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**Move&Connect Caregivers: The Feasibility of a Virtual Group-Based Intervention
for Caregivers of Youth with Persistent Post-Concussion Symptoms**

By

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**Move&Connect Caregivers: The Feasibility of a Virtual Group-Based Intervention
for Caregivers of Youth with Persistent Post-Concussion Symptoms**

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August 25, 2022

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ABSTRACT

Youth with persistent post-concussion symptoms (PPCS) experience challenges in physical, social, and emotional domains. Around 30% of youth experience PPCS that continue beyond four weeks post injury, making it difficult for them to return to meaningful activities. Prolonged concussion recovery has also been found to affect caregivers' mental health and family functioning. Further, parental stress adversely affects the well-being of youth with PPCS. Despite the critical role that caregivers play in youth recovery post-injury, there is no empirically-validated intervention tailored to the specific needs of caregivers of youth with PPCS. The overall thesis objective is to explore the feasibility of a novel, virtual group-based intervention, *Move&Connect-Caregivers (M&C-C)*. The intervention was delivered twice, where the first group included four caregivers, and the second group included five caregivers (total n=9). Feasibility metrics and semi-structured interviews were collected. Interviews were analyzed using qualitative content analysis. Findings demonstrated that *M&C-C* is a feasible intervention for caregivers of youth with PPCS. A visual model was developed to capture the salient features of caregivers' experience with *M&C-C*, and included four categories: (1) Caregiver Background, (2) *M&C-C* Intervention: Structure, (3) *M&C-C* Intervention: Engagement, and (4) Key Takeaways. Results suggest that *M&C-C* is a meaningful virtual intervention that merges the benefits of social support, concussion education, and advocacy tools to support caregivers of youth with PPCS.

To my friends who provided great support on my academic and research journey, thank you for being there throughout this experience. A special mention of thanks must go to my academic anchor and best friend, Iulia Niculescu, who made my graduate school journey feasible and enjoyable.

To my family, I cannot thank you enough for the endless support, love, and tolerance that you have provided throughout my study years.

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LIST OF ABBREVIATIONS

ABI	Acquired Brain Injury
TBI	Traumatic Brain Injury
mTBI	Mild Traumatic Brain Injury
PPCS	Persistent Post-Concussion Symptom
FAB	Family-directed Approach to Brain injury
IM	Intervention Mapping
PCC	Persistent Concussion Clinic
HBKRH	Holland Bloorview Kids Rehabilitation Hospital
NOvEL	Neurorehab Outcomes Via Education & Learning
M	Mean
SD	Standard Deviation
M&C-C	Move&Connect-Caregivers

CHAPTER 1

INTRODUCTION

Pediatric mild traumatic brain injury (mTBI), or concussion, is a public health concern in Canada (Comper et al., 2012; Macpherson et al., 2014). Concussion is defined as an injury induced by biomechanical forces such as a blow to the head or body causing the brain to move rapidly inside the skull (McCrory et al., 2017). Clinical presentation of concussion symptoms in youth are variable and may manifest as a combination of cognitive, physical, emotional, or sleep-related concerns (Polinder et al., 2018). Approximately 30% of youth experience persistent post-concussion symptoms (PPCS) where the symptoms continue beyond four weeks post injury (Zemek et al., 2017). For example, an epidemiological study found that 58.5% of children remained symptomatic after the first month following a concussion, and about 14% at three months post-concussion (Barlow et al., 2010). Youth with PPCS are reported to have significantly lower health-related quality of life in physical, emotional, and social domains (Hunt et al., 2020), making it difficult for youth to return to meaningful activities.

The prolonged concussion recovery of youth can affect caregivers' mental health and family functioning. For example, distress and family burden is reported to be high in parents of children with PPCS (Ganesalingam et al., 2008). Similarly, caregivers report high levels of strain and poor family functioning for youth with traumatic brain injury (TBI) (Rashid et al., 2014). Also, parental stress prior to injury predicts greater PPCS among youth, suggesting that addressing parent health challenges can minimize negative health outcomes of their children (Bernard et al., 2016; Schorr et al., 2020). Consistent with this, there are theoretical models that demonstrate the importance of caregivers' well-being in their child's recovery. For example, the family-directed approach model emphasizes family collaboration and caregiver mental health as it recognizes the impact families have on youth rehabilitation (Fisher et al., 2019).

Interventions provide support to help caregivers manage the challenges their children may experience after brain injury (Miley et al., 2020). A qualitative study that aimed to understand lived experiences of parents of children with TBI reported that the injury impacts a family in many ways (Brown et al., 2013). Parent participants described feeling isolated and unsupported in managing their responsibilities, and noted a desire for support in many areas such as coping strategies, emotional upkeep, and parenting tips. Additionally, group-based programs may enable feelings of connection among parents as they include elements like information sharing and reciprocal support (Calandri et al., 2017). This is true for children with moderate-to-severe brain injury where some intervention support exists for parents. For example, a problem-solving intervention was effective in reducing levels of distress, depression, and anxiety among parents of youth with moderate-to-severe TBI (Wade et al., 2006). However, for youth with PPCS, research on parent intervention is lacking and issues such as finance, travel, parental care, and employment-related factors can preclude caregivers from attending support programs (Damianakis et al., 2016; Narad et al., 2016). Hence, virtual interventions may be beneficial for caregivers of youth with PPCS to promote convenience and accessibility. Despite the critical role that caregivers play in youth recovery post-injury (Brown et al., 2013), there are no interventions tailored to the specific needs of caregivers of youth with PPCS.

This project describes a novel, virtual, group-based intervention named *Move&Connect-Caregivers* (*M&C-C*). The primary objective was to examine the feasibility of the *M&C-C* intervention and to evaluate its utility in order to suggest program improvements**.** Before describing the study protocol in more detail, general terminology and definitions are provided, followed by a review of the concussion literature.

1.1 Definitions and Terminology

This section describes the definitions of terms used throughout this thesis. Within the pediatric literature, the term adolescents is defined as individuals aged 10-18 years old (WHO, 2022), whereas children are defined as those who are younger than 10 years old. For the purpose of this thesis, the umbrella term *youth* will include both children and adolescents through 18 years of age. *Adults* are defined as individuals aged 19 years and above. Within the brain injury literature, acquired brain injury (ABI) refers to an umbrella term that encompasses traumatic (TBI) and non-traumatic brain (nTBI) injuries. Moving forward for simplicity, terminology related to a mild traumatic brain injury (mTBI) is referred to as *concussion*. In addition, the term *caregiver* is broadly defined to reference adult family members, including mothers, fathers, grandparents, and guardians who are responsible for the care of youth with PPCS. Specifically, the term *parent* is used to define the child's mother or father.

1.2 Concussion and Youth

Youth are at an increased risk of sustaining a concussion due to their developing brain (Lax et al., 2015; Rajabali et al., 2016). This section discusses pediatric concussion prevalence rates, development as a vulnerable period for injury, and consequences of concussion among youth.

1.2.1 Prevalence of Injury

In Ontario, concussion-related incidents in emergency departments had a 5.5 fold increase from 2003 to 2013 for youth aged 5–18 years (Zemek et al., 2017). Surveillance of electronic medical records showed that boys had higher concussion rates compared to girls, and those aged 10-14 years and 15-19 years had a higher prevalence of concussion compared with youth aged 1-14 years (Bang et al., 2019). A retrospective study examined recent trends in

diagnosed concussions among youth in a health care system from 2013-2018 (Askow et al.,

2020). Results demonstrate a rise in concussion diagnosis among youth under the age of 18

years, with an overall incidence rate of 1.37 concussions per 1,000 patients. A recent review also

suggested that males sustain a greater number of concussions than females in the general

population, but females may be more vulnerable to concussion in sport settings (Merritt et al.,

2019), and females are more likely to sustain a concussion in gender-matched sports (Baker et

al., 2016). Some of the leading causes of concussion are falls, trauma, and sports. For example,

Haarbauer-Krupa et al. (2018) assessed distribution of injury mechanism among children aged

1-17 years and noted that approximately 70% of concussion injuries were related to sports. When

the injury was not due to sports, the primary mechanisms included being struck by an object or

falling. Considering that up to 25% of individuals with concussion do not seek medical care after

their injury (Lagacé-Legendre et al., 2020), and combined with the underreporting behaviour of

symptoms that is common among youth, these pediatric prevalence rates are thought to be an

underestimation (Daneshvar et al., 2012; Matveev et al., 2018).

1.2.2 Developmental Period

The developing brain is different from that of a mature adult (Araki et al., 2017; Toledo

et al., 2012). Brain regions that are involved in higher processing such as social cognition, reason

and judgment have a protracted development that mature at around 25 years of age (Toledo et al.,

2012). Furthermore, musculoskeletal differences include children having undeveloped neck

muscles, weak head support, smaller skull size, and poor ability to cushion against external

forces (Meehan et al., 2011). Thus, the child's brain may be more vulnerable to injury than the

adult brain due to a combination of immature neural networks and greater potential for brain

structural deformity (Meehan et al., 2011; Toledo et al., 2012). Additionally, the time to recover

from injury is generally longer for youth than adults (Manzanero et al., 2017). For example,

youth athletes who experience a concussion are more likely to have longer recovery times, and

are at a higher risk of sustaining long term injuries than adult athletes (Scopaz & Hatzenbuehler,

2013; Whittington, 2015). Further, adolescence is a developmental period in which there is

increased risk of symptom intensity and delayed recovery after concussion (Blume et al., 2012;

Tanveer et al., 2017). This may be related to brain physiological and neurological factors such as

skull thickness, brain size, and degree of myelination (Kirkwood et al., 2006). In addition to

physical growth, adolescence is also a time period where youth engage in riskier activities like

competitive sports or coping strategies (Patel & Luckstead, 2000; Sampson et al., 2006; Zill,

1995). Adolescence is also a sensitive period for the development of mental health disorders

(Bor et al., 2014; Jane Costello et al., 2006), further highlighting the elevated risk faced by

youth. During the adolescent period, it is difficult to distinguish developmental identity and

behavioral changes from symptom changes due to TBI among adolescents (Brown et al., 2013;

Wade et al., 2006). This is due to uncertainties as to whether a specific behavior would be due to

the brain injury, a developmental stage, life stressors, or comorbid difficulties (Brown et al.,

2013). Hence, the consequences of concussion are broad and can be significant including

affecting youth behaviour (e.g., missing school days) and cognitive skills (Li & Liu, 2012;

Toledo et al., 2012). These consequences are described in more detail in Section 1.3.2.2.

1.3 Concussion Symptoms

Concussion symptoms, both acute and persistent, can be nonspecific and include

physical, cognitive, sleep-related, and emotional symptoms (Dawson et al., 2021). Given the

focus of this thesis is on youth experiencing prolonged symptoms after a concussion, most of this

section will cover PPCS, including different outcomes of PPCS on youth and family, as well as predictive variables of risk.

1.3.1 Acute Symptoms

The clinical presentations of concussion symptoms following injury in youth are variable and can manifest as a combination of physical (e.g., headache, dizziness), cognitive (e.g., poor memory, difficulty concentrating), emotional (e.g., anxiety, low mood), or sleep-related concerns (Polinder et al., 2019: see Table 1). Warning signs for immediate medical attention can include more serious symptoms such as loss of consciousness, increased agitation, or vomiting (CDC, 2022). Acute concussion symptoms include dizziness, headache, feeling in a fog, and visual disturbance (Merritt et al., 2015; McCrory et al., 2017). Cognitive deficits experienced after a concussion may include poor attention and concentration, impaired memory, and challenges with executive functioning (Howell et al., 2013; Tapper et al., 2017). Other acute symptoms consist of sleep disturbance and reduced postural control (Kunker et al., 2020; Worthen-Chaudhari et al., 2017). Children with concussion may also experience emotional challenges such as anxiety and depression (Chrisman et al., 2021; Macartney et al., 2020). Greater severity of acute concussion symptoms presented in emergency departments is associated with prolonged concussion recovery (Grubenhoff et al., 2014). While headaches were the most common acute post-injury symptom in a sample of children 8-15 years old, concerns like irritability, frustration, fatigue and forgetfulness were frequently reported as persistent symptoms (Starkey et al., 2018).

Table 1

Summary of concussion symptoms

Domain	Symptoms

Cognitive	Difficulty concentrating, feeling foggy, impaired memory, impaired executive function, poor attention, slow reaction time
Physical	Headache, nausea, vomiting, balance problems, sensitive to light and noise, fatigue, dizziness, drowsiness, loss of consciousness
Affective	Irritability, emotional, suicidal thoughts, sadness/depression, anxiety
Sleep	Sleeping more, sleeping less, difficulty falling or staying asleep

1.3.2 Persistent Post-Concussion Symptoms

1.3.2.1 Definition. There are several definitions of PPCS where the adult and pediatric population are concerned (Carroll et al., 2014; Marshall et al., 2012). For youth older than 16 years of age, a recent expert consensus-based definition for PPCS (Lagacé-Legendre et al., 2020) included that concussion symptoms cannot be attributed to a pre-existing condition, must have appeared within hours of injury, be present every day for three months after the trauma, and have an impact on at least one domain of an individual's functioning including work, school, or leisure. Specifically, persistent symptoms are indicated if an individual reports struggling with unresolved symptoms that appear within hours after a concussion injury that cannot be better explained by another mental disorder. Also, patients with PPCS have challenges returning to daily activities even if they follow post-injury care and recommendations. Tator et al. (2016) provided a novel and working definition for PPCS based on sample of 221 individuals aged 10 – 72 years old. This involves individuals to have a history of concussion and showcase at least three of the following symptoms for a minimum of one-month duration: fatigue, headache, dizziness, concentration difficulties, irritability, and memory or sleeping problems. Other definitions require the presence of symptoms on the Rivermead Post-Concussion Symptoms

Questionnaire (Lannsjö et al., 2011), or dealing with various cutoffs on the Glasgow Outcome

Scale (Jacobs et al., 2010). Additionally, there is no universal agreement on the time period for

PPCS (Quinn et al., 2018). The *Berlin Expert Consensus* states that PPCS following injury is

defined by a failure of normal clinical recovery with the following timeframes: symptoms

persisting for more than two weeks in adults and more than four weeks in children (McCrory et

al., 2017). However, studies are mixed regarding validity of PPCS duration criteria (Quinn et al.,

2018), demonstrating a range of outcomes from three months (Ponsford et al., 2012) up to one

year (Carroll et al., 2014). Hence, consensus for a precise definition of PPCS following pediatric

concussion is lacking.

  1.3.2.2 Outcomes of PPCS. Persistent post-concussion symptoms can significantly

interfere with the daily activities of youth, like participation in school and sports (McCarty et al.,

2019; Sady et al., 2011), thereby, lowering quality of life in social, academic, and health domains

sectors (Novak et al., 2016). Lack of resolution of concussion symptoms may also have serious

consequences for psychosocial-behavioral development (Daneshvar et al., 2011; Halstead &

Walter, 2010). For example, in a retrospective chart review of patients attending a sports medical

clinic for concussion, Ellis et al. (2015) reported that 11.5% of children and adolescents with

sports-related concussion received a new psychiatric diagnosis. Delayed symptom resolution was

associated with higher scores on anxiety scales compared to children with early symptom

resolution (Grubenhoff et al., 2016). Also, when youth reported more symptoms after

concussion, they were more likely to experience depression during the persistent phase (Stazyk

et al., 2017). A population-based study found adolescents who experience a concussion are at an

increased risk for depressive symptoms, including behaviors of self-injury and suicide attempts

(Yang et al., 2019). Findings of a recent scoping review also show a common trend where high

PPCS scores are associated with mental health symptoms of depression and anxiety (Sheldrake et al., 2022).

   1.3.2.3 Predictors of PPCS. The understanding of the risk factors for experiencing PPCS following pediatric concussion is evolving. Research shows that youth with a pre-existing diagnosis of psychiatric disorders like depression, anxiety, or sleep disorders are at higher risk of experiencing PPCS (Brooks et al., 2019; Gillie et al., 2020; McAllister-Deitrick et al., 2020). Risk for prolonged recovery is also higher in youth who have a family history of mood disorders and other psychiatric illness or migraines (Morgan et al., 2015). There is some evidence to support other pre-existing conditions, such as a history of previous concussions and learning difficulties as contributing factors to the persistence of symptoms (Zemek, et al., 2013). Loss of consciousness post-injury or post-traumatic amnesia can also be associated with PPCS (Ponsford, 2019; McCrea et al., 2013). Moreover, physical symptoms like headache, dizziness, and fatigue that present one to two weeks post injury are associated with prolonged symptoms (Savola et al., 2003; Yang et al., 2009). Vestibular deficits in youth with concussion may also be a marker of extended recovery time (Corwin et al., 2015). In addition, youth who sustain a concussion while playing sport that are not removed quickly from play, or who have delayed attention from health professionals, are more likely to experience PPCS (Morgan et al., 2015). Of note, premature return-to-play of a student-athlete who is still injured from concussion may also result in persistent health challenges (Master et al., 2012).

