value (one-way) is significant correcting for family-wise error rate ($p < .025$ for HADS, $p < .025$ for measures of marital strain and satisfaction, $p < .017$ for PedsQL FIM, and $p < .0125$ for POM).

[a]Higher scores indicate better functioning.

Discussion

The purpose of this study was to compare mothers of children with perinatal stroke with 1) mothers of children with typical development and 2) fathers of children with perinatal stroke. Comparisons with the typical development group revealed a promising finding: most parents of children with perinatal stroke adapt extremely well. More specifically, the mothers of children with mild conditions were indistinguishable from the control group in all of the examined outcomes (i.e., anxiety, depression, perceived stress, marital strain and satisfaction, health-related quality of life, and family functioning). Although variation in outcomes was present among the mothers of children with moderate/severe conditions, these mothers tended to have increased symptoms of depression, decreased marital satisfaction, poorer health-related quality of life, and poorer family functioning. This finding is consistent with pediatric disability research, which supports that these parents may be in need of additional resources and services (Bailey, Golden, Roberts, & Ford, 2007; Duffy, 2011; Ferro & Speechley, 2009; Singer, 2006).

Comparisons of mothers and fathers of children with perinatal stroke revealed that mothers have similar or slightly worse functioning than fathers on the outcome variables examined. The only statistically significant differences between the groups were in measures of guilt and anxiety. Mothers tended to have a greater burden of guilt regarding the cause of their child's condition, which is likely due, at least in part, to their exceptionally intimate involvement with their child at the time of the stroke (in utero or during birth). Similarly, mothers tended to have increased levels of anxiety, which is in line with previous research on pediatric disabilities (Ha et al., 2008; Pelchat et al., 2007), as well as the general caregiver literature (Pinquart & Sörensen, 2006). This finding is

also consistent with the small, but not significantly different, gender effects observed in depression, stress, quality of life, and psychosocial impact – all of which suggest fathers have better outcomes. These effects may have failed to reach statistical significance due to the limited sample of fathers in the current study. Underrepresentation of fathers in caregiver research is a longstanding issue with recognized barriers involving perceived gender roles, restrictions due to employment, and fathers' limited involvement with health professionals (Swallow, Macfadyen, Santacroce, & Lambert, 2012). Swallow and colleagues provide several suggestions to help address the underrepresentation of fathers in caregiver research (Swallow et al., 2012).

Data from this study build upon the existing disability literature in several ways. Foremost, this is the first study known to the authors that examines the impact of raising a child with perinatal stroke. In order to gather a preliminary and broad understanding of the parent and family impact, a case-control study design and survey methodology was utilized. This study design and methodology enabled the authors to assess seven psychosocial constructs in over 135 participants while largely controlling for demographic variables. In addition, the results of this study elicit clinically relevant questions that lay the foundation for future research studies on perinatal stroke. For instance, future research may evaluate the percentage of parents that meet criteria for psychiatric diagnoses, the impact of parent outcomes on children, and the trajectory of parents' psychosocial functioning as the child progresses through different stages of life.

Based on the results of this study, the family impact of perinatal stroke appears to differ from other pediatric conditions in the preponderance of condition severity on parent and family outcomes. This may be because the participants were recruited from a

population-based sample and the consequences of the perinatal stroke varied vastly from neurological normalcy to quadriplegia. In order to fully comprehend how perinatal stroke differs and resembles other pediatric conditions in terms of its family impact, research with chronic disease controls is required.

Limitations

The results of this study must be interpreted within the scope of its limitations. One of the greatest limitations is that condition severity was determined based on mothers' ratings. Hence, we are unable to eliminate the possibility that mothers' psychosocial functioning impacted their perceptions of their child's condition. However, an objective measure of functional impairment (i.e., PSOM) was available for 87.5% of the cases, and the results of the PSOM were in strong agreement with parent ratings. Because PSOM scores were not available for all of the participants in the study, they unfortunately could not be used as the primary measure of condition severity, and instead they were used to validate parent ratings.

Another limitation is the generalizability of the findings. The study sample consisted predominantly of educated mothers of Caucasian descent with gross family incomes of over $70,000 CDN (*Mdn* in Alberta = $89,830; Canada = $72,240; Statistics Canada, 2013). Previous research has shown that socioeconomic status and ethnic minority status are possible predictors of poor coping following the diagnosis of a pediatric disability (Rentinck et al., 2010). As such, the results of this study may underestimate the overall effect of caring for a child with perinatal stroke, and they cannot be generalized to families with different demographic profiles. Future research is

needed to assess the family impact of perinatal stroke among more diverse populations, including in regions beyond southern Alberta.

Lastly, this study utilized a population-based sample and included parents of children with a wide range of ages (0.5 to 18 years). Consistent with the study's intent, this provided an overarching picture of the psychosocial effects of raising a child with perinatal stroke. However, several questions remain about the parental effects across the child's lifespan. For example, parental distress is expected to increase in response to initial diagnoses, as well as in response to realized losses of developmental milestones and other triggers for parental recognition of childhood disability (Pousada et al., 2013; Whittingham, Wee, Sanders, & Boyd, 2013). Longitudinal studies would help elucidate this trajectory for parents of children with perinatal stroke and the periods in which they have the highest risk for psychological concerns.

Conclusions

The results of this study may be used to advocate for families affected by moderate/severe perinatal stroke, as well as to expand and enhance existing resources. There is increasing recognition of perinatal or pediatric stroke as a unique neurological condition that merits specialized clinics and services. Similarly, family supports tailored for this specific population have emerged in the past decade (e.g., the APSP Parent Support Group). The results of this study may inform such supports and services by identifying parents at higher risk for psychological concerns (parents of children with moderate/severe conditions), as well as identifying areas of concern (parent depression, marital satisfaction, health-related quality of life, and family functioning). Family-based supports are not only beneficial for the parents, but also the entire family system (Canary,

2008). Parent well-being has been consistently shown to positively influence the health and psychosocial functioning of children with pediatric disabilities (Carona, Crespo, & Canavarro, 2013; Duffy, 2011; Ferro & Speechley, 2009). Thus, the results of this study may be utilized by clinicians, policymakers, and researchers to help enhance the quality of life of parents, families, and children affected by perinatal stroke.

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Chapter Four: Predictors of Caregiver Depression and Family Functioning after Perinatal Stroke

The perinatal period carries a high risk for stroke, occurring in >1:2500 live births (Raju, Nelson, Ferriero, & Lynch, 2007) and affecting up to 29,500 American children. The consequences often last a lifetime and include motor impairments (cerebral palsy), epilepsy, behavioural and mental health problems, and cognitive deficits (Kirton & deVeber, 2013). Studies on perinatal stroke outcomes are increasing, but examination of its broader impact on parents and families has been limited. A recent study of mothers of children with perinatal stroke revealed that many demonstrate resilience with generally favourable psychological outcomes. However, mothers of children with moderate and severe outcomes carry higher rates of depression symptoms, increased stress levels, decreased quality of life, impaired family functioning, and greater marital distress (Bemister, Brooks, Dyck, & Kirton, 2014). Comparison of couple dyads within this study demonstrated that fathers may also incur psychological morbidity.

In addition, an objective and validated tool has recently been developed to measure the psychosocial impact of raising a child with perinatal stroke. The APSP Parental Outcome Measure (POM) assesses a wide variety of outcomes including parental guilt and blame regarding the cause of the child's condition (Bemister, Brooks, & Kirton, 2014). Parents of children with perinatal stroke often experience misplaced feelings of guilt and blame that may relate to the inability of medical specialists to offer them a specific cause for their child's stroke in most cases (Mineyko & Kirton, 2011). Parents may then erroneously assign causation to occurrences around the timing of the

stroke. For example, mothers may assume that they did something wrong during pregnancy or assign blame to routine events surrounding labour and delivery. This parental guilt and blame may adversely affect parents' psychological well-being, potentially for decades, and has been observed in other populations (Barr, 2012). Importantly, such misplaced feelings may be amenable to change through simple psycho-education regarding the currently unpreventable nature of perinatal stroke (Mineyko & Kirton, 2011).