1.4 Persistent Concussion Symptoms: Impact on Family

The time following a child's TBI is stressful for both the child and family, including concussion injuries (Wade et al., 2006). However, there is limited research on the relationship between concussion injury and family well-being (Ganesalingam et al., 2008). Hence, the research presented in this section relies heavily on the literature describing the experiences and outcomes for caregivers of youth with moderate-to-severe brain injury. It is important to note the bidirectional relationship that exists between parents and children when dealing with health challenges as each side impacts the other (Simons et al., 2019; Taylor et al., 2001). Additionally, brain injury challenges can result in unmet needs related to emotional support, information, and follow-up care that can have an impact on the child, caregiver, and family (Miley et al., 2020).

1.4.1 Mental Health Outcomes

The day-to-day responsibilities of being a caregiver combined with supporting a child with TBI are challenging and can cause distress for caregivers (Kratz et al., 2017). Parents have been shown to experience clinically significant levels of stress after their child's TBI, regardless of TBI severity (mild-to-severe) (Hawley et al., 2003). Following the initial year of pediatric TBI, caregivers report increased burden, worry, and interference with daily routines (Aitken et al., 2009). Parental psychological distress is highly associated with poorer child adjustment (Chow et al., 2016; Palermo et al., 2014). For example, higher levels of caregiver psychological distress are associated with greater externalizing behaviour in adolescent following TBI (Raj et al., 2013), providing further evidence regarding the impact of mental health concerns of parents on the youth behavioral outcomes. Therefore, it is important to consider the psychological needs of parents/caregivers to promote positive health outcomes for youth after brain injury.

1.4.2 Family Functioning

In addition to stress and mental health, brain injury can also influence family functioning and parent-child interactions (Gan & Schuller, 2002). Individuals with ABI and their family members, like mothers and siblings, reported significant distress in family functioning compared to the families who are not dealing with brain injury (Gan et al., 2006). Predictors of positive family functioning after TBI among children include pre-injury family communication, problem solving, role flexibility, and less conflict (J'May et al., 1996). Higher caregiver burden and female gender of the children with brain injury are noted predictors of poorer family system functioning (Gan et al., 2006). Parental stress and family burden post youth TBI may also be alleviated by providing interventions that include improved information and support (Hawley et al., 2003).

1.4.3 Social Support

Caregivers of children experiencing moderate-to-severe TBI report feeling socially isolated following their child's injury (Brown et al., 2013). Research shows that social support is a strong moderator of caregiver distress after youth brain injury, where caregivers' distress increases if they are not provided with adequate social support (Ergh et al., 2002). One study examined the experiences of parents whose children sustained a concussion. Results showed that parents rely on extended family and friends throughout the recovery period and seek social support via social media and the Internet, including watching YouTube videos (Minney et al., 2018).

1.5 The Biopsychosocial Model: Family-directed Approach to Brain Injury

The biopsychosocial model recognizes physiological, psychological, and sociological factors as they dynamically interact to influence recovery following an injury (Gatchel et al.,

2014). It offers a perspective that helps conceptualize the complex pre- and post-injury factors that contribute to PPCS. There are multiple biopsychosocial factors related to PPCS (Wäljas et al., 2015). In particular, family members play an important role in concussion recovery helping their children with rehabilitation and recovery (Taylor et al., 1995). Hence, it is important to increase family competence when implementing support practices.

The biopsychosocial model has led to theoretical frameworks that emphasize family collaboration and caregiver mental health. For instance, the family-directed approach to brain injury (FAB model) consists of four parts: hope, family expertise, education/skill-building, and family-directed interventions (Fisher et al., 2019). First, hope is an important part of healthy coping and adjustment for families after a brain injury. Hope can be promoted by presenting realistic information and education regarding injury as well as fostering an optimistic outlook on injury and recovery. Second, family members are viewed as an integral part of the decision making process in terms of treatment planning and intervention design. Hence, it is important to utilize family experience and understanding for a successful family-centered rehabilitation plan. Third, education and skill-building tools support families to help their children recover. It is important for families to be provided with knowledge to build their own 'tool box' of management strategies, practical skills, and necessary information to facilitate positive rehabilitation outcomes throughout their child recovery. Fourth, family-directed intervention involves clinicians supporting family members to be facilitators of change by providing them with tools to monitor the progress of their youth's injury, and intervene when necessary. This also increases the sense of confidence and mastery among family members. The FAB model approach to brain injury is used to guide the increased involvement of family as active members

in the rehabilitation and recovery process. It also addresses families' support needs and promotes positive health outcomes for individuals with brain injury.

1.6 Interventions for Caregivers

This section describes interventions for parents of children with brain injury. There is limited research on parent interventions for youth with PPCS. Therefore, this section relies on studies with caregivers of youth with moderate-to-severe brain injuries.

1.6.1 Psychoeducation

Psychoeducation groups are helpful as they address caregivers' educational gaps and psychological concerns by equipping families with necessary information to support recovery (Jurek, 2016). Research shows that parents seek information related to prevention of injuries, access to care, and the child's academic achievement (Miley et al., 2020). Providing support and education to help caregivers understand the neuropsychological impact of brain injury has been shown to promote parental wellbeing (i.e., parents reported feeling less stressed) and preparedness to appropriately support their child with brain injury in daily life (Walker et al., 2021). Psychoeducational programs focused on education and skill-building have also been shown to benefit caregivers for up to three months after the child's injury (Bushnik et al., 2015). In addition to providing standardized education, individualized information, and personal advice about brain injury, there is a need to support caregivers in recognizing the relevant symptoms at an earlier stage to minimize future health risks (Renaud et al., 2018).

1.6.2 Problem-Solving

A problem-solving framework has been shown to be useful for identifying challenges, learning new skills, and implementing effective and new strategies in response to injury-related

stressors (Wade et al., 2006). Following a youth TBI, caregivers are faced with many stressors like changes in the child's behavior and identity. Hence, a problem-solving intervention has been shown to be useful to ameliorate these difficulties by equipping caregivers with new ways to approach difficult situations. For instance, a family problem-solving and skill-building intervention has been shown to reduce parental psychological distress, depression, and anxiety in parents of youth with TBI (Wade et al., 2006). Also, a web-based treatment program designed to enhance problem solving and social adjustment demonstrated a significant improvement in parental depression and parent-adolescent conflict (Wade et al., 2008). Additionally, an online problem-solving therapy intervention increased problem-solving skills and decreased depressive symptoms and distress for caregivers of adolescents with TBI (Wade et al., 2012). Hence, implementing a skill-building approach to interventions can be effective to support parents of youth with brain injury.

1.6.3 Stress Management

Stress management interventions typically include techniques and psychotherapy aimed to control and cope with one's level of stress. For example, a stress management randomized control trial has been shown to reduce parental anxiety and depression for parents of youth with TBI (Singer et al., 1994). Interestingly, the results demonstrated that the stress management group reported greater reductions in mental health outcomes than those who attended an informational group. This suggests that education alone may not be sufficient to reduce parental stress symptoms. Also, providing the right type of knowledge and services are vital for families to adjust well to the child's TBI because caregivers of youth with TBI note unmet concerns related to education on stress and coping strategies (Miley et al., 2020). To add, a randomized-controlled trial study evaluating a stress-management intervention for parents of youth with

acquired brain injury was found to improve parental outcomes such as family adjustment and psychological distress (Brown et al., 2015).

1.6.4 Group-based Interventions

Group interventions have been shown to decrease feelings of isolation (Brown et al., 2013; Camden et al., 2012; Plante et al., 2001). For example, group interventions enable participants to connect and learn from each another, thus, creating a social atmosphere of shared experiences. Families of children with brain injuries tend to look for assistance from other families who share similar experiences (Acorn, 1993; Davis et al., 2009). Hence, it is beneficial for parents to interact with other families and form a community as they can exchange unique forms of guidance to address burden and stress associated with their child injury (Davis et al., 2009; Roscigno & Swanson, 2011). Further, participation in group-based programs can help caregivers feel socially supported.

1.6.5 Online-based Interventions

Families of children with TBI may benefit from interventions delivered online for several reasons. First, online interventions eliminate barriers such as travel time and distance which enhance accessibility to families (Narad et al., 2016; Wade et al., 2006; Wade et al., 2020). For example, caregivers reported many reasons for lack of program attendance including distance from the intervention, transportation issues, and fear of leaving youth unattended (Damianakis et al., 2016; Knight et al., 1998; Ponsford & Schonberger, 2010). It is important to note that research shows online treatment is at least as effective as conventional face-to-face approaches (Griest, 1998; Marks et al., 1998; Sturges, 1998). Also, Wade et al. (2004) found that parents of children with TBI may prefer online therapy to face-to-face. Another study conducted by Damianakis et al. (2016) utilized a web-based video support group for caregivers of youth with

TBI. In this program, caregivers reported ease of access to the support group, and improved

outcomes in stress and coping capacity. Also, a web-based parenting program was shown to be

effective in reducing psychological distress among lower-income parents (Caplan et al., 2015).

This finding is important since lower-income parents are vulnerable to both environmental and

injury-related stresses. Hence, conducting online-based programs may benefit families who

otherwise lack the resources to attend face-to-face programs. Also, it is important to note that

virtual interventions are vital to enhance accessibility, convenience, and social support among

caregivers, especially in the current circumstances of multiple COVID-19 waves (Strudwick et

al., 2021).

CHAPTER 2

THE DEVELOPMENT OF *Move&Connect-Caregivers*

2.1 Theory of Intervention Mapping

Intervention Mapping (IM) is a planning framework that provides a detailed protocol for

intervention development and evaluation (Bartholomew et al., 1998). IM incorporates theoretical

and empirical evidence, and engages key stakeholders to promote a multi-step intervention that is

effective, relevant, and meaningful to the target audience. It encourages researchers to reflect on

the complexity of the decision-making process when developing interventions, where decisions

need to be made in an iterative and collaborative manner (Schaalma & Kok, 2009). IM provides

guidance and documentation of decisions at each development step, charting its path from

problem recognition to solution identification and build (Bartholomew et al., 2001). IM has been

previously used to develop an art-based therapy intervention (Haeyen & Heijman, 2018), parent

education program (Rodriguez et al., 2018), mental health psychoeducation (Wheeler et al.,

2013), and stress management program (Kraag et al., 2012).

The IM approach was utilized to guide the development of the intervention,

Move&Connect-Caregivers. Briefly, IM involves a six-step planning process, which includes the

following: (1) needs assessment; (2) objective identification; (3) selection of theory and program

design; (4) program production; (5) creation of an implementation plan; and, (6) development of

an evaluation plan. In addition, it is important to note that IM is an iterative process where the

steps are not necessarily performed in a linear order; they can be re-visited and refined as

appropriate (Bartholomew et al., 2011).

Research shows that a lack of systematic development can lead to ineffective or less useful interventions that lower the likelihood of future adaptation or implementation (Craig et al., 2008). IM was selected because it offered a framework and detailed steps that considers both theoretical and logistical aspects of intervention processes, as well as allowing for the team to iterate intervention design based on the feedback of target audience and stakeholders (Bartholomew et al., 2011). The *Move&Connect-Caregiver* intervention development team is interdisciplinary in nature, and includes a neuropsychologist, a social worker, occupational therapist, knowledge translation expert, and family leaders. Hence, the purposes of this chapter is to illustrate the application of the IM approach in the development of a novel, virtual-based, peer-support program, *Move&Connect-Caregivers*, aimed at increasing caregivers knowledge, social support, and mental health after their youth concussion injury.

2.2 Application of Intervention Mapping

The six steps of IM and its application to *Move&Connect-Caregivers* are described in this section. IM steps one to three have been fully completed and are briefly summarized below; the purpose of this thesis focuses on step four; steps five and six are planned as future study phases. See Figure 1 for intervention development timeline.

Figure 1

IM Steps & Timeline
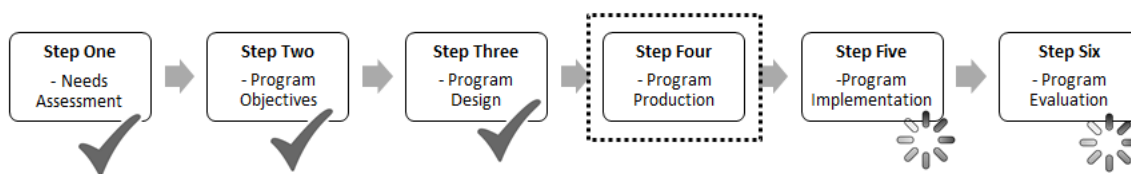
IM Step One: Needs Assessment. The first step of the intervention mapping protocol includes conducting a needs assessment, which involved a literature review (Chapter One) and consultation with key stakeholders through a focus group. This group was formed based on a research study involving youth with PPCS and their caregivers conducted by the NOvEL (Neurorehab Outcomes via Education and Learning) lab at Holland Bloorview Kids Rehabilitation Hospital (HBKRH) led by Dr. Shannon Scratch. Earlier, the research team at HBKRH developed a program called *Move&Connect* for youth with PPCS. In this study, youth participated in a group education and low-intensity exercise program. I conducted exit interviews with youth and parent participants and program feedback was obtained to examine intervention tolerability. The results for *Move&Connect-Youth* were promising and parents appreciated the social elements of their child connecting with peers of similar experiences. Thereafter, a focus group was held with parents (n=5) to understand their needs and challenges. These need for concussion education and peer-support (described below) formed an impetus to develop a complementary program to support caregivers, *Move&Connect-Caregivers*.

(1) Education: Persistent Concussion Symptoms

Parents identified the need to learn more about persistent concussion symptoms and recovery as it impacts youth well-being. This was demonstrated by the following feedback from parents of youth participating in the *Move&Connect-Youth* study:

'I don't want the same general concussion education that is basic – more on the persistent side of things'

'I didn't know until this that concussion could even get like this [severe]'

'It's important for parents to better understand how to support their kids'

'Me and the other parents were able to sort of problem solve and talk about many

different things, so it is important to have an education piece for us as parents as well'

Hence, there is a clear need to address educational gaps in terms of problem-solving skills and

concussion knowledge among caregivers. Further, another issue that was identified during

interviews relates to the importance of connecting with other caregiver for peer support.

(2) Peer Support

Parents also identified the need to be able to connect with other parents who are going

through similar experiences. This is evident by the following quotes:

'I think just the understanding that I'm not the only parent going through this…. I'm not

that bad off; I'm going to be okay. I almost wish that we had been able to connect sooner'

'It was a huge advantage for me, a huge benefit for me to be able to meet and speak to

other parents'

'It would be great if it was socialize but with a learning aspect too for people for just

don't know, because it [concussion] changes everything, you know'

'I found it really beneficial to chat with some other moms who had gone through the

same thing and talk about different ideas and it was interesting cause one of them was a

nurse, one of them was a teacher, um, and um all of us came from different perspectives'

Therefore, results of this step suggest a clear clinical research gap indicating the need for an

intervention for caregivers of youth with PPCS.

IM Step Two: Program Objectives and Outcomes. The objectives were defined by the

results of step one. The collected data from the focus groups, as well as clinicians' expertise,

guided the development of the intervention objectives, which were to: 1) use psychoeducation,

advocacy, and tools to promote positive family and health outcomes, and 2) provide a safe space

for caregivers to share lived experience and strategies with each other. The anticipated outcomes

of *Move&Connect-Caregivers* are increased caregiver social support, PPCS knowledge, and

confidence to support their youth following injury.

IM Step Three: Program Design. In step three, a relevant theoretical method

underpinning intervention objectives was identified. The program design was guided by the FAB

model and its four components of hope, family expertise, education and skill building, and

family-direction intervention (Fisher et al., 2019). For example, education and skill-building are

integral components of the intervention and are integrated in the program's stated objectives. See

Table 2 for application of FAB model components to the development of *Move&Connect-*

Caregivers.

Table 2

FAB Model Components and its application to Move&Connect-Caregivers

FAB Component	Application to *Move&Connect-Caregivers*
Promoting Hope	• Inform caregivers on the acute and prolonged phase of recovery by presenting realistic information • Highlight child's strength and their well-being • Provide caregivers the opportunity to share experiences and learning's among one another • Acknowledge and validate caregivers' efforts in supporting their children • Ease caregivers' feelings of hopelessness regarding their child's abilities
Acknowledging Family Expertise	• Engage family leaders in intervention curriculum design • Incorporate feedback from participants to enhance intervention design • Emphasize caregivers' efforts in supporting their child, and remind them of their expertise and knowledge
Providing Education and Skill-Building	• Provide evidence-based education and strategies • Present information in lay language

- Facilitators sharing their own practical experience when appropriate during sessions
- Provide opportunities to caregivers to share education and strategies among one another
- Provide caregivers with information to develop their toolbox of knowledge and build their practical skills

The educational topics incorporated suggestions provided by the caregivers' participants during the focus group; their feedback include deeper understanding of persistent concussion and recovery process, school advocacy, and elements of social support. It is also important to acknowledge the expertise of the interdisciplinary team (i.e., clinical neuropsychologist, social worker, physical therapist and occupational therapist) who were involved in program design, as their clinical experience working with children with PPCS and their families provided invaluable insight when designing the intervention's curriculum. The result of this step also included building the curriculum of *Move&Connect-Caregivers*. The six-week intervention involves six sessions that are 60 minutes in length. Each session consists of a theoretically-based psychoeducation topic, and a group activity followed by discussion and reflections (See Appendix A for sample session outline). The mode of intervention delivery is virtual using the *Zoom HealthCare* platform. The general topics for *Move&Connect- Caregivers* are outlined in Table 3.

Table 3

Move&Connect-Caregiver Outline

Session	Title	Learning Objectives	Psychoeducation	Activity	Take-Home Reflections
1	The Ripple Effect	1.To learn about persistent post-concussion symptoms and its health outcomes among youth 2.To understand the relationship between youth recovery and caregiver well-being	Persistent Concussion Education	Introductions & Goal-setting	Think about your 'Ripple Diagram' and send it to program assistant
2	School Advocacy	1. To explore the individual school experiences of your children and discuss tips for school advocacy. 2. To identify helpful strategies for advocating youth needs in school settings.	Parent role in school advocacy	Co-create handout on success and challenges with school advocacy	Think about and observe your youth peer relationship or with siblings
3	Consider Your Child's Well-being	1. To understand the role of social support on youth recovery. 2. To explore the mental health and emotional changes in youth with prolonged recovery post-concussion.	Children's peer or siblings relationships Mental health symptoms and concussion	Discussion on youth mental health, sharing of tips and strategies	Think about your own time and your child's time, where can you implement discussions on mental health?
4	Family and You	1. To discuss a framework for how to consider your child's behaviour and emotions 2. To focus on the family ripple after injury	Family Dynamic & Well-being ABC Model	Wheel Wellness	Reflection: how does your wheel play out in your day-to-day?

5	Stress & Daily Challenges	1. To understand the research on stress after concussion, signs of stress, and symptoms of stress. 2. To identify helpful coping strategies that can be utilized in stressful and difficult situations.	Diathesis Stress Model - Yerkes-Dodson Law - Dove-Hawk Model of Prolonged Symptoms Post-concussion	Wheel wellness & discussions on feelings of stress in terms of frequency and intensity, types of stressors	Observe your feelings when stressed and how you handle your stressors
6	Parenting is Hard	1. To discuss parent-youth communication styles and strategies towards positive parenting. 2. To review the key messages and skills learned through the program.	Communication and development, positive parenting Communication style and conflicts - Summary of key lessons learnt	Discussion on communication styles with youth	Review Handouts

IM Step Four: Program Production. Based on the first three steps of IM, intervention materials and products were selected and developed. Numerous iterative meetings were held with the interdisciplinary team to develop intervention components and reference material. A family leader was also integrated into the production process by attending a two-hour design meeting with the team, where the family leader gave input on the curriculum and informed further design iterations. Consultations with a graphic designer expert were also conducted to produce the visual content and presentation slides. Further, I attended all program design and production meetings for observation, learning, and note-writing purposes. See Appendix B &C for slides and handout sample. A final key component of step four includes testing and refining related content and structure of *Move&Connect-Caregivers*. This was established through my Master's thesis in which a feasibility study was conducted, consistent with intervention development methodology (Orsmond & Cohon, 2015). The Methods and Results of feasibility testing are described in Chapter Four and Five of this thesis. Feasibility evaluation of programs provides further information that can be fed back into earlier steps of the IM process, allowing for refinement and enhancement of the intervention. For example, program materials, like handouts and slides, have been updated based on participants' feedback and suggestions for improvement.

IM Step Five: Program Implementation. Key considerations at this step include identifying intervention facilitators, participant recruitment, and resources required for implementation (e.g., time, delivery method). The intervention co-facilitators are a clinical neuropsychologist and a social worker due to their clinical expertise and professional background. Communication with staff of the Persistent Concussion Clinic was also identified as one of the key recruitment strategies to enroll target population. Strategies to maximize

caregivers' participation include offering evening program timings and offering flexibility with data collection. The feasibility study (Step Four) provided larger-scale implementation ideas where recruitment strategies can be broadened to include partnered community medical clinics and organizations.

IM Step Six: Program Evaluation. A formal evaluation plan assessing the effectiveness of *Move&Connect-Caregivers* and its impact on caregivers' well-being is undergoing development as the next study phase. This will be carried through a pilot-controlled trial using mixed methods of quantitative and qualitative measures. Evaluation outcomes will involve the following: social support, mental health, family functioning, parenting competency, and stress levels. Semi-structured interviews will also be conducted to understand the impact of *Move&Connect-Caregivers* on participants.

To summarize, the IM framework promotes a systematic development of the *Move&Connect-Caregivers* processes. A summary of IM steps and related applications to intervention development is provided in Table 4. Further, IM offers a comprehensive framework that clearly documents the process of intervention development, allowing for greater confidence and transparency when exploring the program's efficacy. This process can allow for iterative improvements to the intervention over time, and facilitates smooth translation of intervention implementation to other settings.

Table 4

Application of IM steps to Move&Connect-Caregivers

IM Steps	Description	Outcome
1. Needs Assessment	• Understand the problem and the factors that influence the problem • Consult and work with stakeholders to identify clinical gap	• Through a focus group and literature review, parent need support following their child's PPCS with education and social support
2. Program Objectives & Outcomes	• Identify program objectives • State expected program outcomes	• Obj 1: Utilizing psychoeducation, advocacy, and tools to promote positive family and health outcomes. • Obj 2: Providing safe space for caregivers to share lived experience and strategies among each other.
3. Program Design	• Selection of theory-based methods that informs intervention design • Design program curriculum	• Theory: FAB model and biopsychosocial model • Structure: 6-weeks, 1 hour weekly session • *Move&Connect-Caregiver* Curriculum
4. Program Production	• Prepare plans for program materials and select protocols • Test and refine materials	• Preparation of session slides • Handout design • Facilitator manual: instructional guide to *Move&Connect-Caregivers* delivery • Initial testing phase: feasibility of intervention
5. Program Implementation	• Identify potential users of the program • Develop implementation plan, including steps need to be undertaken by individuals to implement program	• Facilitators: clinical neuropsychologist and social worker • Staff: clinic coordinator, technical support, research coordinators • Recruitment strategies (hospital and community)
6. Program Evaluation	• Specify evaluation plan • Select outcome indicators and measures	• Evaluation plan: pilot-controlled study • Selection of measures and outcomes for evaluation

CHAPTER 3

OBJECTIVES

The objective of this thesis is in line with IM Step 4, which is to explore the feasibility of a

virtual group-based intervention for caregivers of youth with PPCS, *Move&Connect-Caregivers*.

There were two thesis aims: (1) to assess the metrics related to study procedure and intervention

participation to inform feasibility of *Move&Connect-Caregivers*; and (2) to explore participants'

experiences and feedback with *Move&Connect-Caregivers*, and to incorporate their suggestions

for intervention improvement.

3.1 Feasibility Definition and Indicators

Feasibility studies are defined as preliminary research that focuses on the process of

developing and implementing an intervention, and incorporates examination of participants'

feedback to the intervention (Dobkin, 2009). Feasibility studies focus on the intervention process

and answers the question of whether an intervention can work and show promise (Orsmond &

Cohn, 2015). It also sheds light on the implementation of study procedures and informs future

adaptations to enhance participant outcomes (Tickle-Degnen, 2013). Orsmond and Cohn (2015)

also differentiate feasibility studies from pilot studies, where the latter involves testing small-

scale versions of the main trial and includes a heavy focus on outcome evaluation. This is

consistent with other research that states the aim of feasibility studies revolve around initial

testing of an intervention prior to implementation of a large-scale trial (Craig et al., 2008; Kho &

Thabane, 2020).

The design of the current feasibility study was guided by the recommendations provided by

Orsmond and Cohn (2015) where they described five key feasibility domains. First, it is

important to assess *recruitment capability* to identify recruitment rates, potential obstacles to

recruitment, or reasons for study refusal. Second, evaluation and refinement of *data collection procedures and outcomes* shed light on the appropriateness of study methods for the intended population. This involves examining participants' capacity to complete the data collection procedures, any barriers to study completion (e.g., high burden or time commitment), and suitability of study methods. Third, assessing for *acceptability* of the intervention and procedures can be done by exploring retention and follow-up rates as participants move through the intervention, engagement and intervention attendance, and level of safety of study procedures. The fourth domain involves *evaluation of resources* and abilities to implement the intervention and its associated study procedures. This includes protocol compliance, administrative capacity, and logistics to conduct the intervention. The final domain is related to the *evaluation of participants' responses towards the intervention*, which can be achieved through quantitative surveys and/or qualitative feedback (Orsmond & Cohn, 2015). This thesis considered the five key domains to evaluate the feasibility of *Move&Connect-Caregivers*. The first thesis objective covers the first four areas of feasibility domains (recruitment capability, evaluation of data collection procedures, acceptability & evaluation of resources), while the second objective focuses on exploring participants' experiences with the intervention through semi-structured interviews.

CHAPTER 4

METHODS

4.1 Design

A single-arm intervention study was conducted by exploring feasibility metrics and conducting semi-structured interviews to evaluate the feasibility of *Move&Connect-Caregivers*. Because this study aims to explore feasibility issues and suggest program improvements, it is acceptable that a control group is not utilized (In, 2017). The study was approved by Research Ethics Board at HBKRH (#0391), and received administrative clearance from the Office of Research Ethics at the University of Windsor (REB# 21-208).

4.2 Participants

Study enrollment included nine participants across two intervention groups (Group 1: n=4; Group 2: n=5). The participants were recruited from the Persistent Concussion Clinic (PCC) at HBKRH where their children were outpatients. As this is a feasibility study to evaluate a newly developed intervention, the sample size is adequate to achieve study aims (Hertzog, 2008). Inclusion criteria were: caregivers whose children (age 8-18 years) were experiencing PPCS for more than four weeks, fluent in English with access to reliable Internet connection, and ability to provide informed consent.

4.3 Recruitment

The clinicians and intake coordinator briefly introduced the study to eligible caregivers of youth clients of the PPC at HBKRH. If caregivers were interested in learning more about the group intervention, a research team member or the study author – who is not a part of the clinical team to reduce any undue influence – further explained the study procedure. This meeting was

done over the phone, or through email. Participants were assured that their child's clinical care would not be impacted by their decision to participate or not participate in the study.

4.4 Consent

At the first data collection and after eligibility screening, the participant consent form was reviewed by the study author via *Zoom*. Participants were given time to ask questions or raise any concerns about the study. Consent was gathered electronically through the website *REDCap* (Research Electronic Data Capture) prior to study participation. *REDCap* is a secure, web-based platform designed to support data capture for research studies (Harris et al., 2009).

4.5 Procedure

If participants demonstrated an interest in the study and fit the inclusion criteria, they were invited to participate in the first data collection session that included reviewing and obtaining consent forms, collecting demographic information, and administering the pre-intervention questionnaires. The study author met with participants individually via *Zoom* to complete the measures where a *REDCap* link was provided during the session, and the author remained on-call to answer any questions the participant may have. Caregivers were also provided the option to complete the questionnaires at their convenience. In this case, a *REDCap* link was sent to their email address with instructions related to measure completion. The first data collection session lasted approximately 60 minutes. Next, participants joined the *Move&Connect-Caregiver* intervention once a week, for six weeks. Each session also lasted around 60 minutes. In week Eight (post-intervention), participants were invited to fill out the post-intervention measures, which involved similar procedure to first data collection session, as well as participated in the semi-structured interview to give their feedback on the intervention.

4.6 Intervention

Move&Connect-Caregivers is a six-week intervention that involved weekly one-hour sessions. The intervention was run twice during the months of November 2021 to April 2022. The intervention ran virtually using *Zoom HealthCare*, and in the evening hours (6 pm – 7 pm on a week day). See Figure 2 for study procedure and timeline. The study author was present in all sessions for *Zoom* support, observation, and field notes write-up. The intervention details, design, and curriculum are described in Chapter Two.

Figure 2

Study Procedure
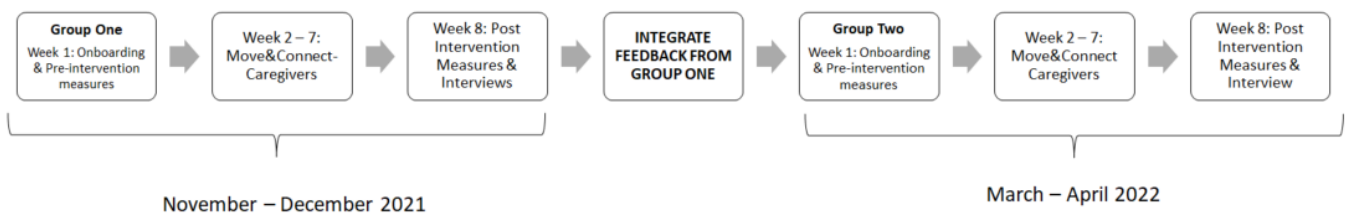
4.7 Data Measures

4.7.1 Demographic Form

The Demographics Form (Appendix D) was developed with the purpose of understanding the general characteristics of study participants and included gender, educational background, and household income. The forms were completed electronically through *REDCap*. Demographic information were downloaded and stored in a password protected Excel file on the secure HBKRH Network.

4.7.2 Feasibility Metrics

Feasibility metrics are based on Orsmond and Cohn (2015) key domain areas, including recruitment, acceptability, refinement of data collection measures, and resources for intervention implementation. *Recruitment rate* was defined as 'number of participants who enrolled in the study' divided by 'number of participants approached.' *Acceptability* involves both retention and adherence rates. *Retention rate* described the proportion of enrolled participants who completed the entire study, including pre- and post-data collection appointments; and, *adherence* was defined as attendance and engagement with the *Move&Connect-Caregivers* sessions. Examination of questionnaire procedures covered duration of data collection sessions and missing questionnaire answers. Although not formally measured, resources utilized to implement the intervention were tracked through field notes, including budget monitoring, and recording of technological issues and adverse study events. See Table 5 for feasibility domain and corresponding information source and measurement. Note: *a priori* success criteria for these metrics are defined in section 4.8.1.

Table 5

Feasibility Metrics

Orsmond and Cohn Domains (2015)	Term	Definition	Information Source	Measurement
Recruitment capability	Recruitment Rate	Number of participants who enrolled in the study' divided by 'number of participants approached'	Excel Recruitment Tracking	• Families invited to participate after screening are successfully enrolled in study

Acceptability	Retention Rate	Number of enrolled participants who complete the entire study, including pre and post data collection appointments.	Excel Data Collection Tracking	• Participants successfully complete the study, including outcome measures
	Adherence Rate	Attendance and engagement with the *Move&Connect-Caregivers* sessions	Excel Attendance List Field Notes	• Participants attend all 6 intervention sessions. • Participants completed the take-home activities. • Participants keep their cameras on for majority of the session duration
Refinement of data collection procedures	Examination of Questionnaires	Duration of data collection appointments and rate of questionnaire completion	REDCap Field Notes	• Duration of both data questionnaire sessions • Response rate of questionnaires/surveys
Evaluation of Resources to Implement the Study	Study Management	Documentation of technological concerns during sessions, protocol deviation, adverse events	Field Notes Study Team Records	• Technology issues • Record of adverse events • Budget monitoring

4.7.3 Semi-structured interviews

As per the fifth key feasibility domain (Orsmond & Cohn, 2015), participants were invited to give their feedback on the intervention through a semi-structured interview. The interviews lasted for approximately 30-55 minutes and were conducted post-intervention through *Zoom*. The questions were open-ended and allowed participants to raise points they felt were important. The interviews were audio recorded using the *Zoom* recording feature and transcribed verbatim by the study author. Interview booking, as per the study protocol, occurred within one week from *Move&Connect-Caregivers* participation.