Despite these recent studies, the specific variables that differentiate parents of children with perinatal stroke who adapt well from those who do not are yet to be determined. Potential determinants of the psychological well-being of caregivers have been explored in other pediatric conditions, however, and they include child, parent, and psychosocial variables (Raina et al., 2004; Rentinck, Ketelaar, Jongmans, & Gorter, 2007). The most common child variables that predict caregiver well-being are condition severity, behavioural problems, cognitive deficits, and adaptive functioning (Raina et al., 2004; Woodman & Hauser-Cram, 2013). Parent variables appear to be more variable as potential determinants of caregiver depression and mental health. Examples include proxies of socioeconomic status (e.g., income level, education level, and occupational status), ethnicity, age, and gender (Eisenhower & Blacher, 2006; Ferro & Speechley, 2012; Garbarski & Witt, 2013; Rentinck et al., 2007). A vast selection of psychosocial variables has also been shown to independently predict caregiver depression, including caregiver stress (Cramm & Nieboer, 2011), social support (Badaru, Ogwumike, Adeniyi, & Kaka, 2013; Werner & Shulman, 2013), and marital quality (Garbarski & Witt, 2013; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Other psychosocial variables that have

been associated with caregiver well-being are anxiety (Chiu, Yang, Wong, Li, & Li, 2013), guilt (Gallagher, Phillips, Oliver, & Carroll, 2008), self-esteem (Werner & Shulman, 2013), self-efficacy (Raina et al., 2004), and coping strategies (Raina et al., 2004).

Fewer studies have examined predictors of family functioning, despite its relevance to family-centered care and the child's health and psychosocial functioning (Duffy, 2011). Research to date has demonstrated that family functioning is associated with child, parent, and psychosocial variables. Family distress and functioning can be affected by the child's condition severity, cognitive deficits, behavioural problems, and motor abilities (Isa et al., 2013; Lach et al., 2009; Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2012). Less consistent findings exist regarding the impact of demographic variables on family functioning, such as parent age, gender, income, education, and ethnicity (Isa et al., 2013; Majnemer et al., 2012). Other studies focus on psychosocial variables like self-esteem (Thompson, Hiebert-Murphy, & Trute, 2013), positivity (Trute, Benzies, Worthington, Reddon, & Moore, 2010), and marital status (Al-Krenawi, Graham, & Al Gharaibeh, 2011) and highlight their contributions to family adjustment.

These studies largely align with the Double ABCX Model (McCubbin & Patterson, 1983), an established caregiver stress model that helps explain why some families adapt better than others. This model suggests that adaptation ("X") may depend on the combination of the caregivers' stressors ("A" e.g., child's condition severity, behavioural problems, and cognitive deficits), available resources ("B" e.g., social support, good marital quality, and stress management), the meaning attributed to the situation ("C" e.g., guilt and blame regarding the cause of the stroke), and their

accumulation over time. Based on this model, available resources and attributed meaning may mediate the effects of the child's disability on parent and family outcomes.

Additional caregiver models and frameworks may inform potential mechanisms of caregiver and family adaptation to raising a child with perinatal stroke (G. King, King, Rosenbaum, & Goffin, 1999; Raina et al., 2004; Rentinck et al., 2007). Although variations exist within these models, psychosocial variables (e.g., social support and stress) have been consistently identified as potential mediators of caregiver well-being (G. King et al., 1999; Raina et al., 2004). For instance, studies have confirmed the role of stress as a mediating variable between pediatric disabilities and parents' psychological well-being (Benson, 2006; Cramm & Nieboer, 2011). However, studies on the process and mechanisms of caregiver and family adaptation remain scarce, especially with respect to family functioning. They also never have specifically addressed perinatal stroke families.

In addition to caregiver stress models supporting a role for psychosocial variables as mediators, other research has shed light on potential moderators of caregiver well-being. For instance, Gallagher and Whiteley (2012) found that child behavior problems moderated the relationship between stress and physical health among parents of children with intellectual disabilities. Garbarski and Witt (2012) also found that the child's functioning in daily activities moderated the relationship between marital status and maternal mental health among parents. The aforementioned findings on mediators and moderators are consistent with Wu and Zumbo's (2008) distinction between the two types of variables; mediators are typically cognitive, affective, physiological, motivation,

or social states, while moderators are typically innate characteristics, background variables, or traits.

The primary aim of this study was to examine the predictors of well-being among parents and families affected by perinatal stroke. It was hypothesized that child variables (i.e., demographic variables, condition severity, and presence of impairments), parent variables (i.e., demographic variables), and psychosocial variables (i.e., stress levels, anxiety symptoms, social support, marital quality, guilt, and blame) would significantly predict caregiver well-being (depression) and family functioning. A secondary aim was to examine potential mechanisms of caregiver well-being and family functioning by investigating mediators and moderators. It was hypothesized that psychosocial variables would act as mediators and child and parent factors would act as moderators between condition severity and parent and family outcomes.

Methods

Procedure

Participants were recruited through the Alberta Perinatal Stroke Project (APSP)'s population-based research cohort (refer to Bemister, Brooks, and Kirton's 2014 study for a detailed description of the methodology). APSP consists of more than 180 children 0-18 years of age with clinico-radiographically confirmed perinatal stroke in southern Alberta (i.e., neonatal arterial ischemic stroke, periventricular venous infarction, and arterial presumed perinatal stroke; Kirton & deVeber, 2009). Parents from APSP who agreed to be contacted for research purposes were informed about the study via telephone or email. All consenting parents were then emailed a link to the questionnaire battery, as well as a

reminder in two weeks' time if the questionnaires were not yet electronically submitted. All participants were given the option to fill-out paper versions of the questionnaires, and they received a $10 eGift card in recognition of their contribution. Participants were excluded from the analyses if they had less than nine years of formal education (excluding schooling prior to four years of age), were unable to fluently read English, or were not in a married or common-law relationship. Ethics approval to collect these data was obtained from the Conjoint Health Research Ethics Board at the University of Calgary.

Measures

A total of nine questionnaires were administered as part of an ongoing research project (see Bemister, Brooks, & Kirton, 2014 for details). Six of these measures were included in the present study in order to minimize multicollinearity and theoretical overlap among the variables. The six measures are described below:

HADS. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is one of the most commonly used research measures for depression symptoms (HADS-D) and anxiety symptoms (HADS-A). A review of over 750 studies established its reliability and validity, as well as its two-variable structure (Bjelland, Dahl, Haug, & Neckelmann, 2002). Although HADS-D and HADS-A were initially developed for medical patients, they have since been validated in outpatient and community populations (Bjelland et al., 2002). Moreover, these scales have been widely used among parents of children with chronic conditions (Cheshire, Barlow, & Powell, 2010; Cramm & Nieboer, 2011; Hsieh, Huang, Lin, Wu, & & Lee, 2009) including perinatal stroke (Bemister,

Brooks, Dyck et al., 2014). Unlike HADS-A, HADS-D was shown to be highly sensitive to differences between mothers of children with perinatal stroke and mothers of children with typical development. As such, HADS-D was chosen to be the primary outcome variable in this study.

PedsQL-FIM. The Pediatric Quality of Life Inventory – Family Impact Module (PedsQL-FIM; Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004) measures the impact of pediatric chronic health conditions on parents' quality of life and family functioning, creating a total of three summary scores: Health-Related Quality of Life (HRQL), Family Functioning, and Total. The psychometric properties of the PedsQL-FIM and its summary scores have been demonstrated in several studies, including studies with families of cerebral palsy and birth defects (Varni et al., 2004), chronic pain (Mano, Khan, Ladwig, & Weisman, 2011), and sickle cell disease (Panepinto, Hoffmann, & Pajewski, 2009). The PedsQL-FIM has also been used among parents of children with perinatal stroke, and the Family Functioning score was chosen to be the secondary outcome variable based on these results (Bemister, Brooks, Dyck, et al., 2014).

PSS. The Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) measures the extent to which situations are judged as being stressful, uncontrollable, unpredictable, and overloading. The scale's reliability and validity was demonstrated in its original validity study with three samples (two college and one community; Cohen et al., 1983). Since then, the scale has been regarded as an effective tool for evaluating stress in parents of children with disabilities and it is commonly used with such populations (Lessenberry & Rehfeldt, 2004).

DAS. The Dyadic Adjustment Scale (DAS; Spanier, 1976) is one of the most established questionnaires assessing marital and common-law relationships (Bradbury, Fincham, & Beach, 2000). The scale's theoretical basis, validity, and reliability are illustrated in several studies examining its psychometric properties (Carey, Spector, Lantinga, & Krauss, 1993; Graham, Liu, & Jeziorski, 2006; Montesino, Gómez, Fernández, & Rodríguez, 2013). Furthermore, the DAS has been widely used among parents of children with cerebral palsy (Britner, Morog, Pianta, & Marvin, 2003), epilepsy (Cottrell & Khan, 2005), and intellectual disabilities (Norlin & Broberg, 2013).

POM. The APSP Parental Outcome Measure (POM) measures the psychosocial impact of raising a child with perinatal stroke. The POM yields an overall score with three subscales – Psychosocial Impact, Guilt, and Blame – that were recently validated among parents of children with perinatal stroke (Bemister, Brooks, & Kirton, 2014). The POM and the outcome variable of interest, PedsQL-FIM Family Functioning, are both family impact measures for pediatric health conditions (Bemister, Brooks, & Kirton, 2014; Varni et al., 2004). As such, these scales have substantial theoretical overlap. The POM, however, has relatively unique subscales of Guilt and Blame. These subscales were included in the analysis as predictors of family functioning and caregiver well-being.

Demographics Questionnaire. The Demographics Questionnaire was created to obtain background information about the parent (e.g., gender, age, ethnicity, education level, occupational status) and child (e.g., condition severity, presence of behavioural and cognitive impairments) as part of an ongoing research project. The scale additionally

assesses parents' perceived levels of social support by asking them to rate how helpful the following people are in caring for their child with perinatal stroke on a four-point Likert scale: spouse/partner, child's siblings, grandparents, and friends. These ratings were combined to create a total social support score between 0 and 16, which was used in the analyses, along with the demographic variables listed above.

Statistical Analyses

Descriptive statistics were first calculated for the sample's demographic variables. The predictor variables were then chosen according to statistical and theoretical considerations. More specifically, Pearson *r* correlations, analyses of variance (ANOVAs), and scatterplots were conducted to examine the strength of the relationship between expected predictor variables (based on the parent, child, and psychosocial variables reviewed) and the outcomes of interest (caregiver depression and family functioning). The variables that demonstrated the greatest association with caregiver depression and family functioning were included in the hierarchical regression analyses ($p < .01$), with the child and parent variables in the first block and the psychosocial variables in the second block. Separate analyses were conducted for the caregiver outcomes of depression (HADS-D) and family functioning (PedsQL-FIM Family Functioning). The assumptions of regression analyses – normality, linearity, and homoscedasticity – were examined through residual scatterplots, and transformations of data were conducted as needed. Multicollinearity and singularity were assessed through the variance inflation factor (VIF) and tolerance values.

In order to further explore the relationship between condition severity and parent and family outcomes, moderator and mediator analyses were conducted using the child and parent variables as moderators and psychosocial variables as mediators. Moderator analyses were conducted according to Baron and Kenny's procedure (Baron & Kenny, 1986; Holmbeck, 1997), while the mediator analyses were conducted according to Preacher and Hays' procedure using the bootstrapping method (Preacher & Hayes, 2004; Preacher & Hayes, 2008). IBM SPSS Statistics for Windows Version 20.0 was used for all analyses.

Results

Sample

A total of 110 parents of children with perinatal stroke were recruited from APSP and participated in an ongoing research project. Among them, 103 parents completed measures of marital quality and therefore were included in the present study (76 mothers and 27 fathers; mean age = 39.2 years; mean child age = 7.46 years). According to parents' self-report, the majority of the sample were of Caucasian descent (89.3%), caring for a child with motor impairments (78.6%), and a mild condition (66.0%; validated by the Pediatric Stroke Outcome Measure [deVeber, MacGregor, Curtis, & Mayank, 2000], $n = 94$, Goodman and Krusk's gamma correlation [γ] $= 0.62$, $p < .001$). See Table 1 for a summary of the child and parent demographic variables.

Bivariate Analyses

An examination of the relationships between the demographic variables and outcome variables revealed that the strongest relationships ($p < .01$) existed with the

following child variables: severity of condition (for caregiver depression and family functioning), presence of cognitive impairments (for family functioning), and presence of behavioural impairments (for family functioning). No parent variables were strongly associated with the outcome variables at p-value < .01 (Table 2).

Summary statistics of the psychosocial variables and their correlation to the outcome variables are presented in Table 3. The results demonstrate strong relationships between all of the psychosocial variables and the outcome variables ($p < .01$) in the expected direction. The PedsQL-FIM Total and HRQL scores were excluded from these and subsequent analyses because their correlation with Family Functioning exceeded the cut-off of .80 suggested by Sweet and Grace-Martin for multicollinearity (2012, p. 180), Total: $r = .92$; HRQL: $r = .86$.

Table 1

Parent and Child Demographic Variables

Demographic Variables	Frequency (%)
Parent gender	
Male	27 (26.2%)
Female	76 (73.8%)
Child gender	
Male	56 (54.4%)
Female	47 (45.6%)
Parent ethnicity	
Caucasian/White	96 (93.2%)
Other	7 (6.8%)
Child ethnicity	
Caucasian/White	92 (89.3%)
Other	11 (10.7%)
Type of perinatal stroke	
nAIS	37 (35.9%)
APPIS	25 (24.3%)
PVI	25 (24.3%)
Unclassified	16 (15.5%)
Severity of condition[a]	
Mild	68 (66.0%)
Moderate	31 (30.1%)
Severe	4 (3.9%)

Motor impairments	
Yes	81 (78.6%)
No	22 (21.4%)
Cognitive impairments	
Yes	33 (32.0%)
No	70 (68.0%)
Behavioural impairments	
Yes	22 (21.4%)
No	81 (78.6%)
Seizures	
Yes	22 (21.4%)
No	81 (78.6%)
Total gross household income (CDN)	
<$70,000	30 (29.1%)
$71,000-$110,000	28 (27.2%)
>$110,000	45 (43.7%)
Parent education level	
Grade school certificate	4 (3.9%)
High school certificate	17 (16.5%)
College certificate	35 (34.0%)
Bachelor's degree	30 (29.1%)
Master's, doctorate, or professional degree	17 (16.5%)
Psychological concerns present prior to child's birth	
Yes	21 (20.4%)
No	82 (79.6%)
Demographic Variables	Mean (SD), Range

Parent age (years)	39.26 (1.70), 26-59
Child age (years)	7.46 (5.42), 0.5-18
Years since perinatal stroke diagnosis[b]	5.59 (4.58), 0.5-18
Years since first clinical presentation[b]	6.41 (5.00), 1-18

Note. nAIS = neonatal arterial ischemic stroke; APPIS = arterial presumed perinatal ischemic stroke; PVI = periventricular venous infarction; CDN = Canadian; SD = standard deviation.

[a]Rating is based on parents' self-reported perceptions of the severity of their child's condition. [b]n = 86.

Table 2

Bivariate Analyses between Outcome Variables and Demographic Variables

Demographic Variables	*F* value (*p*-value)	
	HADS-D	PedsQL-FIM Family Functioning
Parent gender	.49 (.49)	.74 (.39)
Male		
Female		
Child gender	.02 (.90)	1.76 (.19)
Male		
Female		
Parent ethnicity	.74 (.39)	.05 (.83)
Caucasian/White		
Other		
Child ethnicity	.007 (.94)	.004 (.95)
Caucasian/White		
Other		
Type of perinatal stroke	2.11 (.13)	2.82 (.07)
nAIS		
APPIS		
PVI		
Unclassified		
Severity of condition[a]	7.89 (.001)*	18.82 (<.001)**
Mild		
Moderate		

Severe		
Motor impairments	.21 (.65)	1.91 (.17)
Yes		
No		
Cognitive impairments	4.48 (.04)	13.35 (<.001)**
Yes		
No		
Behavioural impairments	2.15 (.15)	16.75 (<.001)**
Yes		
No		
Seizures	0.03 (.89)	.78 (.38)
Yes		
No		
Total gross household income (CDN)	0.95 (.39)	3.64 (.03)
<$70,000		
$71,000-$110,000		
>$110,000		
Parent education level	.39 (.82)	1.97 (.11)
Grade school certificate		
High school certificate		
College certificate		
Bachelor's degree		
Master's, doctorate, or professional degree		
Psychological concerns present prior to child's birth	4.35 (.04)	2.71 (.10)
Yes		

No

Demographic Variables	Pearson *r* (*p*-value) HADS-D	PedsQL-FIM Family Functioning
Parent age (years)	.015 (.88)	-.02 (.81)
Child age (years)	-.12 (.25)	-.01 (.89)
Years since perinatal stroke diagnosis[b]	-.10 (.34)	.004 (.97)
Years since first clinical presentation[b]	-.10 (.34)	-.08 (.47)

Note. HADS-D = Hospital Anxiety and Depression Scale – Depression; PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module; nAIS = neonatal arterial ischemic stroke; APPIS = arterial presumed perinatal ischemic stroke; PVI = periventricular venous infarction; CDN = Canadian.