4.7.3.1 Interview Guide. The interview guide (Appendix E) revolved around several concepts such as group support, session structure, and satisfaction with the program. The questions were designed to explore such concepts through a series of steps that invite comments and feedback from participants in an open-ended manner. The questions in the guide addressed the following topics:

- General *Move&Connect-Caregivers* feedback: satisfaction with sessions, and gathering suggestions to improve session components

- Intervention psychoeducation: questions related to relevance and applicability of topics, take-home activities, and feedback on handouts

- Group-based experience: likes and dislikes of group format, comfort sharing in a group format, experience meeting other caregivers

- Online Platform: experience completing the program via *Zoom HealthCare*, and barriers and facilitators to intervention access

4.8 Data Analysis

4.8.1 Demographic Information & Feasibility Metrics

Descriptive analysis was used to summarize the demographic information. Feasibility metrics were summarized using frequencies and ratios. As part of best practice when evaluating feasibility interventions (Thabane et al., 2010), specific criteria for defining feasibility success have been selected based on literature guidelines or similar study designs. First, in terms of recruitment capability, a minimum 10% response rate has been deemed the minimum feasible response rate for a randomized control trial (Rothwell, 2006). Second, a 90% retention rate was chosen to indicate feasibility based on the rate of a previous study with similar methods (Sandgren et al., 2022). Adherence information chosen to indicate feasibility includes attending

intervention sessions (80% attendance rate), completing take home activities (80% completion rate), and keeping their video cameras on for majority of session duration (>45 minutes). Third, with regards to examination of data collection procedures, measures were deemed to be acceptable if there was greater than 80% completion rates and if any missing data occurring at random order was less than 10% (Bennet, 2001). The duration of the questionnaire sessions were also captured by REDCap, and were compared to the scheduled appointment duration (45 minutes) to check whether it exceeded allocated time. Research procedures were acceptable if there were no significant burdens, time delays, or issues raised by participants (Palmcrantz et al., 2015).

       4.8.1.1 Note on Measures. The current study does not involve evaluation and analysis of the questionnaire outcome measures due to the small sample size. Rather, the focus was on examining the study protocol in terms of data collection procedures, including missing data and session duration, to inform a future trial. However, description of the measures is important to note as conducting feasibility studies often involve examining the suitability of data collection processes to guide researchers in larger-scale study design (Orsmond & Cohn, 2015; Tickle-Degnen, 2013). See Appendix F for questionnaires descriptions.

4.8.2 Qualitative Analysis: Semi-Structured Interviews

       Conventional content analysis (Hsieh & Shannon, 2005) was utilized to examine the interview data. This includes coding and categorizing (Coffey & Atkinson, 1996) as well as model building when appropriate (Saldana, 2016). The analytic strategy of coding involved the following: (1) identifying a topic or a pattern, (2) collecting examples of the topic from interview transcripts, and (3) analyzing the text by looking at connections and links between the topic codes (Coffey & Atkinson, 1996; Saldana, 2016). Codes were then sorted into categories based

on how the codes are related and linked (Hsieh & Shannon, 2005). Data context was enriched by any additional notes taken during the interview session (Kvale, 1996; Morrow, 2005). Additionally, field notes were collected during the intervention sessions to aid in the process of reflection (Morrow, 2005), and, a journal was kept during the interview process recording any notes and reactions to aid in the process of reflection (Morrow, 2005).

4.8.2.1 Preparing the Data. The initial process of data analysis involved understanding of the transcripts which was achieved by multiple readings of the data (Kvale, 1994) to allow for a deeper understanding of interview transcripts. The study author transcribed the audio recorded semi-structured interviews, and listened again to the recordings to check for accuracy. The transcripts were also double-checked by the second research team member, who was not a part of session facilitation or observation.

4.8.2.2 Coding. The first step of the analysis included the creation of a preliminary code list. A code is a word used to capture the essence of a sentence, paragraph or idea from the interview data. This code list can come from different sources including the study research question, interview data, or the literature (Saldana, 2016). The interviews were inductively coded independently by two research team members. The process involved coding each transcript independently, then meeting to review the transcript and checking for agreement related to the assigned codes to create a relevant codebook. The initial list of codes was iterative and flexible as it changed during the transcript coding process. An explanation of each code was provided to ensure consistency. Also, each code was linked to the research objectives to ensure the study focus remained central (Elo & Kyngäs, 2008).

4.8.2.3 Categories and Conceptualization. The next step in qualitative content analysis included organizing codes into categories. After coding, interview transcripts were physically cut out and re-arranged into columns under the code categories (See Appendix G for data display). This presentation method helped to provide different perspectives and elements of data displays during analysis. The process ensured all data elements related to a code were physically located in the same place, so they were accessible for reading and exploring (Coffey & Atkinson, 1996). The visual chart (Appendix G) demonstrated how the coding process was used to organize and collect data under a certain category. Once the data display was organized, the data could be explored to generate meaning and identify links with other codes to find conceptual coherence within the data. Patterns, connections, contrasts, and irregularities within the coded data were explored (Coffey & Atkinson, 1996). A color scheme was used to indicate relations between the codes, and a diagram was built that aimed to capture the essence of the study research question. This analytical process brought fragments of interview transcripts together, and helped promote the creation a comprehensive list of categories used to build a conceptualized model. The process was also repeated electronically using Microsoft Word. The categories and conceptual model are explained in Chapter Five.

4.8.2.4 Rigor and Trustworthiness. Several measures to enhance rigor and trustworthiness were applied. For example, two individuals coded all interview transcripts independently. The second research team member was not involved in the *Move&Connect-Caregivers* sessions and had no interaction with participants, hence, minimizing potential bias during the data analysis process. Checking of results and concept mapping was also conducted with members of the research team which further enhanced credibility of the findings. Peer debriefing (Hseih & Shannon, 2015) also occurred in each analysis stage (e.g., codebook

creation, model building). To promote dependability of the findings, an audit trail in the form of a journal was utilized. The journal described definitions of the codes, interview observations, and the accounts of decisions made throughout the analytical process (Merriam & Tisdell, 2016).

4.8.2.5 Positionality. Positionality is a term that refers to the views, background, and position of the researcher in relation to the social context of the research (Holmes et al., 2020). Although not a requirement in the case of qualitative content analysis and more commonly used in thematic analysis (Braun & Clarke, 2006), I will offer a disclosure of my positionality because it is important for the reader to consider as the researcher's background may have an influence on the way the qualitative research is conducted or interpreted.

I am a graduate student in Clinical Neuropsychology with research experience focused on supporting the well-being of youth with PPCS and their families through intervention evaluation. Previously, I have been trained on qualitative analysis (content analysis) by an expert in this field (Dr. Katie Mah) and applied my qualitative knowledge to other studies in the NOvEL lab. As a research assistant with the NOvEL Lab, I learned the value of client-centered and family-centered care where families are the experts of their own experiences with concussion, and their inputs and contributions are necessary to develop relevant and meaningful interventions. I was involved in all *Move&Connect-Caregiver* sessions as an observer and conducted the data collection sessions, including the interviews. Also, I was the primary coder and conducted content analysis of the interview data. A research assistant from the NOvEL lab, Andrew Lovell, was involved as a secondary coder. He has an educational background in Human Health and Nutritional Sciences, and was not involved in the intervention or data collection sessions. Further, the input and guidance of my research advisors supported the *Move&Connect-Caregivers* content analysis. Please see Appendix H for thesis-related activities.

<div align="center">CHAPTER 5</div>

<div align="center">**RESULTS**</div>

5.1 Descriptive Data

A total of 9 mothers participated in *Move&Connect- Caregivers*: 4 mothers in the first feasibility round of the program (November – December 2021) and 5 mothers in the second feasibility round of the program (March – April 2022). All participants were mothers of youth between the ages of 13 – 18 years (M=15.33, SD= 1.58). The average number of concussions sustained by these youth is 2.11, with time since most recent injury ranging between 5 to 48 months (M= 25.8, SD=16.31). See Table 6 for demographic information.

Table 6

Demographics Information

Parent Participant Demographics						Their Child's Demographics & Injury Information			
#	Pseudonym	Gender	Ethnicity	Household Income	Educational Background	Prior Support Group	Youth (Gender, Age (yrs))	# of concussion injuries	Time since last Injury (months)	Recent Injury Mechanism
Group 1 (November – December 2021)										
1	Ashley	F	Caucasian	91,000-100,000	College	N	F,15	3	24	Sports (Volleyball)
2	Julie	F	Caucasian	>100,000	University	N	F,13	1	12	Head strike
3	Hannah	F	Caucasian	<30,000	College	Y	F,17	1	30	Head strike (Self-defense class)
4	Sarah	F	Caucasian	>100,000	University	N	F,14	1	48	Sports (Swimming)
Group 2 (March – April 2022)										
5	Anna	F	Caucasian	>100,000	University	N	F,15	2	36	Sports (Basketball)
6	Vickie	F	Caucasian	91,000-100,000	University	N	F,14	5	5	Fall
7	Lucy	F	Chinese	-	Masters	N	F, 16	1	6	Sports (Hockey)
8	Emily	F	Black	>100,000	Masters	N	M,18	2	48	Sports (Hockey)
9	Rachel	F	Caucasian	>100,000	University	N	F, 16	3	24	Sports (Hockey)

5.2 Feasibility Metrics

5.2.1 Recruitment Capability

Twelve caregivers expressed interest in learning about the study. All participants met eligibility criteria and were invited to enroll. Nine out of twelve caregivers joined the study, which represents a 75% recruitment rate.

5.2.2 Acceptability: Retention Rate

All participants (100%) completed the entire study procedure, including the pre-and post-questionnaire and interview sessions.

5.2.3 Acceptability: Adherence Rate

For the first group cohort, there was 100% attendance rate from all four mothers, except for the sixth session where one mother connected with the team in advance to say that she was unable to attend the session due to a work conflict. For the second group, there was a 100% attendance rate from all five participants across all sessions.

During the week 1 session (for both groups), a take-home reflection activity was assigned where participants were instructed to send in their responses. All nine mothers (100%) completed this activity, demonstrating strong session engagement. In addition, all participants kept their videos on for the majority duration of each session (i.e., <45 minutes) with one exception: for the first group, one mother connected with the facilitators to let them know her camera is off for the first two sessions as she would join to *Zoom* during her commute to work.

5.2.4 Examination of Questionnaires & Research Procedures

Specific to the pre- and post-data collection sessions, the percentage of questionnaire completion was 100% with no missing answers, and the average length for a data collection session was approximately 37 minutes. This is in comparison to the scheduled 45 minutes to complete a data collection session, demonstrating that the questionnaires were performed in a timely manner. None of the participants reported any issues or perceived burdens with any of the study procedures. There were no adverse events reported or major technological concerns observed throughout the intervention procedures.

5.3 Qualitative Findings

A visual was developed to capture the salient features of caregivers' experience with *Move&Connect-Caregivers (M&C-C)*. The visual includes four categories: (1) Caregiver Background, (2) *M&C-C* Intervention Structure, (3) *M&C-C* Intervention Engagement, and (4) Key Takeaways. *Caregivers Background* describes the lack of awareness and limited education related to the long-term impact of concussion injury. *M&C-C Structure*, which includes design, content, and delivery, promoted a positive and engaging experience for participants. *M&C-C Engagement* was reflected with the following participant attributes: camaraderie among caregivers, information sharing, psychoeducation on PPCS, and having a safe space and dedicated time for self-expression. *Key Takeaways* were also highlighted, including lessons learned and personal and family insights gained from the *M&C-C* intervention. A summary of the categories is provided along with quotes capturing the essence of each category. The *M&C-C* Visual is shown in Figure 3.

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Figure 3

M&C-C Visual
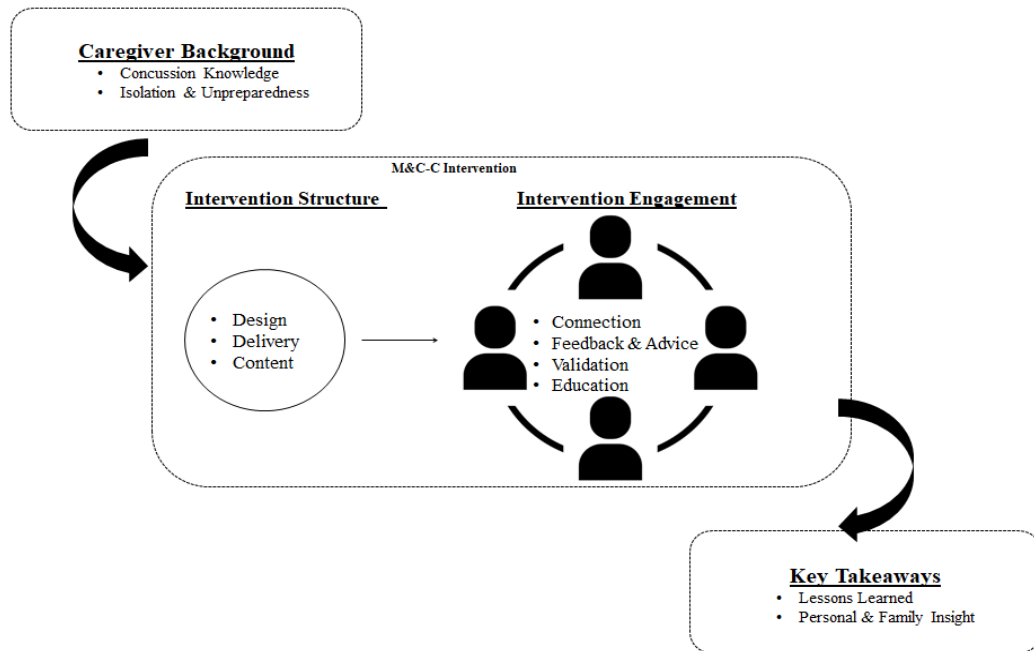
Caregiver Background

This section covers the first category of the *M&C-C* visual (Fig. 2) and consists of two elements: Concussion Knowledge, and Feelings of Isolation and Unpreparedness. Detailed descriptions are provided below on the background of parents of youth with PPCS in terms of concussion education, and the feelings of isolation and lack of preparation common among parents of youth with concussion injury.

Concussion Knowledge

Many mothers stated that they had the expectation that a concussion injury tends to resolve quickly on its own. This view is based on the lack of knowledge related to long-term consequences of concussion, as well as their observations of friends and family members who

sustained a concussion and recovered in a short timeframe. Hence, mothers were unaware that

prolonged symptoms can continue to impact the health of their youth for months to follow.

> Hannah: I don't know how you would let people know that a concussion doesn't always
>
> just last a day or two or week. 'Cause like I said that I had no clue about like this - that
>
> threw me all on its own. My son, my older son had a concussion from reckless stuff, has
>
> had more concussions than you could care to shake a stick at. But typical concussions, so
>
> when this happened, I didn't even know this [prolonged symptoms] could happen.
>
> Anna: I had the conception that it was, one concussion almost, you know, it would fit all.
>
> Like my daughter, uh, couple of her friends has had concussions and at the end of two
>
> weeks, you know, they were better and then that was - that's what our expectation was
>
> after my daughter's concussion.

Feelings of Isolation & Unpreparedness

Mothers' lack of concussion knowledge contributed to feelings of isolation and unpreparedness

when dealing with their youth's injury. In fact, many participants wished they had access to

M&C-C earlier in their recovery journey to equip them with necessary knowledge and strategies

to support their child.

> Julie: I don't know a lot of people who have had concussions, you know, people have
>
> kind of popped up once you say oh, yeah, you know, I have - my friend - you know, my
>
> daughter has a concussion and someone will say "oh, I had one," that sort of thing. But
>
> you don't really talk about what that is, what that impact is on your family and your
>
> school and things like that.

Hannah: It's nice to hear because when you get involved [in the program] you don't feel

alone for starters, because I did … like I didn't know concussions could last so long, but

hearing how they cope or what works for somebody that was fantastic.

Ashley: I don't know where I would point people to that kind of information or if she had

another concussion and she wasn't involved with this team, I'm not sure I know where I

would go for that, sort of initial information… we just maybe didn't realize the

seriousness of it.

In general, caregivers' background describes concussion knowledge and associated feelings prior

to joining *M&C-C*. Participants reported a lack of awareness and limited education related to the

long-term impact of concussion injury. This has contributed to parents' feelings of frustration

and isolation when trying to provide the appropriate support for their youth after concussion.

M&C-C: Intervention Structure

The middle component of the *M&C-C* visual, *M&C-C* Intervention, consists of two

categories related to Structure and Engagement. This section focuses on the *structure* of the

intervention in terms of the following elements: program design, educational content, and session

delivery.