[a]Rating is based on parents' self-reported perceptions of the severity of their child's condition. [b]*n* = 86.

Depression

Regression. The predictor variables included one child variable (i.e., condition severity) and six psychosocial variables (i.e., anxiety symptoms, stress levels, social support, marital quality, guilt, and blame). Examination of the residual scatterplots revealed that the data was highly skewed. As such, the data was transformed using a log10+1 transformation, which yielded a normal distribution. In addition, examination of the Tolerance and VIF values for the predictor variables revealed that multicollinearity was not present.

The regression analysis showed that condition severity significantly predicted caregiver depression scores, explaining 10% of the variance, $F(1, 101) = 10.76$ $p = .001$ (Table 4). Anxiety symptoms (HADS-A), social support, stress levels (PSS), marital quality (DAS), guilt, and blame accounted for an additional 56% of the variance in caregiver depression scores, $F(7, 95) = 25.42$, $p < .001$ (F change = 25.28, $p < .001$). The total variance accounted for in this model was 65%. However, only condition severity, anxiety symptoms, stress levels, and blame were independent predictors (Table 4).

Mediation. The mediation analysis demonstrated that the psychosocial variables mediated the relationship between condition severity and caregiver depression (total indirect effect = -1.10 with 95% CI of -2.41 and -0.03; Figure 1). A closer examination revealed that blame was the only independent variable that significantly mediated the relationship between condition severity and depression (indirect effect = -0.27 with 95% CI of -0.91 and -0.03).

Moderation. No moderators were examined for the relationship between condition severity and caregiver depression, since no child and parent variables were significantly related to HADS-D at *p*-value of < .01 besides condition severity (Table 1).

Table 3

Descriptive statistics and Pearson r Correlations between Psychosocial Measures and Outcomes Variables

		Outcome Variables	
Psychosocial Variables	Mean (*SD*), Range	HADS-D	PedsQL-FIM Family Functioning[a]
HADS-A	6.52 (3.72), 0-16	.70 (<.001)**	-.57 (<.001)**
PSS	21.95 (9.18), 5-44	.72 (<.001)**	-.67 (<.001)**
DAS[a]	111.50 (19.07), 65-147	-.62 (<.001)**	.58 (<.001)**
Social Support[a]	8.73 (3.91), 0-16	-.26 (.009)*	.25 (.01)*
POM Blame	7.38 (4.82), 0-19	.41 (<.001)**	-.39 (<.001)**
POM Guilt	5.79 (4.48),0-16	.36 (<.001)**	-.33 (.001)**

Note. SD = standard deviation; HADS-D = Hospital Anxiety and Depression Scale – Depression; PedsQL-FIM = Pediatric Quality of Life Inventory – Family Impact Module; HADS-A = Hospital Anxiety and Depression Scale – Anxiety; PSS = Perceived Stress Scale; DAS = Dyadic Adjustment Scale; POM = (Alberta Perinatal Stroke Project) Parental Outcome Measure.

[a]Higher scores indicate better functioning with respect to the construct being assessed.

*p-value ≤ .01 (two-tailed). **p-value ≤ .001 (two-tailed).

Table 4

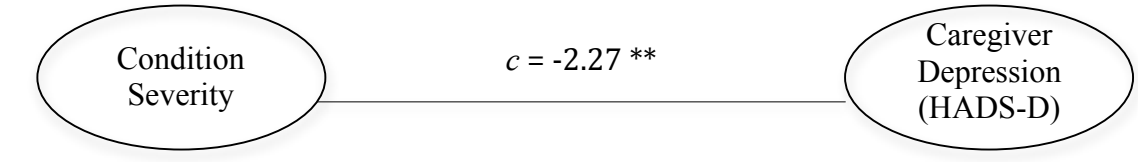
Hierarchical Regression Analyses Predicting Depression and Family Functioning

Criterion Variable	Step	Predictor Variable	β	Adj. R^2	F	ΔR^2	ΔF
HADS-D	1	Condition severity	-.31**	.09	10.76**	.10	10.76**
	2	Condition severity	-.16*	.63	25.42**	.56	25.28**
		HADS-A	.36**				
		Social support	-.03				
		PSS	.33*				
		DAS	-.10				
		POM Guilt	-.03				
		POM Blame	.17*				
Family Functioning	1	Condition severity	.39**	.26	12.80**	.28	12.80**
		Cognitive impairments	-.07				
		Behavioural impairments	-.17				
	2	Condition severity	.30**	.63	20.63**	.39	20.99**
		Cognitive impairments	-.07				
		Behavioural impairments	-.09				
		Social support	.02				
		HADS-A	-.13				
		PSS	-.29*				
		DAS	.22*				
		POM Guilt	-.08				

POM Blame	-.10	

Note. HADS-D = Hospital Anxiety and Depression Scale – Depression; HADS-A = Hospital Anxiety and Depression Scale – Anxiety; PSS = Perceived Stress Scale; DAS = Dyadic Adjustment Scale; POM = (Alberta Perinatal Stroke Project) Parental Outcome Measure.

* $p \leq .05$. ** $p \leq .001$.


Condition Severity
c = -2.27 **
Caregiver Depression (HADS-D)

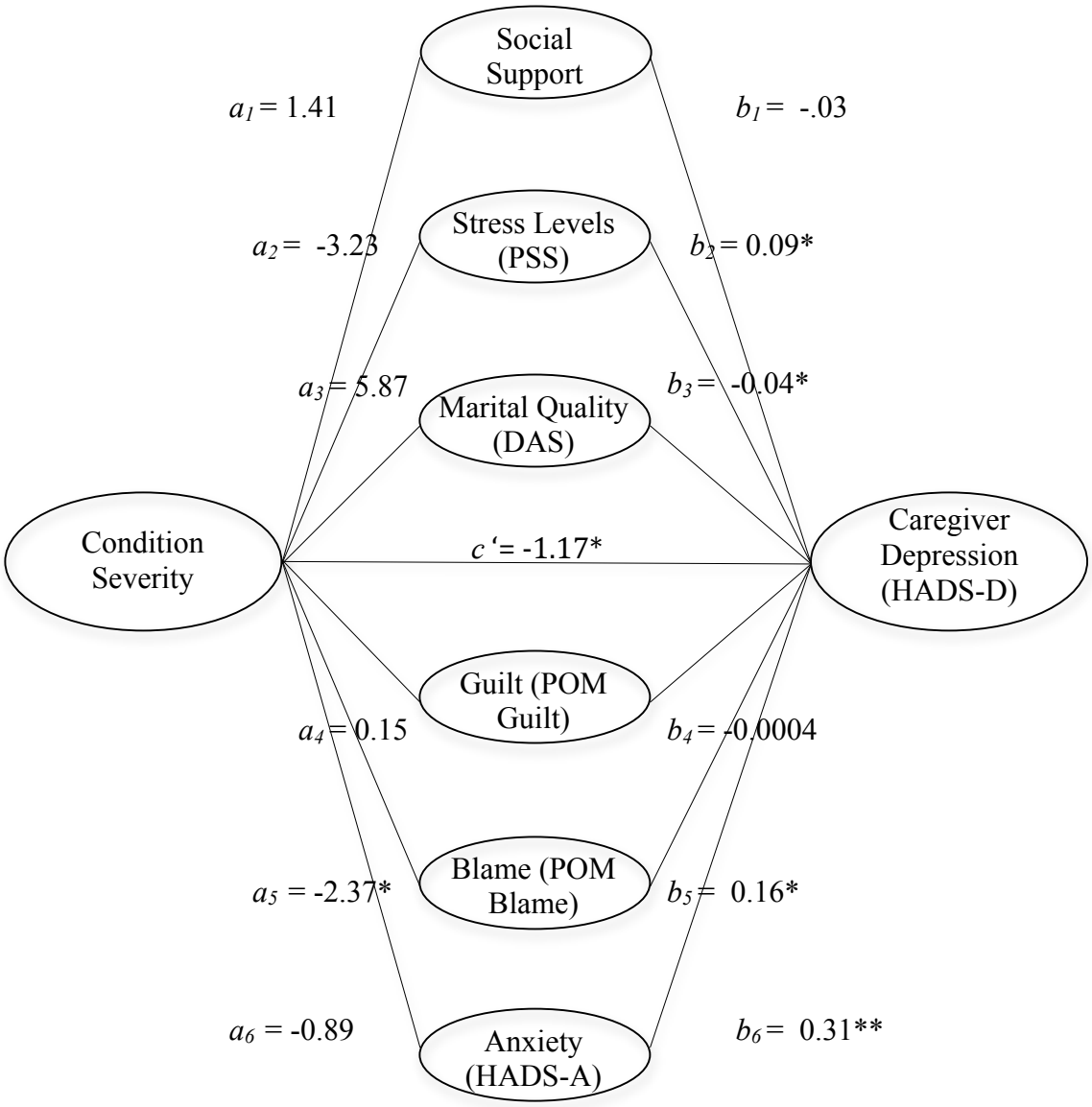

Social Support
a1 = 1.41
b1 = -.03
a2 = -3.23
Stress Levels (PSS)
b2 = 0.09*
a3 = 5.87
b3 = -0.04*
Marital Quality (DAS)
Condition Severity
c ‘= -1.17*
Caregiver Depression (HADS-D)
Guilt (POM Guilt)
a4 = 0.15
b4 = -0.0004
Blame (POM Blame)
a5 = -2.37*
b5 = 0.16*
a6 = -0.89
Anxiety (HADS-A)
b6 = 0.31**

Figure 1. Mediation model for relationship between condition severity, psychosocial variables, and caregiver depression symptoms. $n = 103$. HADS-D = Hospital Anxiety and Depression Scale – Depression; PSS = Perceived Stress Scale; DAS = Dyadic Adjustment Scale; POM = (Alberta Perinatal Stroke Project) Parental Outcome Measure. HADS-A = Hospital Anxiety and Depression Scale – Anxiety.

$^{*}p \leq .05$. $^{**}p \leq .001$.

Family Functioning

Regression. The predictor variables included three child variables (i.e., condition severity, presence of cognitive impairments, and presence of behavioural impairments) and six psychosocial variables (i.e., anxiety symptoms, stress levels, social support, marital quality, guilt, and blame). Examination of the residual scatterplots revealed that the data were normally distributed. In addition, multicollinearity was not present as evidenced by the Tolerance and VIF values for the predictor variables.

The regression analysis revealed that condition severity, presence of cognitive impairments, and presence of behavioural impairments significantly predicted family functioning scores, explaining 28% of the variance, $F(3, 99) = 12.80$ $p < .001$ (Table 4). Social support, anxiety symptoms (HADS-A), stress levels (PSS), marital quality (DAS), guilt, and blame accounted for an additional 39% of the variance in parents' family functioning scores, $F(9, 93) = 20.63$, $p < .001$ (F change = 17.96, $p < .001$). The total variance accounted for in this model was 67%, although only three predictors independently reached statistical significance (condition severity, marital quality, and stress level; Table 4).

Mediation. The mediation analysis demonstrated that the psychosocial variables did not significantly mediate the relationship between condition severity and family functioning (total indirect effect = 7.04 with 95% CI of -0.74 and 15.41; figure not shown).

Moderation. The moderation analysis found no significant interactions between condition severity and child variables (i.e., presence of cognitive impairments and

presence of behavioural impairments) on family functioning (cognitive: F change = 0.80, p = 37; behavioural: F change = 0.16, p = .69).

Discussion

This study is the first of its kind to examine the process of adaptation for parents of children with perinatal stroke. Therefore, it serves to help explain why some parents and families affected by perinatal stroke adapt better than others. The primary aim of this project was to examine predictors of caregiver depression and family functioning among affected parents. We hypothesized that child, parent, and psychosocial variables would predict caregiver depression and family functioning. The results provide partial support for this hypothesis. Because no parent variables were strongly associated with caregiver depression or family functioning in the bivariate analyses, they were not incorporated into the regression analysis. Child variables significantly predicted caregiver depression (i.e., condition severity) and family functioning (i.e., condition severity, presence of cognitive deficits, and presence of behavioural problems). All of the examined psychosocial variables were strongly associated with caregiver depression and family functioning. Anxiety symptoms, social support, stress levels, marital quality, guilt, and blame predicted caregiver depression and family functioning after controlling for child variables. Furthermore, condition severity, anxiety symptoms, stress levels, and blame independently predicted caregiver depression, while condition severity, stress levels, and marital quality independently predicted family functioning.

These results may be interpreted within the context of the Double ABCX Model (McCubbin & Patterson, 1983). Our findings suggest that parent and family well-being

depend on the combination of stressors (namely the child's condition severity and presence of behavioral and cognitive impairments), resources (social support, good marital quality, and stress management), and the meaning they attribute to the situation (guilt and blame regarding the cause of the child's condition). Substantial variation exists in the adaptation of parents and families of children with perinatal stroke, even among children with moderate and severe conditions (Bemister, Brooks, Dyck et al., 2014); parents and families may be buffered from the otherwise negative effects of raising a child with moderate or severe impairments through social support, positive marital relationships, and management of stress levels. These results agree with previous research on pediatric disabilities, demonstrating that satisfaction with social support and network size (Raina et al., 2004), marital status and marital quality (Al-Krenawi et al., 2011; Garbarski & Witt, 2013; Kersh et al., 2006), and stress levels and management (Cramm & Nieboer, 2011) positively influence caregivers' mental health.

It is worth noting that our exploration of predictors of caregiver depression and family functioning was partially limited by the data collected. Although the child and psychosocial variables we examined accounted for substantial proportions of variance in the models, a host of other variables exist that could impact parent and family well-being. For example, child adaptive functioning and parental positivity or self-esteem were not examined, and may each relate to caregiver well-being and family functioning (Brehaut et al., 2004; Trute, Benzies, & Worthington, 2012; Werner & Shulman, 2013). These variables are worthy of future investigation among parents of children with perinatal stroke.

In addition, the number of variables included in the regression model was restricted by the sample size and statistical considerations. With the current number of predictor variables, this study has an adequate sample size for multiple regression analyses according to Brace and colleagues (10:1 ratio of cases to predictor variables; Brace, Kemp, & Snelgar, 2012). Nonetheless, this study fails to reach Tabachnick and Fidell's recommended sample size ($N > 104 + m$) for testing individual predictors (2007; m = number of predictors). Some of the predictor variables, therefore, may have failed to reach statistical significance as predictors of caregiver depression and family functioning due to Type II error. Future research may utilize larger sample sizes to determine this.

The secondary aim of this study was to explore the relationships between condition severity and caregiver depression and family functioning outcomes by examining mediators and moderators. We hypothesized that psychosocial variables would mediate the relationship between condition severity and these outcomes. This hypothesis was not supported for family functioning and partially supported for caregiver depression. The psychosocial variables (anxiety symptoms, social support, stress levels, marital quality, guilt, and blame) were found to mediate the relationship between condition severity and caregiver depression. Blame regarding the cause of the child's condition was the only independent mediator of this relationship. These results align with the Double ABCX Model (McCubbin & Patterson, 1983), as well as other caregiver models and frameworks that emphasize the mediating role of psychosocial variables in parent and family well-being (G. King et al., 1999; Raina et al., 2004; Rentinck et al., 2007). Our study differs from the existing literature in its emphasis on caregiver blame. Parents may be inclined to blame others or themselves for their child's condition because

the primary cause is usually unknown (Mineyko & Kirton, 2011). Our results provide the first empirical evidence of the aversive effects of caregiver blame on their psychological well-being. Moreover, the average amount of time that has passed since the child's diagnosis was 5.6 years, which implies that some parents carry these feelings of blame for many years. Our clinical experiences support this finding and suggest that such feelings may be altered through careful and deliberate psycho-education regarding the unpreventable nature of perinatal stroke.