Design

The design of *M&C-C* includes six weekly sessions of one-hour duration. Participants felt that

the sessions were well-structured and flowed naturally. For example, they liked the consistent

program design in terms of its structure starting with education followed by activities and

discussions. This is illustrated by the following quotes:

Ashley: I liked how each week focused on one particular [topic] so you weren't dealing with two or three of the topics in one. I liked how the hour was just dedicated to, you know, either the stress or, I really liked that and I did like the topics that were touched on, you know, from week to week.

Emily: It was a natural flow, so I kind of had an idea in preparing for signing into the group. So, yeah, I just found it provided a sense of organization in our busy lives- in my busy life so I quite preferred that and I felt reading the hand-out more just provide a sort of anticipation because it was the overview of what was to come.

Rachel: I like how you flowed through it and you had different sort of, okay, this is what we're doing now. I liked that. It was very organized structured. So there was an obvious beginning, middle, and an end to it. And I found that the way that you conducted it was always the same, like it didn't change which I liked too. So, we knew that, okay, now we're doing this and we know that we're going to have a discussion about this.

Also, the one-hour duration of *M&C-C* has been described as suitable and timely; Anna shares, "I really also appreciated that we always stuck to our hour like that was nice um, even you know, if people chatted bit longer it all worked out and slideshows were an appropriate like length for what we were doing."

Content

The curriculum of the intervention was built using six different modules that offer a wide breadth of topics to participants. The quality of the information presented during each session was described as reliable and informative. Hannah shared:

> "Everything in there was valuable; I think they kind of hit the nail on the head for the
>
> topics that they picked."

Also, parents especially appreciated that the content of topics included theory and evidence-

based research, for example:

> Sarah: I think it was good because like, it's nice to have some real numbers just to back
>
> stuff up or just to have you know, kind of like expert opinions and not just a, you know,
>
> well, here are some things that you could try like there, it was just nice to have something
>
> that's a little bit more tangible with that.

> Julie: I think I've learned a lot in terms of the theory, I think the theory was really
>
> important for me and I felt that that was very helpful not just for concussions, but just in
>
> general.

Two mothers commented that the topics could have been explained further in-depth but they

agreed that due to time limitations, it may not have been feasible; Vickie noted:

> "It [M&C-C] touches on all the aspects of you know, how it impacts the kid the family,
>
> um you know the symptoms, how you manage them, um, Of course it - it could be
>
> deeper, but given the time right, its only 6 sessions and one hour per session and there's
>
> five parents so everyone's trying to you know, share experience."

Delivery

The *M&C-C* virtual delivery was done using PowerPoint presentations covering various

educational topics and reflection activities. Mothers positively described the visual slides as

promoting the simplification and understanding of content. For example, Lucy states "The charts

and graphs it's kind of easy to- to memorize... the visuals they're easier for people to grasp."

Further, participants commented on the slides facilitating session delivery and interactivity

through discussions, questions, and annotation features, as illustrated by the following excerpts:

> Vickie: Slides added to visual to it instead of just talking… I liked how they had the slide
>
> up and then we continued on the conversation so we could see the slide and then talk
>
> about it while it was up so that I found helpful, if they had to kind of showed the slide for
>
> like a minute or so and then taken it down, it would have been, I think not as beneficial-
>
> not for me anyways, but I did like the slides. I like how they had them up while the
>
> discussion was being had.

> Anna: I love a slideshow, haha, especially with the annotating in it, I really thought that
>
> people like cause you know you talk around a slideshow and nothing really happens but
>
> when you see your ideas written down you feel more engaged, I think so, and they were
>
> lovely.

Parents also shared that the sessions were engaging and conversational. Specifically, the time

dedicated for discussions among one another was an important component of session delivery.

Anna notes:

> 'Um, I think the ability that we had to share, like there were tons of opportunities to
>
> share. uh it- it certainly wasn't lecture driven at all and I wasn't fully sure what to expect
>
> there so I really liked uh, that part there wasn't always a lot of discussion, but we had the
>
> opportunity to do it If we wanted to so that was kind of nice.'

Another aspect that contributed to the successful program delivery relates to the group

facilitators' expertise. For example, participants described facilitators as knowledgeable,

resourceful, and kind. They created a warm environment by providing informational and emotional support.

> Julie: the facilitators, who really do work well together and they're very capable, they're very warm and they're very, open and I think that those things are very helpful and, you know, they're very validating and you know, so I think those things are very important.

Lastly, the intervention delivery mode was convenient because of its virtual nature [through Zoom HealthCare]. It was important for mothers to participate in the sessions from the comfort of their homes as it saved them commute time, offered flexibility with their schedules, and accessibility from various geographical locations. For example:

> Sarah: Like for me to come down to the hospital like to make that work and with everybody's schedules and to do the kids at the same time like I think that would have been really difficult. So I think this [virtual delivery] definitely facilitates that piece.

> Vickie: We're already riddled with so many appointments when we're caring for a child that's in this situation that to have to, like, get up and - not get up, but like, get out of your house and drive to Holland Bloorview, for example, is a solid, you know, 40 minute drive for me and that's easy compared to a lot of people, right? So it would, you will get more participants offering it online than you would if it was in person.

In addition, it is important to note that while 8 out of 9 parents preferred an online format due to increased convenience and access, some acknowledged that the personal connection element with other group members may have been minimized due to the inherent nature of virtual groups.

For example:

> Ashley: I do like adding the connection one-on-one, um, in person, but convenience of
> having it online, you know, especially being winter, you didn't have to worry about going
> out, you're in your own home. So I liked that aspect of it, so I'm kind of mixed as far as
> having that personal connection, but given the circumstances it's, you know, it is what it
> is, right? With everything-   all the zoom and online – it was good.
>
> Hannah: It would be better in person because it's hard talking to a screen, you know, it's
> not the same, but I mean, what can you do right now, right? I would prefer the in-person
> thing over this techie stuff. I am not really a tech person. But yeah, that's just a me thing,
> I don't like any of it, computers.

In summary, *M&C-C* structure describes the design, content, and delivery of the intervention sessions. Parents appreciated the design of *M&C-C* with a focus on one topic per week with relevant content and engaging delivery. The curriculum content was described as covering a breadth of PPCS and related topics. Intervention delivery included the facilitation of visual presentations and interactive discussions by knowledgeable and warm facilitators. The virtual mode of the sessions promoted increased convenience and accessibility to caregivers. The structure of *M&C-C* set the stage to allow for a positive and interactive experience for participants as described in the next section.

M&C-C: Intervention Engagement

This section also covers the middle component of the *M&C-C* visual focusing on the category of Intervention Engagement. It describes the different attributes that contribute to positive and engaging *M&C-C* participation. Therefore, *M&C-C* engagement was depicted in

terms of the following parents' perspectives: camaraderie, information sharing, psychoeducation, and self-expression in a safe space.

Camaraderie among parents

It was common for participants to describe how the group format led them to feel a greater sense of belonging and community. Mothers who attended *M&C-C* reported a sense of camaraderie and kinship with one another. They commented about the value of meeting and interacting with other mothers of similar lived experiences. In the sessions, they connected with one another by listening to personal stories, and exchanging feedback and advice. Participants emphasized the positive impact of networking with others who experience similar challenges, as well as with the group facilitators who have extensive knowledge in the field.

> Julie: I think it's helpful to hear other people's experiences and feel like you're not, you're not in this on your own. I think that's the thing that maybe is even more amplified right now because, you know, you're not sort of meeting or engaging with lots of other people right now so, you don't hear a lot about other people's experiences with concussions.

> Hannah: It's nice to know you're not alone and to hear other feedback and how they can deal with something.

> Vickie: The connect part of *Move&Connect*; it ended up being all mothers in our group…just the connection was the best part. There are other moms going through the exact same thing I'm going through.

Lucy: It is a place for us to, for the parents who have the same experience to share some of their thinking, their feeling, uh, so it um, it uh, you know, otherwise you kind of isolated and keep it to yourself.

Emily: I could be on a, like in a public situation, and you never know like who you're beside or what they're managing and so in this situation, I think we came in the group session as strangers but certainly left feeling more connected or at least I did.

All participants were parents to children of similar ages. Organizing parent groups based on youth age has been emphasized to enhance engagement among caregivers and increase group rapport and other commonalities:

Sarah: Parenting a teen is going to be different than parenting someone young. So that was really good with, our group, they were all older so I think that helped with the experience.

Emily: because it was the teen group that they were our children were within the same sort of age range. So, it just automatically meant that there were certain things that were common. I think our shared experiences were transferable. So I think that that helped with the cohesion and the ability of us to feel that connectedness. So that was you know, I would recommend more of that in the sense of keeping like the age range of the children like similar.

Rachel: I noticed that most of our group, they were teens, and some had had longer concussions, like my daughter like years since, and I just thought it was extremely helpful knowing that, you know, you have the same… similar experiences, similar concerns and you're also not just dealing with the concussion, but you're also dealing with a teenager

who's going through their own stuff, right now in the teenage- and with COVID, on top

of that.

In fact, the most common suggestion for improvement was integrating strategies for maintaining

contact with other parents such as sharing email and phone number with one another, assuming

parents' consent.

Information sharing

Giving and receiving information and personal stories was seen as a useful exchange for parents

to support their child's recovery. Sharing previous experiences, resources, and what had worked

(or not worked) was of value to all involved as it allowed parents to reflect on their situation and

learn from one another about beneficial strategies and other ways of coping. As an exemplar:

Anna: they were experiencing maybe the same things maybe on a different scale, but it

was something that I hadn't or even listening to something that I haven't heard before. So

I think that was the best, having it in the group setting and getting feedback from the

other parents.

Rachel: I think it was great because you don't feel so alone. Got to meet other people and

pretty much everyone sort of had the same sort of concerns and there was a lot of stories

that were basically the same story across the board, just different kid and I felt that was

really helpful.

It is important to note that not all mothers wished to participate in the session discussions

as some preferred to only listen to stories and advice. However, listening to the experiences of

other group members was described as an opportunity to learn. Vickie noted:

"Like, sometimes I just didn't feel like talking 'cause it's at the end of the workday and it's at dinnertime and, you know, maybe you've had enough of your day but, you know, I still wanted to get from the session but maybe not, wasn't feeling like participating very much but still listening."

PPCS Psychoeducation

The educational topics were reported to be beneficial and informative. The education approach was described as holistic and comprehensive because it touched on many aspects related to concussion injury and recovery.

Anna: I think the program touched on the real important things, right? Like the relationship, like mental health was is a biggie, the stress, the school, being an advocate. I think that was a huge one, um, for the girls especially being at the age [teenage years].

Sarah: So I think that everything in there was valuable, like there's nothing that I would say…I think they kind of hit the nail on the head for the topics that they picked.

Vickie: I could certainly see like when we did the review session, it sort of confirmed what I was kind of seeing that I was reflecting on, which was, there was quite a bit of information in a very short amount of time. It was you know, it felt like although it was only 10 minutes or so that there was like you needed to be there just some right off the hop to get it all because there was quite a bit but I don't say that as a negative.

All mothers highlighted the benefit of the topic of mental health & concussion, where the facilitators shared a list of mental health and concussion symptoms and discussed commonalities. Also, the topic of "ripple effect" and "school advocacy" was heavily mentioned across interviews as it resonated with participants. For example:

Ashley: The mental health is a biggie and the other one that I really liked, was the difference between the symptoms of concussion and the typical teenager, you know, the anxiety the stress, the depression, the overlapping and how they can overlap. I got a lot out of that one.

Anna: I know other parents were really taken by the concussion vs. anxiety symptoms in kids but I had already been through that, my daughter is diagnosed with anxiety already but if I hadn't known that like people's minds seemed blown by that when they saw it um, so yeah for me the-the the hawk and the dove and the stress curve were pretty cool. Um, even the balance wheel when I looked at how balanced my life was wasn't great, haha, so yeah, I think those ones but the, the stress one I found very interesting.

Vickie: I thought the ripple effect, the discussion of like the ripple effect of a concussion was a good reminder of how-   just how far the impact can go. Not only on your immediate household. There was also one where we did sort of a pie chart of our roles and to actually write that down, you realize, oh my God, how many slices of pie you're chopped up into and then like the stress level for each piece of pie, each slice, so that's why I'm so tired, that's why I feel burnt out like, you know, it was just good to take a look at yourself. Take the time.

In addition to psychoeducation, the take-home reflections and activities were described to be relevant and useful for caregivers. Many mothers stated that they were taking notes during the psychoeducation portion of the session to be able to reflect on the content throughout the week.

Ashley: It just kind of makes you take notes and when you write things down, I find that helpful. There's one thing talking about it, but when you actually put it, you know, on paper it get kind of reinforces, you know, you might be stronger in one area compared to

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another depending on you - how you feel that day. So I thought take home activities, I thought they were great, I got a lot out of them.

Julie: Yeah, I liked those, I thought that they sort of got you thinking about the theory and trying to apply it which I think is helpful. I think it's, yeah, I think it's important to have like the theory and then try to apply it and sometimes applying it right in the moment then because obviously, like me, maybe I'm the only one, but would forget sort of what the activity was to apply it later so at least if you, like apply it briefly in the moment and then apply sort of in the week, I think that's a good model to use.

Emily: Yeah, so no, let's put it this way, if we have reflection and then it was never referenced it would feel like, oh gosh, like why did we do that? But that wasn't the case, so I could see sort of the flow in that respect. So I would, I guess, suggest like to continue that it's good because it's certainly a verification of you're not just doing this for no reason and it has a place.

Outlet for self-expression

There were many references to the positive impact and quality of relationships that emerged during the sessions. Group meetings were described as a safe space for parents to discuss their feelings and concerns related to their family. They underlined the importance of sharing their experiences without being judged.

Julie: I actually think it's nice to talk to people you don't really know, um, about those things because they don't have a vested interest in your child and so they're not, you know, like they're not judging the situation in a way through like, you know, through their lens of - their experience with the family.

Lucy: In general I really like it, I really like the time that we, it's like even giving us um, an outlet to- to, speak otherwise we would keep it to ourselves.

The comfort level was high among participants because they felt that they could share challenges openly with other members. This is due possibly to group atmosphere, virtual nature of sessions, and the group rules on maintaining the privacy of discussions. For example,

Lucy: You feel comfortable because you are in your own house right.

Ashley: It was stated that, you know, it was privacy and basically what we talk about stays within, you know, the conversation kind of thing and I appreciated that. So I didn't feel like I had to hold back any information, I felt comfortable sharing whatever it is that I wanted to share. I wasn't hesitant at all and there was no, I didn't feel there was any judgment on the other end of the - anybody else which was nice.

Rachel: So I thought it was easier to share because it felt like everyone else is experiencing similar, right? There's no judging, there's no… that's what I felt.

In summary, intervention engagement consists of several elements that cover camaraderie, information sharing, education, and self-expression which have contributed to promoting a positive group experience for caregivers. This includes increased feelings of community and belonging, shared experiences, reflective discussions in a safe space, and concussion knowledge.

Key Takeaways

This section covers the key intervention takeaways which constitutes the final category of the *M&C-C* visual. It consists of two elements covering the lessons learned and insights gained by participants. Descriptions are provided on parents' key learning's as supported by their quotes

and experiences. Further, mothers provided self-reflections following *M&C-C* participation on personal insights that can aid with youth care and recovery.

Lessons Learned

Various learning outcomes have been shared by parents. A common learning take-away was related to the applicability of educational topics to the caregivers' daily life. For example, many mothers worry that their child is at-risk for another concussion injury. And, they mentioned that participation in the group promoted preparedness to deal with future injuries. To illustrate:

> Vickie: I think you know, for our situation, it's almost inevitable that she'll become concussed again. So I think like I remember a lot of the advocacy pieces around school and there was some input there that I'll carry with me next time and I think next time I'll just, again, remember that there's other people in this situation and supports are available.

> Julie: Although, you know, now they've kind of had one concussion, they might be in risk for another one if they get hit again, you know, certainly that information will be helpful.

In addition, few mothers reported increased awareness and education of PPCS, while others felt validated and learnt that they are "not alone" as they support their child with their injury. Many mothers shared that they appreciated the benefits of the intervention and *M&C-C* participation was worth their time. A list of key learnings shared by caregivers is provided in Table 7.

Table 7

Parent Learning Lessons

Pseudonym	Learning takeaway
Ashley	I've learned too is that everyone's experience is so different to the extreme of their symptoms after the concussion
Hannah	As sad as it is, it made me feel better. 'Cause you're not alone, but then it helps

	because okay what might work for- like when you- like I have eight kids, what works for one kid in general, doesn't work for another so it's nice when you can hear what other people have tried and oh, okay let's- let's see if that works like, you know, you got nothing to lose
Sarah	Kind of the biggest piece when I look back now and realize, like, how hard it was and as parents we don't do a good job taking care of ourselves or like supporting ourselves through all of this. So, you know, you don't realize it when you're in the middle of it and so to see a program that is going to support the parents as well is huge.
Anna	It is nice to know it's not only your kid. Nice to know you're not the only one who tried something that failed.
Lucy	You know concussion, and how it impacts the family. It's quite normal actually you learn it's a normal thing like I felt so bad after my daughter's concussion. In the beginning I wasn't but then I as I dragged on I felt bad and then, um. So I learned it's quite normal to feel that way yeah.
Vickie	I'll carry with me next time and I think next time I'll just, again, remember that there's other people in this situation and supports are available.
Emily	I certainly think I have- I'm more equipped after the group then I was going in. So, you know, I think that it was absolutely a great investment of time

Personal and Family Insight

Mothers have shared useful insights from participating in the intervention. Many stated that the intervention helped them to become more aware of their typical reactions during conversations with their youth, providing them with tools to reflect and proceed in an effective manner. Hence, they were applying the knowledge learned in the program to their own family routines. For example:

Rachel: I think just being able to reflect on things and kind of like self-reflecting as well, right? Like what can I do to make things better? Or you know, what can I change to not cause, you know, more frustration [with my daughter].

Sarah: I was surprised by how much it like, how much it made me reflect over things and, and look back a little bit more objectively now, which I'm sure is a good thing. So that was good and I mean, I hugely see the benefit of all the topics and creating a group that can relate to each other like I see huge benefits there.

Therefore, participants' self-reflection and questioning of their past patterns when communicating with their children were important program outcomes. Also, they reported various learning lessons and reflected upon insights related to themselves and their families. Such insights were thought to lead to improved understanding of how to address the impact of concussion injury on family dynamics.

M&C-C Iterations: Parent Suggestions for Improvement

Parents provided several suggestions to improve the intervention. Implementing their suggestions is an ongoing process that incorporates delivering the intervention and seeking participants' feedback (See Figure 4).

Figure 4

M&C-C Iteration Flow
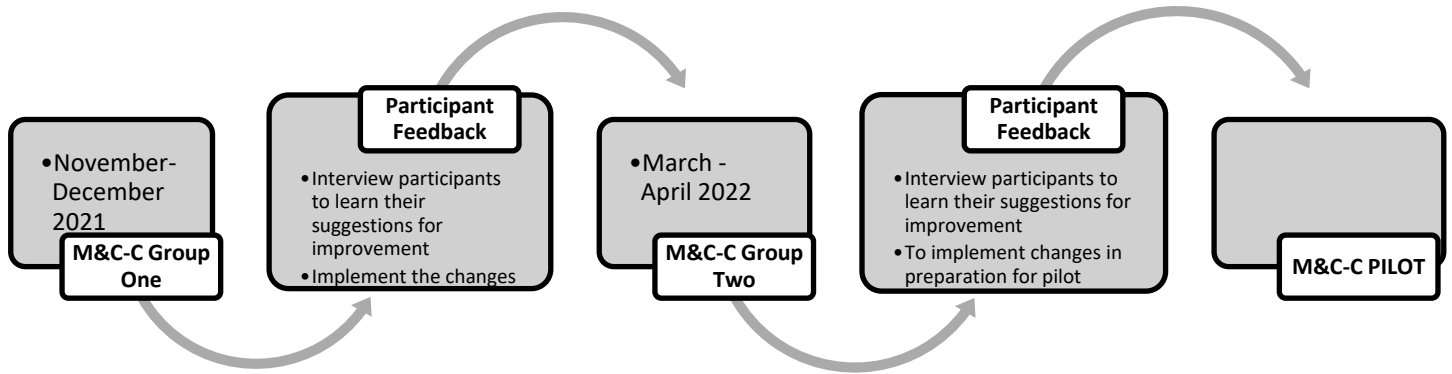
The first round of suggestions that resulted from the first intervention cycle has already

been implemented. Table 8 describes the Group One suggested changes after running the first

cohort of *M&C-C.* Next, the improved *M&C-C* sessions were run for a second time to a new

cohort of caregivers. Table 9 describes the suggestions and modifications recommended by

caregivers in Group Two and the ways they will be implemented in future interventions. Hence,

the second round of suggested improvements will be included in the next phase of the

M&C-C program in preparation for the pilot-controlled study. It is interesting to note that both

sets of modifications are unique; the changes suggested by Group One were not brought up in the

second run by Group Two. This is an indication of the participants' growing satisfaction with the

program intervention.

Table 8

Proposed Modifications for Move&Connect-Caregivers (Group One)

Group One			
Proposed Modifications #1	Data *(e.g. Example Quote)*	Implemented Changes	Done?
Addition of Program Handouts	"Um, I'm just thinking. I can't remember if we had a handout one- it was the, the symptoms like I said previously for the- symptoms from the concussion and then the just the regular teenage or- I think something… I don't even know if we got a handout, it was more of a discussion. Yeah, so I think a handout- something to that would have been helpful just to see how many things in our own personal experience do cross the line."	Handout creation for each session	✓
Topic Suggestion: Promoting Physical Well-Being	"The physical aspects in terms of like, promoting physical well-being with yourself and your child that might have been helpful. What would physical health look like and how do you promote that with your child who, A, has a concussion and, B, is- for all of us in the group somebody who was a teenager."	Physical well-being topic integrated in session one curriculum	✓
Logistics: Email Reminder to include take-home activities	"Maybe just sending take-home activity reminders out when you send the link as a reminder because I sometimes forget."	Take-home activities included in weekly email reminders	✓
Website Resources	"Just some general links to places where you can find good information on concussions, might be helpful, ….what would you tell somebody else who had had a concussion and it started to get me thinking about, well, what if someone, you know, I knew had to concussion and, you know, I wanted to point them towards some good valuable resources."	Compile a list of helpful websites to include in program handout	✓

Table 9

Proposed Modifications for Move&Connect-Caregivers (Group Two)

Group Two		
Proposed Modifications #2	Data	Changes to be implemented
Group facilitators promoting connections among caregivers	"I don't know if there's a way that when someone says, oh I found this support, if the facilitators can contact that person at some point and say are you willing to provide the information for that service, so that maybe at the end, you walk away with those- that information. (C09)" "Perhaps in the last session if you'd like to provide your email, your phone number, or your Instagram, you know, put it on this document, you know, so then people could have tried to connect."	Strategies for maintaining contact with group members after the program is over (e.g., a sharing email and phone numbers) will be integrated, assuming consent is gathered. This may be done by allowing parents to connect with one another at the end of the session: the facilitators can leave Zoom open and exit the meeting to give space for caregivers to connect with one another without the facilitators. The caregivers would also be free to leave if they do not wish to be part of the session.
Topic Elaboration: Mental Health & Concussion	"Yeah, so I just think, like, more in-depth information around that piece of it would be really helpful. And I don't know if there are other pieces that would warrant like more in-depth but there are certain things parenting." "You know, in terms of the- the bread- the breadth its good, the depth it could be a little deeper um, but its- its normal right, its only 6 session."	Time will be allocated to further topic discussions on mental health & concussion. If time allows, this may be done in session three. It may also be explained again in session six, before conducting the intervention review content.
Topic Addition: Independence for Teens	"So I think that social part where in terms of moving forward, the peer connections for the different phases of their, you know, development that they're in and the situation as an eighteen-year-old going to embrace more independent living. So it's just, you know, that sense of how to navigate them toward, whether it be a more independent phase of their development and things like	The topic of independence will be discussed in session five; specifically in groups where parents have teens with PPCS.

	that."	
Slide Decks For Reference	"Because I loved the stress curve and I would like to see it again and I was going to screenshot it but I didn't but um, I really- yeah for me I would have loved the slideshows, not beforehand but afterwards as reference." "That would be the only thing that I would say was like I enjoyed the information so much that I would have liked to have it to keep – the actual teaching."	The handouts will be modified to include more psychoeducation key-points so parents can keep it for reference.

Hopes for Program Access

Parents reported that they wished they had access to the information provided in *M&C-C* earlier

in their recovery journey, and provided suggestions to enhance resource access for other

families. This includes collaborating with community clinics and hospital emergency

departments, sharing the study opportunity on social media, or posting it in the hospital

(HBKRH) website.

> Ashley: I wish something like this had it been when [my daughter] first had her
>
> concussion, like this information that we received is, um, yeah, so beneficial, but I think
>
> that would be my only… if parents are given the opportunity or like I said some type of
>
> handout of some sort, um, at the beginning that would be beneficial because I think at the
>
> very beginning we were kind of flying by like we had no idea.
>
> Hannah: I wish the families had more access to you, but I don't know how you would-
>
> unless you let the people in the emergency rooms and stuff know, you have this program,
>
> but wait so damn long, you know what I mean? That would be good, like, get it out there
>
> more.

Results Summary

In summary, a visual model was developed to capture the salient features of caregivers'

experience and feelings with *M&C-C*. The visual includes four categories: (1) Caregiver

Background, (2) *M&C-C* Intervention Structure, (3) *M&C-C* Intervention Engagement, and (4)

Key Takeaways. The first category of the visual describes the background of caregivers of youth

with PPCS in terms of concussion education and their feelings of isolation as they care for their

youth. The middle component of the visual focuses on two categories: Intervention Structure and

Intervention Engagement. *M&C-C* structure was acceptable to parents in relation to intervention

design, educational curriculum and intervention delivery. The sessions were described as well-organized and had consistent flow. The educational content was comprehensive and encompassed broad topics related to PPCS and its biopsychosocial impact. The virtual delivery of *M&C-C* was described as convenient to families as they participated from the comfort of their homes. The structure of *M&C-C* set the stage to allow for a positive and interactive experience for participants where they connected with one another, shared information and personal stories, enhanced their knowledge, and expressed their feelings in a safe space. *M&C-C* key takeaways cover lessons learned and insights gained following intervention participation. Here, the visual model is presented again with the addition of illustrative comments (Figure 5) that reflect the essence of the components of each stage and highlight the main attributes of the three stages in terms of influences, feelings and chronological flow.

Figure 5

M&C-C Visual (with quotes)
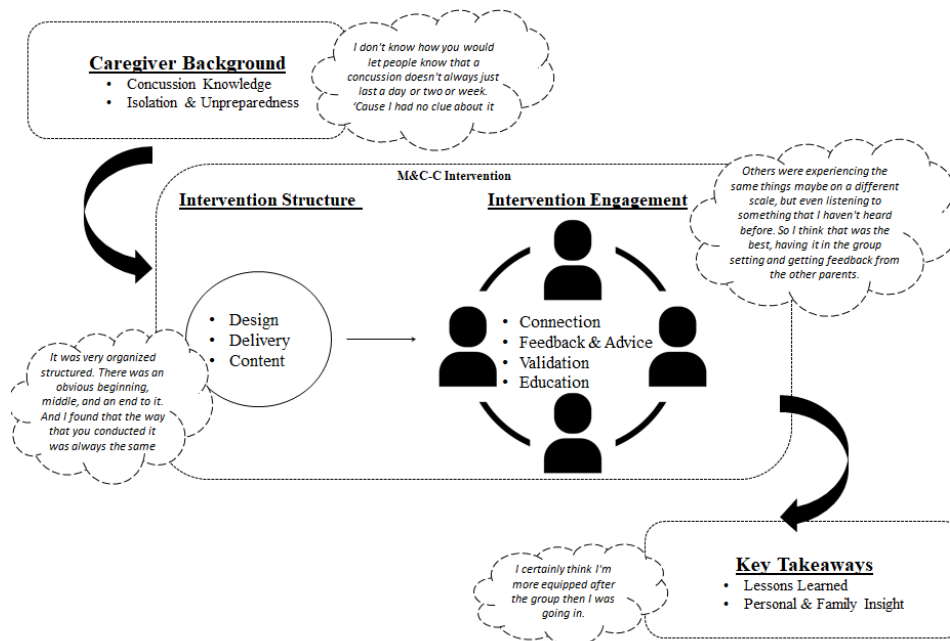
CHAPTER 6

DISCUSSION

6.1 Summary of Findings

The overall objective of this thesis was to explore the feasibility of a group-based virtual intervention for caregivers of youth with PPCS, *Move&Connect-Caregivers.* The first aim examined the four areas of feasibility domains (Orsmond & Cohn, 2015) related to recruitment capability, intervention acceptability, evaluation of data collection procedures and resources. The study findings clearly demonstrate that *M&C-C* is a feasible intervention for parents, as we achieved all *a priori* assumptions of feasibility. The metrics collected, including the high attendance rate, take-home activity completion, and data collection participation demonstrate that participants are engaged with *M&C-C*. There were no adverse events, burden, or serious technical issues reported as a result of *M&C-C* participation.

The second objective focused on the fifth feasibility of domain on exploring participants' experiences with the intervention. A visual was developed to capture participants' full experience with *M&C-C*. The visual includes four categories: (1) Caregiver Background, (2) *M&C-C* Intervention Structure, (3) *M&C-C* Intervention Engagement, and (4) Key Takeaways. The first category focused on the background of caregivers including the knowledge gaps and concussion experiences of mothers prior to enrolling in *M&C-C*. The second category provided details on the intervention program in terms of its structure (design, content, and delivery), and sets the stage for participants to have an engaging experience. The third category, *M&C-C* Engagement, was reflected with the following participant attributes: camaraderie among caregivers, information sharing, psychoeducation on PPCS, and having a safe space and dedicated time for self-expression. The fourth category, Key Takeaways, highlighted caregivers' lessons learned and personal and family insights gained from the intervention. Results

demonstrate that the intervention is meaningful for caregivers because the benefits of social

support, concussion education, and advocacy skills are combined to provide caregivers with the

needed support in addressing youth challenges.

6.2 Move&Connect-Caregivers Feasibility Indicators

Results indicate that *M&C-C* is a feasible intervention for caregivers of youth with PPCS.

In terms of feasibility metrics, there was 75% recruitment rate. All of the enrolled participants

completed the entire study procedures, including the questionnaires and interview sessions,

demonstrating a (100%) retention rate of participants. All intervention sessions were highly

attended (>98%) across both feasibility groups. Strong session engagement was also

demonstrated via completion of reflection activities and participants opting to keep their video

cameras on for the majority of sessions. Results, based on the *a priori* feasibility indicators,

suggest that the intervention was feasible and engaging for caregivers. While feasibility metrics

on intervention delivery for caregivers of youth with ABI and TBI is lacking, the recruitment,

retention, and adherence rates in the current thesis are comparable to indicators reported in

interventions studies to support caregivers in other populations. For example, in a study which

delivered a virtual cognitive behavioral therapy to caregivers of youth with chronic pain, these

metrics were observed: adherence rate of (>90%) and retention of (80%) (Palermo et al., 2016).

The current thesis used e-mail reminders through the intervention, provided flexibility

around completion of measures, and compensated participants for their time to complete

measures, all of which are suggested to facilitate retention and adherence (Duncan et al., 2020).

Parent participants expressed appreciation for the email communications and calendar invites

serving as reminders supporting their busy schedules. The communication prompt included

weekly email notices with the *Zoom* link, session objective, and a reminder of the take-home

activity. The second group had an additional weekly handout attached to the emails. Evidence

suggests that implementation of technology prompts, such as frequent emails and program tips

(e.g., quick snippet on session content) fosters intervention adherence (Muller et al., 2022). This

is also consistent with other studies that employ automated reminder methods promotes study

adherence (Titov et al., 2013, Hamine et al., 2015). In terms of the data collection sessions, the

study measures were administered remotely through *Zoom* in a convenient and timely manner to

all caregivers. The flexibility in allowing the participants to complete measures at their own time

was appreciated by two parents who found this option convenient. In addition, there were no

concerns or burdens with study requirements identified by participants, suggesting acceptability

of measures and research procedure (Palmcrantz et al., 2015). Throughout *M&C-C* participation,

parents did not experience significant technical issues or clinical concerns, which have been

identified as a key barrier to telehealth success (Lin et al., 2018). On a few occasions, minor

technical concerns occurred during sessions that involved orienting participants on how to view

the full PowerPoint screen and modify display names. These were quickly resolved by session

facilitators. While virtual interventions generally increase access and convenience, it is important

to also provide participants with adequate technical support to promote meaningful session

participation. Feasibility metrics will also be considered in a future pilot study involving a larger

sample size (Tickle-Degnen, 2013).