Our study's moderator effects may have been particularly difficult to detect given the relative homogeneity of the sample (Holmbeck, 1997). The sample consisted mostly of mothers of Caucasian descent with children who do not have behavioral and cognitive impairments. Thus, underrepresentation of groups, such as fathers, may have minimized the power to detect differences in the bivariate analyses. Underrepresentation of groups in the moderation analyses, such as parents of children with behavioural problems, may have similarly minimized the power to detect significant interactions with the outcome variable. As well, the compounded measurement error of the moderator and predictor variables may have contributed to the null findings. Future studies with greater representations across sociodemographic variables (e.g., gender, age, income, education level, ethnicity, etc.) and condition variables (e.g., presence of impairments) may enhance present knowledge on moderators of parent and family outcomes.

Other limitations of this study are inherent to its study design. For instance, causal inferences cannot be drawn from the data due to the study's cross-sectional design. Longitudinal research is needed to determine the impact of child, parent, and

psychosocial variables on caregiver depression and family functioning over time. Such a design would also clarify the direction of the examined relationships. We currently cannot eliminate the possibility that the relationships between child variables, psychosocial variables, and outcomes operate in the opposite direction than we speculated or in a bidirectional manner. For instance, some evidence exists that the relationship between parenting stress and child behavioural problems is bidirectional (Baker et al., 2003).

In addition, our study depended on parents' subjective reports, which introduces the potential for biased responses and shared variance among the measures. Future studies may benefit from incorporating objective data into the study, such as formal diagnoses of depression or the number of diagnostic criteria met for depressive disorder. Lastly, the generalizability of our results is limited by the study sample. There is reason to believe that parent and family well-being differs for fathers (Ha, Hong, Seltzer, & Greenberg, 2008), ethnic minorities (Eisenhower & Blacher, 2006), and parents with low family incomes (Cho & Hong, 2013). These groups were underrepresented in the current study.

Conclusions

Despite these limitations, this study has important theoretical and clinical implications. This study contributes to current knowledge about the impact of raising a child with perinatal stroke by identifying mechanisms through which parents and families successfully adapt. Based on our results, medical professionals and support workers who assist affected families should seek to reduce caregiver blame and guilt through simple

psycho-education. Additional priorities for intervention and services may include teaching parents stress-reduction strategies and ways to strengthen their marital relationship when faced with adversity. Consistent with family-centered care models, these results may guide policymaking to provide tailored support for families affected by perinatal stroke. Family-centered care promotes the psychological well-being of both caregivers and affected children (S. King, Teplicky, King, & Rosenbaum, 2004), and it has been associated with greater satisfaction of services. Thus, our study contributes to the growing literature on the family impact of perinatal stroke by identifying targets for intervention and enhancing knowledge on the caregiver adaptation process.

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Chapter Five: General Discussion

Summary of Findings

The purpose of this dissertation was to examine the impact of raising a child with perinatal stroke. This was accomplished through three carefully planned and executed studies. In the first study, the APSP Parental Outcome Measure (POM) was developed to reliably assess the psychosocial impact of raising a child with perinatal stroke, including quantifiable measures of parental guilt and blame. In Chapter Two, the POM was validated on 110 parents of children with perinatal stroke, providing strong evidence for its internal consistency, test-retest reliability, concurrent validity, convergent validity, incremental validity, and factor structure.

In the second study, the psychosocial impact of raising a child with perinatal stroke was examined. Mothers of children with perinatal stroke were compared with mothers of children with typical development and fathers of children with perinatal stroke on measures of well-being. The results illustrated that the majority of mothers of children with perinatal stroke were indistinguishable from controls. However, mothers of children with moderate and severe conditions had worse outcomes on measures of depression, quality of life, marital satisfaction, and family functioning. Furthermore, mothers of children with perinatal stroke had similar or slightly worse outcomes than fathers with the most pronounced differences in their anxiety symptoms and feelings of guilt.

In the third study, predictors of parent and family outcomes were examined, along with mediators and moderators, in order to better understand the process of adaptation to raising a child with perinatal stroke. The results showed that child and psychosocial

variables predicted parent and family outcomes. Mores specifically, condition severity, social support, anxiety symptoms, and blame independently predicted caregiver depression, while condition severity, stress levels, and marital quality independently predicted family functioning. An evaluation of mediators and moderators also yielded evidence that parental blame mediates the relationship between condition severity and caregiver depression.

Together, these three studies capture areas of need for affected parents and families, some of which are common to parents of children with disabilities (e.g., increased stress levels and symptoms of depression) and some of which are more specific to this population (e.g., feelings of guilt and blame regarding the cause of the child's condition). This was accomplished through the development of a questionnaire specifically designed for parents of children with perinatal stroke (POM; Chapter Two), as well as through the use of commonplace measures to assess parental well-being (Chapter Three). In addition, the commonalities and nuances of these parents' needs were illuminated by the determinants of their well-being (Chapter Four). Consistent with other pediatric disability studies, condition severity, social support, anxiety symptoms, stress levels, and marital quality predicted parent and family outcomes. Unlike previous studies, however, parental blame regarding the cause of the child's condition was found to be a determinant and mediator of parental well-being. Thus, this dissertation helps capture the nomothetic and idiographic experiences of parents of children with perinatal stroke through the aggregation of three unique, but complementary, studies.

One of this study's greatest contributions is the examination of the familial impact of a condition that has not been previously investigated. Several research studies have been conducted on related conditions, such as cerebral palsy, which likely include perinatal stroke populations (perinatal stroke accounts for over 30% of all cases of cerebral palsy; Raju, Nelson, Ferriero, & Lynch, 2007). However, no previous studies have examined parents of children with perinatal stroke as a distinct group, even though evidence exists that cerebral palsy, epilepsy, and developmental disabilities differentially affect parental well-being (Eker & Tüzün, 2004; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Tzoufi et al., 2005). This dissertation addresses this existing gap in the literature, and it shines light on the apparent benefits of studying perinatal stroke as its own syndrome. As outlined in Chapter One, perinatal stroke is a specific condition with a distinct mechanism of injury (i.e., ischemia), motor presentation (i.e., unilateral motor impairments), and associated challenges (i.e., parental guilt and blame).

Theoretical Considerations: Grief Theories and Stress-Process Models

Despite this, affected parents still share many experiences with other parents of children with disabilities, which are captured by stress-process models and grief theories (reviewed in Chapter One). Although no explicit measures of chronic sorrow or complicated grief were incorporated into this research project, evidence was gathered for parents' ongoing sense of anger, sadness, and guilt across different stages of life (the children's ages ranged from 0.5 to 18 years; Chapter Three). Furthermore, the results did not appear to support a linear grief process. There were no significant correlations between the child's age and parent/family outcomes, nor were there significant correlations between the time since diagnosis and parent/family outcomes, even of a

small magnitude (Chapter Four). Parents' feelings of anger, sadness, and guilt did not appear to remit with age, which may be interpreted according to Olshanky's chronic sorrow theory (1962). This theory suggests that parents will continue to experience anger, sadness, and guilt, along with feelings of joy and happiness, throughout their child's life. Grief responses are theorized to occur when parents become acutely aware of the discrepancy between their child's hoped-for abilities and actual abilities, which may follow developmental milestones, anniversaries, and other triggers (e.g., trips to the hospital). Thus, this dissertation strongly supports Olshanky's chronic sorrow theory over Solnit and Stark's time-bound theory (1961), which appears consistent with recent trends in the pediatric disability literature.

Similarly, the parents' experiences may be interpreted according to the stress-process models and theories. Chapter Four contains a detailed discussion of how parent and family outcomes depend on the combination of stressors and available resources, which is in accordance with several stress-process models (e.g., double ABCX model and Lazarus and Folkman's model). As would be expected based on these models, variation in maternal well-being was observed across *and* within groups that were classified based on condition severity (Chapter Three).