6.3 Gaps with PPCS Education & Support Needs

The first category described by parent caregivers through exit interviews, Caregiver

Background, discussed caregivers' lack of PPCS education and the feelings of isolation and poor

preparation common among parents dealing with PPCS challenges of their youth. Based on

caregivers' personal observations of their friends and family, they were unaware of the long-term

consequences that can result from a concussion injury. Many caregivers in *M&C-C* also wished

they had access to *M&C-C* earlier in their recovery journey to equip them with the necessary

knowledge to support their youth. They noted feeling lost and confused as they attempted to try

to access appropriate care and information for their child. This is consistent with the literature,

where parents of youth with concussion request comprehensive information on their child

recovery and treatment (Brown et al., 2013). Specifically, parents of children with PPCS

reported unmet information needs due to the low quality and brief information received upon

hospital discharge; and, as a result, may resort to the Internet for further concussion education

where the risk of misinformation is common (Minney et al., 2018). Overall, parents of youth

with concussion report gaps related to education and strategies to support children with

prolonged symptoms. Similarly, other studies have found parents of youth with TBI report unmet

needs in the domain of TBI-related education. (Armstrong & Kerns 2002; Roscigno &

Swanson 2011; Brown et al. 2013). Parents attending *M&C-C* also expressed feelings of

isolation and frustration as they tried to manage their child's ongoing symptoms and

relationships both within and outside their family. This is consistent with the broader TBI

literature, where parents reported experiencing loneliness that benefited from peer support and

education (Brown et al., 2013). This is an important consideration because the lack of caregiver

support can lead to poor expectations of the child recovery, thus exacerbating PPCS (LI Wood et

al., 2004; Yeates et al., 2009). Indeed, many parents in the intervention noted their lack of

confidence while supporting their youth PPCS and they expressed appreciation towards the

knowledge they have gained as a result of *M&C-C* participation. Further, parents acknowledged

that they gained tools and strategies that they are able to implement in their daily routines to

support their youth well-being.

6.4 Move&Connect-Caregivers: Structure & Engagement

The second component in the *M&C-C* Visual consists of two categories, Intervention Structure and Intervention Engagement.

6.4.1 Intervention Structure

The structure of the *M&C-C* program details the following elements: design, content, and delivery methods. The design of the intervention was described to be easy to understand and followed consistent patterns during sessions. For example, the *M&C-C* slides included fewer words, colorful visuals, and relevant analogies in order to explain concepts in plain language. This is in line with the knowledge and translation exchange principles recommending that delivering information to knowledge users (i.e., parents) in a consistent and understandable manner is essential to promote knowledge uptake (Provvidenza et al., 2013; Reardon et al., 2006). Participants attending *M&C-C* also highlighted the importance of facilitators being friendly, respectful, and knowledgeable. Parents felt understood, and validated by the facilitators. Indeed, families note the importance of attitude and demeanor when interacting with clinicians (Minney et al., 2018). This is important as research reflects the benefit of therapeutic alliance to enhancing intervention outcomes (Holth et al., 2021; Tschuschke et al., 2020). In addition, research shows that video conferencing platforms offer less intimidation and greater personal control between clients and therapists, which contributes to enhancing the therapeutic rapport. Participants also commented that they appreciate the consistent structure and scheduling of *M&C-C*. For example, the sessions are held at the same time each week, and follow the same structure (i.e., psychoeducation followed by activity and reflections). This is important to keep in mind when delivering intervention for families dealing with numerous responsibilities and busy schedules to enhance their experience with the intervention.

In terms of intervention delivery, the virtual format of *M&C-C* was convenient and efficient for families. For instance, parents appreciated that they were able to complete the intervention from the comfort of their own homes. In general, caregivers of youth with concussion deal with various responsibilities and costs including travelling to medical appointments over long distances, which can lead to caregivers missing work and experiencing economic hardship (Graves et al., 2020). This is important to consider as increased parental stress plays a role in the child recovery following concussion (Brown et al., 2013). A recent systematic review also found that remote interventions may improve caregiver stress outcomes, and maybe as effective as in-person intervention in supporting caregivers of adults with TBI (Suntai et al., 2021). Virtual interventions and data collection sessions reduce the burden of family participation by minimizing time and distance barriers (Graven et al., 2021). Online delivery limits the family physical journey and transportation costs to receive the required care. In addition, it allows for families to receive the intervention from the comfort of their own home (Retamal-Walter et al., 2022), which is a feature that was emphasized by parents in *M&C-C*. However, a few participants did mention that meeting face-to-face may contribute to enhanced connections directly or indirectly, like waiting in the session room or walking together to the car. Nevertheless, it seems even these parents felt the convenience and safety of virtual interventions outweighed these potential benefits, especially given past and ongoing pandemic considerations.

6.4.2 Intervention Engagement

The category of *M&C-C* Intervention Engagement describes the interactive experiences among caregivers in terms of psychoeducation and commonalities of experiences.

6.4.2.1 PPCS Education. Findings demonstrate that caregivers valued the education received in the intervention group, as presented by facilitators. Specifically, the psychoeducation shared in the group was described to be applicable and relevant to caregivers' daily life. Participants emphasized the importance of complementing the chosen topics with statistics (e.g., prevalence and incidence rates) and references of empirical studies. Another important feature of *M&C-C* education is its broad curriculum, which is based on the theoretical foundations of biopsychosocial approach (Conder et al., 2020) and the FAB model (Fisher et al., 2019). These frameworks are applicable to concussion management (Register-Mihalik et al., 2020) and provide a scientific-based intervention to support families' well-being. Participants felt that the topics aligned with their areas of educational interests and need, including school advocacy, mental health, and impact of concussion to many important life domains (i.e., concussion ripple effect). Caregivers value evidence-based information about concussion symptoms and management addressing identified educational gaps, like, parents having limited knowledge about persistent concussion resulting in difficulty communicating with school staff to advocate accommodations and support for their child (Miley et al., 2008). Also, the topic of mental health and concussion was of high relevance to parents, as PPCS can lead to increased feelings of anxiety and depression among youth (Chrisman et al., 2021; Sheldrake et al., 2022). The concussion ripple effect covered information related to PPCS sequelae and recovery as well as exploring the impact of concussion injury on the family as a whole (Minney et al., 2018). In general, psychoeducation for caregivers of youth dealing with mTBI have been shown to be beneficial. For example, '*Concussion & You*' is a self-management education program designed to instruct youth and their caregivers on concussion recovery (Hunt et al., 2016). However, the impact of psychoeducation interventions on families dealing with PPCS specifically remains to

be investigated (Kamba & Plourde, 2022). *M&C-C* is a first step of value that provides psychoeducation to families of youth with PPCS.

   6.4.2.2 Commonalities of Experiences. Participants expressed appreciation about being able to meet other parents with similar lived experiences. Parents were able to connect, learn from each other's experiences, and express their concerns and worries in a safe environment. They reported that this group-based program helped them realize that they are not alone in supporting their child experiencing PPCS. This is consistent with past studies that have shown that peer-support programs may be particularly beneficial in this population to help foster information sharing and social support because it promotes feelings of connectedness and understanding (Bellon et al., 2017; Brown et al., 2013; Jordan & Linden, 2013). Similarly, findings of Aitken et al. (2004) demonstrated that caregivers desire peer support and talking to other families with similar experiences throughout the recovery process. This is because parents benefit from a common venue to share their feelings about their child injury and its impact on their lives (Bellon et al., 2017). In a qualitative study that aimed to broaden the understanding of caregiver support of youth with ABI, findings identify the value of a peer support network where they can share their experience with others and to instill caregivers with encouragement and hope (Gan et al., 2010). Given the qualitative findings where parent participants felt alone as they managed their youth's PPCS prior to *M&C-C* participation, as well as the emphasis of increased belonging during *M&C-C* sessions, this study highlights the need to provide caregivers with the space to connect with one another and exchange experiences. In fact, one of the major suggestions to improve *M&C-C* was to provide caregivers with the opportunity to connect with one another and form friendships beyond sessions' participation.

6.5 Move&Connect-Caregivers Takeaways

The final category, Key Takeaways, covers key lessons learned and insights gained following *M&C-C* conclusion. Parent participants reported increased concussion awareness and personal insights as a result of *M&C-C* participation. For example, parents were able to apply the psychoeducation learned in the sessions to their daily routines. Furthermore, the actions of reflecting on information and connecting to previous experiences enabled them to challenge existing knowledge and patterns. The relevance of *M&C-C* topics allowed parents to engage with the sessions in a personal way that improved their family lives. Consistently, peer-support interventions provide positive outcomes for parents, including improved mental health, decreased feelings of isolation, and enhanced learning (Bellon et al., 2017; Shilling et al., 2015).

6.6 Link to Intervention Mapping

The development of *M&C-C* was guided by IM protocol that involves a systematic planning process (Bartholomew et al., 1998). IM is based on six-steps: (1) needs assessment, (2) program objectives, (3) program design, (4) program development, (5) implementation, and; (6) evaluation. This thesis focused on the fourth step of IM, which involved testing and refining the intervention structure and related content and curriculum of *M&C-C*. This was established through examining feasibility indicators and conducting qualitative interviews to gain participants' feedback on the intervention. Through this step, program materials have been enhanced based on the parents' suggestions and opinions. For example, participants of Group One requested handouts that include key psychoeducation points and additional topics to the curriculum. These suggestions have been implemented and tested with the second group of participants (Group Two). Step Four of IM allowed for modification and enhancement of the intervention material where information was fed back to improve the intervention quality. It also

provided insight and further information to inform an implementation plan for a future pilot study (Fernandez et al., 2019). For example, it was helpful to gain participants' feedback on intervention timing, recruitment approach, and suggestions to improve intervention access. Hence, the next task will include conducting steps Five (Implementation) and Six (Evaluation) of IM, where a pilot-controlled trial, using mixed methods of quantitative and qualitative measures, will be implemented to evaluate intervention effectiveness. It is also important to note that the systematic and rigorous development of *M&C-C* allows for attention to detail, documentation of decisions, and iterative improvements to the intervention.

6.7 COVID-19 Considerations & Study Impact

Like many studies, this thesis was impacted by the COVID-19 pandemic and its associated lockdowns and restrictions. Firstly, participant recruitment was challenging as the affiliated clinic saw a slow-down in referrals reflecting the reduced concussion incidence in the community following periods of intense lockdowns and school closures. Despite this, data saturation was achieved, indicating that the study sample size was sufficient to achieve thesis objectives in accordance with the feasibility literature (Orsmond & Cohon, 2015). Also, COVID-19 emergency measures introduced stress and various burdens to populations at large (James et al., 2020), so it may have slowed down the interest with research participation in general. Conducting the *M&C-C* intervention virtually and associated data collection sessions in a flexible manner (e.g., offering evening and weekend times for data collection booking) helped in mitigating this challenge, and likely promoted the high attendance and data completion rates observed in this study. It is also worth noting a benefit that results from the pandemic, accelerated use of telehealth to enhance accessibility of care (Fernández-Álvarez & Fernández-Álvarez, 2021; Pfender, 2020). Hence, families are adapting well to videoconferencing

technologies, removing basic technology confidence and knowledge as a barrier to intervention participation.

6.8 Strengths

This is the first study to explore caregivers of youth with PPCS experiences participating in a virtual group-based intervention. The feasibility metrics collected were informed by existing feasibility guidelines by Orsmond and Cohn (2015), where key feasibility areas related to recruitment, acceptability, refinement of data collection sessions, administrative capacity, and participants' feedback were considered. The collection and analysis of qualitative data from both groups highlighted caregivers' experience with *M&C-C* in terms of its tolerability, engagement, and benefits. This enabled the incorporation of caregivers' perspectives and opinions from the first cohort to improve the intervention delivery for the second cohort. A future expanded pilot study will also benefit from the accumulated feedback as research demonstrates that listening and incorporating users' feedback and suggestions leads to positive outcomes and improved overall intervention satisfaction (Axford et al., 2014; Bombard et al., 2018; Liverpool et al., 2020).

6.9 Limitations

There are some important limitations worth noting as they relate to the participant sociodemographic factors, like gender, caregiver's role, race, and socioeconomic status.

6.9.1 Gender & Caregivers' Role

In this *M&C-C* feasibility study, our participants comprised of only women caregivers (nine mothers). In general, research demonstrates female bias in research participation; in addition, fathers are underrepresented in pediatric research in comparison to mothers, especially in therapeutic interventions for pediatric concerns (Phares, 1992). There are clear indications to

including fathers in family-based interventions (Phares et al., 2005). For example, research shows that fathers of youth with TBI are more likely to use different coping strategies (e.g., denial) whereas mothers were more likely to prefer acceptance and emotion-focused strategies (Wade et al., 2010). These patterns could be reasonable targets to consider when delivering interventions to caregivers. Consideration and recruitment of diverse families including same-sex parents and single parent families is also necessary. Hence, it is important to target and enroll caregivers in the future *M&C-C* pilot, and to understand their experience with the intervention in relation to their needs. In addition, the *M&C-C* intervention is designed to support all caregivers including mothers, fathers, grandparents, etc., and our study inclusion criteria were open to caregivers broadly. However, the thesis sample size is limited to only mothers participating with *M&C-C.* Although caregivers who are actively caring for family members with health issues are more likely to be women (Sharma et al., 2016), this study sample was not representative of the general population.

6.9.2 Race, Socioeconomic Status, & Age

There is a lack of heterogeneity in the current study sample. Hence, a larger and more diverse sample may have provided further insight into the feasibility of the intervention. A majority of *M&C-C* participants were of Caucasian ethnicities (78%), had a high household income (78% participants with income greater than $90,000), and were highly educated. While this may reflect family demographics seen at the PCC (Agnihotri et al., 2021), youth clients' PPCS presentations are typically complex requiring interdisciplinary care. In general, research demonstrates that there has been little focus on impact of race and ethnicity on concussion (Mollayeva et al., 2018). Moreover, non-English speaking participants who have youth with concussion report difficulty with communication and cultural understanding when receiving

concussion care (Moore et al., 2015). Recommendations to address such barriers include

providing translated materials and increasing cultural humility. Future work will benefit from

understanding experiences of culturally and socioeconomically diverse caregivers with *M&C-C*.

Research also demonstrates that families with lower socioeconomic status experience increased

challenges (e.g. higher rates of youth behavioral problems) following pediatric TBI (Wade et al.,

2020). Hence, to accommodate this in the larger pilot trial, recruitment efforts should be

expanded to the various internal communities residing in Toronto to support families with

diverse backgrounds. In addition, the majority of caregivers' children were teenage girls between

13 – 18 years old. Of note, study participants stated the importance of having their youth be of

close ages in the group as it increases rapport and team harmony. This is an important

consideration for group enrollment moving forward where caregivers could be grouped

according to their child's age (e.g., elementary school, high school).

7.0 Future Directions

This thesis established the feasibility of *M&C-C* through exploring various metrics and

conducting qualitative semi-structured interviews. Based on this feasibility study, there are

several suggestions to improve future PPCS-intervention research. First, intervention mapping is

an iterative nonlinear process; hence, findings from the thesis will help improve a future *M&C-C*

pilot study. Second, while the focus of the current study is not to make statistical inferences

regarding the effectiveness of the intervention, future research should examine the trends of

caregiver outcomes pre- and post-intervention participation. Thus, future directions include

conducting a large-scale pilot study with a focus on outcome evaluations, and the addition of a

control group to assess *M&C-C* efficacy. This may involve a pilot wait-list control design where

control participants would complete the pre-post questionnaires prior to joining *M&C-C.* Third,

the study results were useful in shedding light on outcome measures that could be of value and worth pursuing. For example, qualitative analysis showed that caregivers experienced an increased sense of belonging and connection with one another. Hence, it may be appropriate to include an additional measure looking at the construct of connectedness (e.g., UCLA Loneliness Scale, Russell et al. 1980) in the future pilot study. Fourth, in terms of recruitment, future research should target a broader group of caregivers with diverse backgrounds by using a variety of recruitment methods with the wider community. Fifth, although all caregivers in this study appreciated the online nature of the intervention due to its increased convenience, it is worth examining whether an in-person arm of *M&C-C* would be of interest to families of youth with PPCS. It would be of interest to conduct a head-to-head comparison of outcomes associated with each modality. Sixth, the development of an instructional resource (e.g., toolkit of best-practices) to promote quality facilitation of *M&C-C* would be a necessary guide for future facilitators. Overall, the thesis lays the foundations for a larger evaluation to determine the effectiveness of *M&C-C*, and provides necessary resources to support caregivers.