This dissertation additionally illustrated the profound effect of perinatal stroke on family functioning (Chapter Three), which is consistent with Bronfenbrenner's social ecology theory (1979) and Minuchin's family system theory (1988). According to Bronfenbrenner, pediatric disabilities significantly impact families and subsystems within the families across time, including marital relationships. Family relationships exist within

the child's microsystem, and can be influenced by more distal systems, such as his/her exosystem (e.g., parents' social support networks; Chapter Four) and macrosystem (e.g., general cultural beliefs on disabilities). Minuchin similarly asserts that pediatric disabilities ought to be conceptualized at a level broader than the individual. His work stresses the interactional nature of family systems, as well as family responses to pediatric disabilities (e.g., enmeshment and disengagement). The present research project did not evaluate families' interaction styles, but it did document the undeniable impact of perinatal stroke on family functioning. Moreover, the stress-process models and grief theories undoubtedly informed the study designs (including the items chosen for the POM and the variables chosen as predictors) and interpretation of data.

Clinical Implications: Parent and Family Interventions

Research on families affected by perinatal stroke has lagged behind clinical initiatives. Family resources, supports, and interventions specific to pediatric stroke have exponentially increased in recent years. In the past three years alone, the Canadian Pediatric Stroke Support Association was founded (including its Ambassador Program to support families following a new diagnosis; 2011), the Canadian Stroke Network published its first family guide to pediatric stroke (2011), the International Alliance for Pediatric Stroke was created (2013), and local support groups were formed in Calgary, Alberta (e.g., Calgary Pediatric Stroke Program [CPSP] Parent Support Group and Peer Group; 2011 and 2012). Prior, parents were able to receive formal support from online forums for children with hemiplegic cerebral palsy (e.g., www.hemikids.org) and only one in-person parent support group apparently existed in North America (i.e., MADE Support Group at the Children's Hospital of Philadelphia). These trends reflect increasing

recognition of pediatric stroke as a unique condition, as well as the imperative need for research to inform such supports, resources, and services.

Although the consequences of stroke are devastating at any age, they often last a lifetime in perinatal populations. This amplifies the burden to the individual, caregivers, and entire family system. Specialized therapeutic supports need to be available for affected parents, couples, and families, as clearly delineated in this dissertation. At minimum, parents and families at higher risk should be identified and monitored, such as individuals whose children have moderate and severe conditions, behavioural difficulties, and cognitive problems. Parents' social support and stress levels also ought to be regularly assessed in order to identify those who may best benefit from additional support. The POM may be particularly useful in this respect, as well as for identifying potential targets for intervention. The POM takes approximately five minutes to complete, and it assesses the impact of the child's condition on the respondent's personal activities, family functioning, and psychosocial well-being, as well as their feelings of guilt and blame regarding the cause of the child's condition.

As outlined in Chapter Four, parent and family outcomes may be optimized if efforts are devoted to improving parents' social support networks, marital support, stress management techniques, and feelings of guilt and blame. This may be accomplished through various intervention strategies ranging from simple psycho-education to structured groups.

Ample evidence exists that parent support groups increase parents' sense of social support (Banach, Iudice, Conway, & Couse, 2010; Mueller, Milian, & Lopez, 2009).

They also empower parents by enhancing their sense of self-efficacy and knowledge about their child's condition. My clinical experiences co-facilitating the CPSP Parent Support Group support the generalizability of these findings to perinatal stroke populations; parents at the support group frequently reported that they felt supported, heard, and understood. Although the CPSP Parent Support Group is professionally facilitated, parent led groups may be particularly appealing in the future because of their relatively low cost, sustainability, and efficacy. Furthermore, such groups may protect parents against depression as alluded to in Chapter Four.

Parent support groups have also been shown to be efficacious in reducing stress levels among parents of children with disabilities, along with cognitive behavioural groups, parent management training, and behavioural family interventions (Hastings & Beck, 2004; Roberts, Mazzucchelli, Studman, & Sanders, 2006). The latter two interventions focus on managing child behavior problems and may be particularly useful for parents of children with perinatal stroke in which this is a concern. Extrapolating from this dissertation, these interventions may not only improve the child's behavioural outcomes and parents' stress levels, but also their family functioning. Evidence also supports the usefulness of cognitive behavioural groups or skills training. In a review of parent interventions for children with intellectual disabilities, cognitive behavioural training was deemed the most empirically-supported intervention (Hastings & Beck, 2004). However, a meta-analysis of parent interventions for children with developmental disabilities found the combination of parent and cognitive behavioural training to be the most effective intervention strategy for parents (Singer, Ethridge, & Aldana, 2007). As far as the author is aware, no such groups yet exist for perinatal stroke populations.

This dissertation also supports the potential benefit of enhancing marital bonds and support among affected families. Scarce research exists in this area with respect to pediatric disabilities. Nonetheless, there is widespread recognition of the impact of marital relationships on the child's development and functioning (Risdal & Singer, 2004). Intervention strategies may involve psycho-education regarding intimacy, co-parenting, and supportive strategies. Evidence also exists for use of emotionally focused therapy to decrease marital distress among parents of children with chronic conditions and disabilities (Ramisch, Timm, Hock, & Topor, 2013), which serves to facilitate couples' awareness and expression of their emotions.

Lastly, the results of this dissertation highlight the value of providing parents with psycho-education regarding the generally unpreventable nature of perinatal stroke. This is a relatively inexpensive intervention strategy that may help ameliorate symptoms of depression or prevent their development in the future. This psycho-education may be provided by physicians, nurses, and caseworkers who are in first contact with parents following their child's diagnosis. It also may also be incorporated into other interventions, such as parent support groups or cognitive behavioural groups.

All in all, the existing research on parent interventions is quite promising. The research demonstrates the presence of evidence-based interventions for reducing distress among parents of children with disabilities.

Limitations and Future Directions

This dissertation's clinical and theoretical implications ought to be considered with respect to its limitations. A large portion of the limitations have been discussed at

length in the preceding chapters, including threats to external validity (e.g., homogeneity of sample), construct validity (e.g., biases in condition severity ratings), and statistical conclusion validity (e.g., type II errors due to small sample sizes). In addition, limitations of the cross-sectional study design have been described, including the inability to draw causal inferences or capture parents' trajectory across the child's lifespan. As such, the remaining discussion will focus on three broader limitations that span across the research studies.

First, one of the greatest limitations of this dissertation is the lack of a disease-control group. This research project was originally designed to compare mothers of children with perinatal stroke with mothers of children with epilepsy. However, significant difficulties recruiting the latter group unfortunately rendered these comparisons meaningless and altered the direction of this dissertation. As such, the differences and similarities between mothers of children with perinatal stroke and other chronic conditions are yet to be determined. Future research may address this void in the literature. Mothers of children with epilepsy may still be an ideal comparison group in future studies given that epilepsy is a pediatric neurological condition with well-understood impacts on parents and families (Duffy, 2011). As such, it would be highly informative to compare the needs of these parents to those affected by perinatal stroke while controlling for socioeconomic variables and condition severity. Depending on the results of such data, the findings could potentially be used to advocate to policymakers regarding the need for resources comparable to those available for families affected by pediatric epilepsy.

Second, this study was limited by the number of constructs assessed in parents of children with perinatal stroke. As such, there was a greater emphasis on traditional constructs of maladaptation as opposed to strength-based measures of adaptation. The current study may have benefitted from a greater focus on strength-based constructs, such as resiliency (Bayrakli & Kaner, 2012) or parenting morale (Benzies et al., 2011). Research on caregivers of children with disabilities appears to be increasingly taking a strength-based approach, focusing on such constructs. However, as Turnball (2007) highlights, these constructs often simply measure the absence of more traditional constructs of stress, depression, and maladaptation. Hence, it can be argued that the debate between the use of strength-based measures and more traditional measures is one largely based on nomenclature and political astuteness.

Nonetheless, future research on parents of children with perinatal stroke may incorporate strength-based measures in order to form a holistic understanding of parents' functioning. More traditional measures of caregiver well-being were used in present research project in order to form a foundation in which to understand the impact of raising a child with perinatal stroke. Although decades of research have established the increased risk for psychological and physical concerns among parents of children with disabilities, condition-specific differences have been observed among parents of children with neurodevelopmental conditions (Eker & Tüzün, 2004; Mugno et al., 2007; Tzoufi et al., 2005). Moreover, the traditional constructs measured in the present study clearly identify needs for resources and interventions for affected families. Once the needs are identified and appropriate resources are allocated to them, there is an immense additive

benefit of examining strength-based measures to further inform intervention strategies and enhance preventative efforts.