Conclusion

The thesis aimed to evaluate the feasibility of a virtual peer-support intervention to provide guidance to caregivers of youth with PPCS. It is important to highlight the interdisciplinary, family-centered, and systematic design approach of *M&C-C*, which was developed in partnership with families, and based on scientific principles and clinical expertise. Findings from this study demonstrated that *M&C-C* is a feasible and meaningful intervention for caregivers of youth with PPCS. The virtual format of *M&C-C* was reported to be convenient, accessible, and a safe space to share personal experiences. Participants valued sharing and receiving advice from facilitators and their peers in the group. In addition, they appreciated the

evidence-based psychoeducation provided by facilitators. Intervention outcomes included increased knowledge, personal insight, and feelings of support as reported by the study participants. This is the first step towards clinical implementation of *M&C-C* where the intervention has the potential to combine the benefits of social support, concussion education, past experiences, and advocacy tools in order to produce positive and relevant outcomes as illustrated in the *M&C-C* visual leading to improved care and support to caregivers of youth with PPCS.

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APPENDICES

Appendix A: Move&Connect Sessions Outline

Week 1**:**	
Completion of consent & caregiver pre-intervention questionnaires	60 mins

Week 2**:**	
Introduction to *Move&Connect-Caregiver*	10 mins
• Ice breaker to meet participants and group leaders	
Ground Rules	5 mins
• Establish rules and etiquette for group discussion	
Goal Setting	15 mins
Set goals to achieve by the end of the intervention	
General Education on Concussions and PPCS	25 mins
• Share and discuss any questions or comments	
Take-Home Exercises	5 mins
• Receive handout and return next week with any questions	
Introduction to *Move&Connect-Caregiver*	10 mins
• Ice breaker to meet participants and group leaders	

Week 3 – 6**:**	
Welcome back!	15 mins
• Share thoughts on last week's exercises and goal progress	
Topic Introduction*	20 mins
• Learn about this week's discussion topic and receive hand-out	
• Participate in exercises or activities for the week	
Discussion	20 mins
• Share any questions or comments about discussion topic	
Take-Home Exercises	5 mins
• Receive exercises or activities to practice at home	
Welcome back!	15 mins
• Share thoughts on last week's exercises and goal progress	

*The educational topics discussed in *Week 3-6* will include: Family & You; stress and daily challenges; Parenting is Hard; school advocacy

Week 7**:**	
Welcome back!	15 mins
• Share thoughts on last week's exercises and goal progress	
Topic Summary	10 mins
• What are some skills you acquired? Have you reached the goals you originally set?	

Discussion	15 mins
• Additional resources are shared. Other questions or topics are discussed.	
Debrief	15 mins
• Discuss caregiver experiences (Favorite and least favorite discussion topics?)	
Program Wrap-Up	5 mins
• Reminder about post intervention assessments	
Welcome back!	15 mins
• Share thoughts on last week's exercises and goal progress	

*The educational topic discussed is youth well-being

Week 8:	
Completion of caregiver post-intervention questionnaires	45 mins
Post-intervention exit interview	30 mins

Appendix B: M&C-C Sample Handout

MOVE & CONNECT: CAREGIVER GROUP

Week 5: Stress & Daily Challenges

Learning Objectives:

1. To understand the research on stress after concussion, signs of stress, and symptoms of stress.

2. To identify helpful coping strategies that can be utilized in stressful and difficult situations.

Psychoeducation:

- Research shows that most of family's burden and stress is related to parent concerns about their child's injury. Research indicates that parents exhibited clinically significant stress regardless of the severity of their child's injury.
- The Yerkes-Dodson Law looks at stress, arousal, and performance. The model demonstrates that performance increases with stress but only up to an optimal level. After this point, the level of stress becomes too high and performance decreases.
- Dove-Hawk Model of Prolonged Symptoms Post-concussion outlines two distinct profiles that are often observed.

Notes:

_____

_____

_____

_____

Take Home Activity:

This week try to be mindful of your stress level and how it changes throughout the day and week. Check in with yourself - is there a pattern that you are noticing? The purpose of this activity is not to judge yourself but to just start to notice what patterns might be present.

STRESS LEVEL

LOW   HIGH
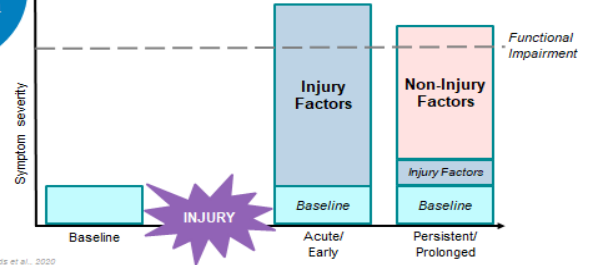
Appendix C: M&C-C Sample Slides

Persistent Post-Concussion Symptoms

o 30% of youth experience persistent post-concussion symptoms (PPCS) which continue beyond 4 weeks post-injury

o Time frame of PPCS includes symptoms persisting for more than 4 weeks in children[7]

o Children and adolescents with PPCS are reported to have difficulty returning to daily meaningful activities

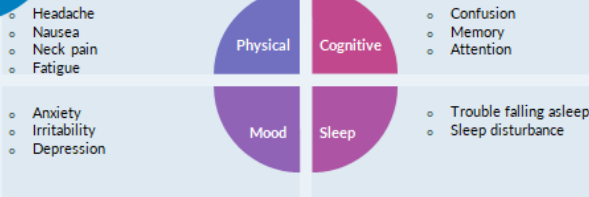o Caregivers can also experience distress, which impacts family functioning

Persistent Post-Concussion Symptoms

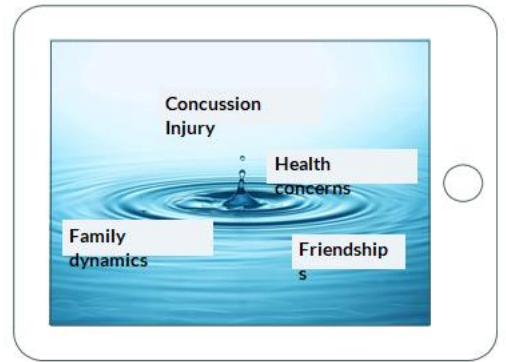*Concussion is a biological injury, but PPCS are maintained by a mix of biological+psychological+social factors*

Symptom severity

Functional Impairment

Injury Factors

Non-Injury Factors

Injury Factors

Baseline

Baseline

Baseline

INJURY

Baseline | Acute/ Early | Persistent/ Prolonged

Adapted from Rickards et al., 2020

Persistent Post-Concussion Symptoms

o Headache
o Nausea
o Neck pain
o Fatigue

o Confusion
o Memory
o Attention

o Anxiety
o Irritability
o Depression

o Trouble falling asleep
o Sleep disturbance

Physical | Cognitive | Mood | Sleep

Persistent Post-Concussion Symptoms

Concussion Injury

Health concerns

Family dynamics

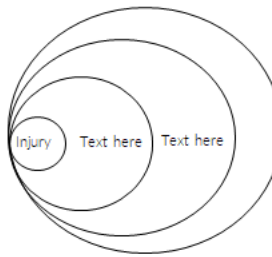Friendships

Take-home reflections

o Complete a ripple diagram

o Email your diagram as a screenshot before the next session

o We will compile the answers (anonymously) and discuss next week

Injury | Text here | Text here

Discussion

What are you leaving with to start the week?

Appendix D: Parent Demographic Information Form

Initials: _____

What is your gender? _____

What is your ethnicity? _____

What is your educational background? _____

What is your annual household income?

☐   Less than 30,000

☐   31,000-50,000

☐   51,000-70,000

☐   71,000- 90,000

☐   91,000-100,000

☐   Greater than 100,000

Have you attended a support group before?   Yes/No

Describe: _____

Do you have any previous experience with therapy?   Yes/No

Describe: _____

The questions below pertain to your child who has a concussion:

What is your relationship to the youth with concussion? _____

What is the gender of your child? _____

What is the age of your child? _____

How was your child's injury sustained? _____

How long ago was your child injured? _____

Appendix E: Interview Guide for Parents

The purpose of this interview is to learn about your experience with the *Move&Connect-Caregiver* program. The questions will be open-ended to allow you the chance to raise the issues that you feel are important. You do not have to answer any question you feel uncomfortable with, and you can stop the interview at any time. Your responses will be confidential and anonymized in any findings we may publish. Your responses will not affect the care your child receives at Holland Bloorview Kids Rehabilitation Hospital. Quotes from the interviews may be used, but it will not be possible to identify their source.

Throughout this interview, I would like to ask you about your experience with the *Move&Connect-Caregiver* program. Please remember that you can share as much or as little as you like because I wish to get your relevant feedback. Please note the interview will be audio recorded so that the research team can keep a record of the interaction. This will let the team review and analyze the interview responses along with other participants' feedback to help with our research study. And, I will be happy to answer any questions. Do you have any questions for me before we begin?

I'd like to get your opinion on the *Move&Connect-Caregiver* program. How would you describe your experience?

- Do you feel that this program was worth your time? Can you tell me more?
- What did you enjoy about the program? What did you not like about the program?

Now, I am interested to learn about your thoughts on the program topics (Ripple Effect, Stress, Family & You, Parenting is Hard, School advocacy and Youth well-being)

Topics: What do you think about the educational topics delivered by program leads?

- Were these topics relevant or applicable to your daily life? Did you find them useful?
- Can you give me an example of a topic you found relevant or useful?
- What additional topics would you like to see included in program?
- What are your thoughts on the 'take home' activities provided?
- Were the 'take-home activities' of benefit to you?
- Do you have any suggestions to improve the psychoeducational component of the program?

Strategies/activities: Now I want to learn about your thoughts with the program activities (Wellness wheel, co-creating handouts, reflections and discussions).

- What did you think about the activities and strategies taught in the program?

- What is your feedback on the discussion content?
- Do you think that you will be able to apply the program activities/strategies to your daily life? Can you tell me more?
- Do you have any suggestions to improve the activity portion of the program?

Handouts: What is your feedback on the program handout and resources?

- Do you have any suggestions to improve handouts or resources feature of the program?

Group: I am interested to learn about your experience meeting other parents with similar experiences in the program so I want to ask some questions related to the group format.

- How did you feel meeting other parents in the group?
- What did you like and not like about the group format?
- Did you feel comfortable sharing your experience in a group setting? Do you have examples to share in terms of connecting with other caregivers?
- If not, what could have been done to better facilitate connections among caregivers?
- Do you have any suggestions to improve the group component?

Online: How was your experience completing this program virtually?

- What are some benefits to delivering the program online?
- What did you not like about the online format?
- Do you have any suggestions to improve your online experience with *Move&Connect-Caregivers?*
- Do you have any suggestions to enhance the programs convenience or accessibility?

What were your initial expectations signing up for this program?

- Now at the end of program: Did your initial expectations change? If yes, how so?
- Are there any expectations or learning objectives that have not been provided that you wanted to learn about?

After reflecting on Move&Connect-Caregiver program during this interview, I'm wondering if you have anything else to add in terms of describing your experience with the program.

- What did you think was the best feature of this program? Why?
- What did you like the least about the program?
- What improvements or changes to the program would you suggest to enhance the program?

Is there anything that we haven't spoken about today that you'd like for me to know?

Appendix F: Questionnaires Description

Measure	Description	Duration
Depression, Anxiety and Stress Scale (42) (Lovibond & Lovibond, 1995)	Measures depression, anxiety, and tension/stress	10 minutes
Family Assessment Device (Berry et al., 2015	Measure of family functioning. Each item is a statement about a family and participants rate how well it describes their own family.	15 minutes
Perceived Stress Scale; Cohen et al., 1983).	A self-report questionnaire of an individual's stress level over the past month	5 minutes
Parental Stress Scale (Zelman & Ferro, 2018)	Measures feelings and perceptions about the experience of being a parent.	3 minutes
Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978)	Measures perceived parental competence	5 minutes
Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)	Measures perceived social support from family, friends, & significant other	4 minutes
		Total: 45 minutes

Appendix G: Data Display
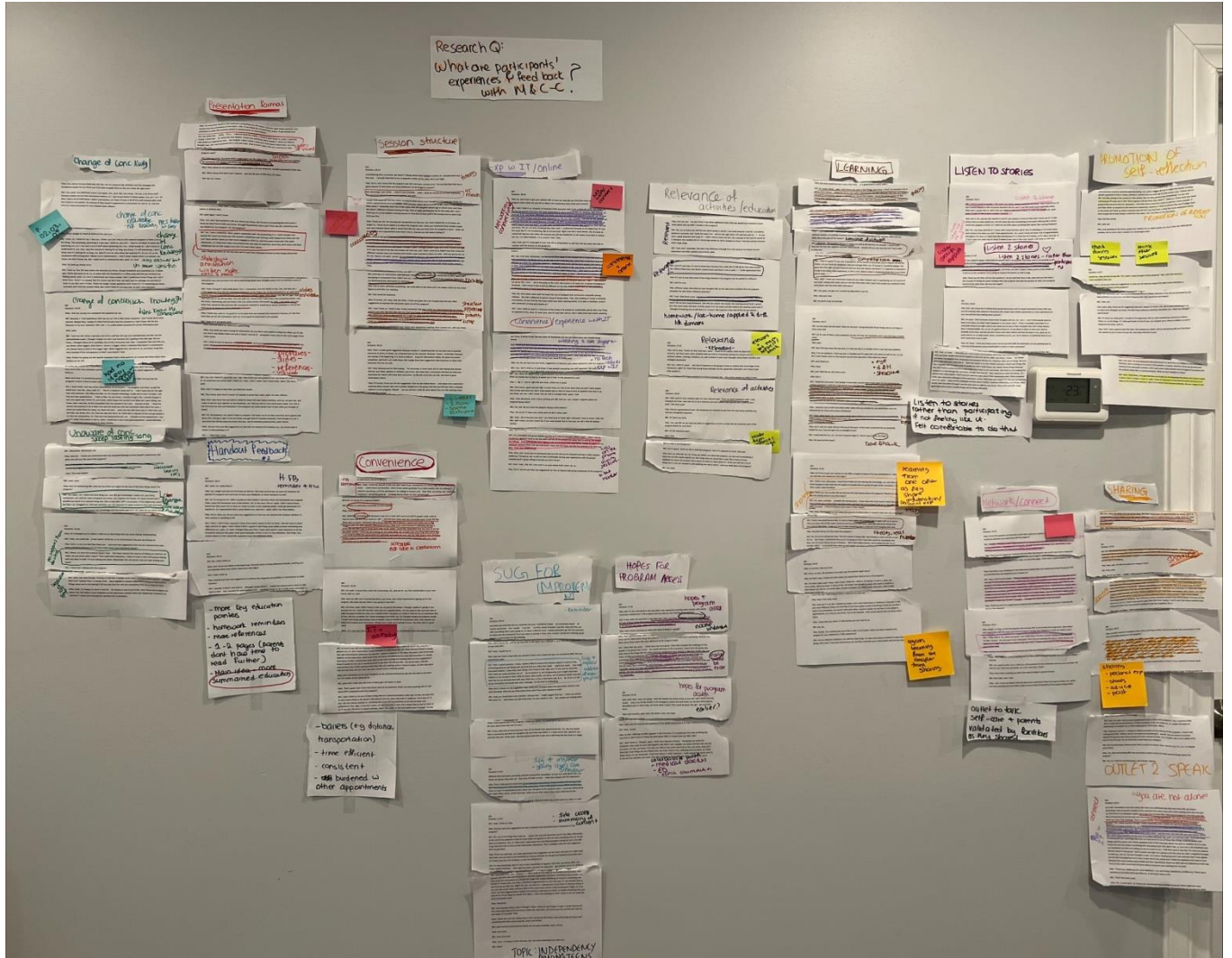
Appendix H: Thesis-related Activities

Awards

1. Canadian Institutes of Health Research Canadian Graduate Scholar - Doctoral Award
2. Canadian Traumatic Brain Injury Research Consortium Scholar Award
3. Canadian Institutes of Health Research Canadian Graduate Scholar – Masters Award

Oral Presentations

1. Move&Connect-Caregivers: The Feasibility of a Virtual Group-based Intervention for Caregivers of Youth with Persistent Post-Concussion Symptoms.	Canadian Traumatic Brain Injury Research Consortium, Winter Meeting.	January 2022
2. The Development of a Virtual Group-Based Intervention for Youth with Persistent Post-Concussion Symptoms and their Caregivers: An Intervention Mapping Approach.	International Neuropsychological Society, New Orleans (virtual).	February 2022
3. Development of a Virtual Group-Based Intervention for Caregivers of Youth with Persistent Post-Concussion Symptoms: An Intervention Mapping Approach	2021 Virtual World Congress on Brain Injury.	July 2021

Poster Presentation

1. Exploring the Feasibility of Move&Connect: Experiences of Youth with Prolonged Post-Concussion Symptoms and their Parents with a Virtual Group-based Interdisciplinary Intervention.	Canadian Concussion Network, Montreal.	June 2022

VITA AUCTORIS

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