Third, the experiences of parents of children with perinatal stroke captured in this dissertation were limited by the questions asked. Survey design methodology was used, which was conducive to gathering large quantities of data, but it did not give due consideration to the participants' individual experiences. Hence, the parents were not given a voice to discuss their feelings, thoughts, and behaviours. Qualitative researchers have been studying human experiences for centuries, arguing that it cannot be minimized to scientific algorithms and generalizations (Willig, 2013). There are overwhelming benefits of qualitative *and* quantitative data, and I believe these approaches do not need to be mutually exclusive. Future research studies on parents of children with perinatal stroke may build on the foundation that this dissertation establishes to delve into the individual experiences of parents and families. Such studies may employ mixed method designs, grounded theory, or phenomenology to understand parents' unique emotions and perspectives.

Conclusions

The purpose of this study was to systematically examine the parental and familial impact of raising a child with perinatal stroke. The results not only demonstrate progress towards a more advanced understanding of the wide-spanning impact of perinatal stroke, but they also shed light on fruitful future directions. Future studies may build on these findings to examine interventions ranging from preventative efforts (e.g., psycho-education after diagnosis) to intensive treatment (e.g., cognitive-behavioural therapy). In

addition, future research may further explore the complex interplay that exists between the family system and child's condition through evaluation of the family members' strengths, resilience, and individual experiences. Through these efforts, the most efficacious interventions can be identified and the long-term outcomes can be optimized for families affected by perinatal stroke.

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Appendix A: Demographics Questionnaire for Parents of Children with Perinatal Stroke

1. How old are you? _____

2. How old is your child who has a diagnosis of perinatal stroke? _____

3. What is your child's sex? □ Male □ Female

4. Have you been a caregiver for your child with perinatal stroke since his or her birth? □ Yes □ No
   a. If **no**, how many years have you been a caregiver to this child?
      _____

5. Does your child have impairments? Please check all that apply:
   □ Motor
   □ Cognitive (e.g., learning difficulties)
   □ Language (e.g., speech impediments or language delay)
   □ Behavioural
   □ Visual (e.g., cross-eyed or poor eye sight)
   □ Seizures
   □ Unknown

6. Please rate the severity of your child's impairments on a scale of **0** (non-existent) to **4** (severe) based on your observations:

   ❖ **Please enter 0 if an option is not applicable**

   _____ Motor
   _____ Cognitive
   _____ Language
   _____ Behavioural
   _____ Visual
   _____ Seizures

7. In your opinion, how severe is your child's condition overall?
   □ Mild □ Moderate □ Severe

8. How old was your child with you first noticed that he/she may have a neurological concern? _____

9. How old was your child when he/she received a diagnosis of perinatal stroke?
   _____

10. Has your child EVER experienced a seizure? □ Yes □ No
    a. If **yes**, is your child currently taking anti-epileptic medication to manage his/her seizures? □ Yes □ No

11. Is your child the youngest, middle or eldest child in your immediate family?
    □ Youngest
    □ Middle
    □ Oldest
    □ Not applicable (only child)

12. How many kids do you have?
    □ 1
    □ 2
    □ 3
    □ 4+

13. Does anyone else residing in your home have a chronic illness or condition?
    □ Yes □ No

    a. If **yes**, please indicate who and which illness or condition he or she has:

    _____

14. What is your current caregiver status?
    □ Lone caregiver in the home
    □ Co-caregiver in the home (e.g., partner or adult family member also cares for the child)
    □ Other (please specify):
    _____

15. What best describes your caregiver status throughout your child's life up to now?
    □ Lone caregiver in the home
    □ Co-caregiver in the home (e.g., partner or adult family member also cares for the child)
    □ Other (please specify):
    _____

16. Do you receive community support for caregiving (e.g., formal respite care)?
    □ Yes □ No

a. If **yes**, please specify:

_____

17. Do you receive community support for services (e.g., funding for children with disabilities)? □ Yes □ No

a. If **yes**, please specify:

_____

18. On a scale of **0** (not at all) to **4** (extremely), please rate how helpful the following people or resources have been in caring for your child with perinatal stroke:

*** Please enter 0 if an option is not applicable**

Spouse/partner		Friends	
Child's siblings		Community supports	
Grandparents			

19. Approximately how many hours a week do you spend caring for your child with perinatal stroke?

□ <10
□ 10-20
□ 20-30
□ 30-40
□ >40

20. Approximately how many hours a week do you spend working outside of your home?

□ <10
□ 10-20
□ 20-30
□ 30-40
□ >40

21. What is your marital status?

□ Married/common-law
□ Divorced/separated – currently single
□ Divorced/separated – currently remarried/common-law
□ Single

22. How would you rate your marriage/ relationship prior to having a child with perinatal stroke?
    - □ Very satisfying
    - □ Satisfying
    - □ Neutral
    - □ Dissatisfying
    - □ Very dissatisfying
    - □ Not applicable (I was not in a relationship at the time)

23. Please indicate how having a child with perinatal stroke has impacted your marriage/ relationship:
    - □ Strengthened the relationship
    - □ Did not have a significant impact on the relationship
    - □ Placed strain on the relationship
    - □ Not applicable

24. Prior to the birth of your child with perinatal stroke, did you ever feel that you might need to seek psychological services (e.g., for anxiety or depression)?
    □ Yes □ No

25. Are you currently seeking psychological services? □ Yes □ No

26. Are you currently taking any medications for a psychological disorder?
    □ Yes □ No
    a. If **yes**, please specify the type of medications:

    _____

27. Do you fluently read and write in English? □ Yes □ No

28. What is the highest level of schooling you obtained?
    - □ Grade school certificate
    - □ High school certificate
    - □ College certificate or diploma
    - □ Bachelor's degree
    - □ Master's, doctorate, or professional (e.g., law, dentistry, pharmacy) degree

29. Current occupation (if applicable):

    _____

30. What was the total gross income (before taxes end deductions) in your household in the past year?

- □ < $30,000
- □ $30,000 to $70,000
- □ $71,000 to $110,000
- □ $111,000 to $150,000
- □ >$151,000

31. Please indicate your ethnic origin by checking off the appropriate boxes:

- □ Hispanic/Latino (Mexican, Central and South American)
- □ Pacific Islander (Australian Aboriginal, Polynesian-Hawaiians, New Zealanders, Tahitians, Samoans, Melanesian, Micronesian)
- □ Caucasian/White (North American, European, Australian, New Zealand, Former Soviet Union)
- □ Black (African, African American/Canadian, Caribbean: excluding North Africa)
- □ Southeast Asian (Chinese, Japanese, Korean, Vietnamese, Cambodian, Thai, Laotian, Taiwanese, Filipino, Malaysian)
- □ East Indian/South Asian (East Indian, Pakistani, Sri Lankan, Bangladeshi)
- □ Middle Eastern (North African, Arab Countries)
- □ First Nations/Aboriginal (Canadian/American)
- □ Other (please provide country): _____
- □ Unknown

27. Please indicate the ethnic origin of the other biological parent of your child by checking off the appropriate boxes:

- □ Hispanic/Latino (Mexican, Central and South American)
- □ Pacific Islander (Australian Aboriginal, Polynesian-Hawaiians, New Zealanders, Tahitians, Samoans, Melanesian, Micronesian)
- □ Caucasian/White (North American, European, Australian, New Zealand,

Former Soviet Union)

- ☐ Black (African, African American/Canadian, Caribbean: excluding North Africa)
- ☐ Southeast Asian (Chinese, Japanese, Korean, Vietnamese, Cambodian, Thai, Laotian, Taiwanese, Filipino, Malaysian)
- ☐ East Indian/South Asian (East Indian, Pakistani, Sri Lankan, Bangladeshi)
- ☐ Middle Eastern (North African, Arab Countries)
- ☐ First Nations/Aboriginal (Canadian/American)
- ☐ Other (please provide country): _____
- ☐ Unknown

28. Please indicate how much you agree or disagree with the following statements:

	Strongly Agree	Slightly Agree	Neither Agree Nor Disagree	Slightly Disagree	Strongly Disagree
Professionals at clinic have educated me about my child's condition					
I have discussed my concerns about my child's condition with a professional who specializes in perinatal stroke					
I have educated myself about my child's condition through books, the Internet, and other sources					
I have reviewed information on the Calgary Pediatric Stroke Program website					
I have attended support groups for parents of children with perinatal stroke					

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