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Caregiver Experience with The Applied Coaching Model on Supporting Adherence to Home Exercise Programs for Children with Developmental Delays: A Mixed Methods Research Study

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

Home exercise programs (HEP) are a form of treatment for children with delayed motor, sensory, cognitive, or speech skills. Studies show improvement in developmental and barriers that affect adherence, there is still a lack of standardized rehabilitation models that can address this issue. This interpretive phenomenology study explores the lived experiences of caregivers of children with developmental delays regarding adherence to HEPs. Participating caregivers interacted with therapists using an Applied Coaching Model (ACM), a model of multiple theories focusing on holistic rehabilitative care. Qualitative results of this mixed-methods study identified specific factors that affect adherence to HEPs. Quantitative results found that adherence was associated with increased exposure to the ACM. With these findings, future rehabilitative interventions may be improved by integrating an applied coaching model to increase adherence to HEPs.

Terminologies

For documentation purposes, abbreviations of terms that are included in this study are displayed below (listed in alphabetical order):

Abbreviation	Name of Term
ACM	Applied Coaching Model
FCC	Family Centered Care
HEP	Home Exercise Program
SMART	Specific, Measurable, Achievable, Relevant, Time-bound
TR	Therapeutic Relationship
AIC	Akaike's Information Criterion

Keywords

Home Exercise Program, Adherence, Qualitative Study, Physiotherapy, Occupational Therapy, Speech Language Pathology, Lived Experience of Caregivers, Children with Developmental Delays, Applied Coaching Model, Factors Affecting Home Adherence

Summary for Lay Audience

Home exercise programs (HEP) are a form of treatment for children with delayed motor, sensory, cognitive, or speech skill development. Studies show improvement in outcomes for these children if their families adhere to home exercises. Despite the many barriers that affect adherence, there is still not a specific rehabilitation program model that can address this issue. This study explores the lived experiences of caregivers of children with developmental delays regarding adherence to home exercises using the Applied Coaching Model (ACM), a model that combines multiple theories focusing on holistic care. This study found specific factors that affect adherence to HEPs, and that adherence was associated with increased exposure to the ACM. With these findings, future rehabilitative interventions may be improved to increase adherence level to home exercises.

Co-Authorship Statement

I declare that I, Mackenzie Cheng, have completed this thesis independently with aid from my supervisor Dr. Laura Brunton and my advisory committee consisting of Dr. BJ Cunningham and Dr. Jennifer Irwin. All references and other sources included in my work are appropriately acknowledged as references.

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Chapter 1

1 Introduction

For many children, chronic health conditions present themselves as delayed development in motor, sensory, cognitive, and speech skills which may or may not be long-standing (Sices et al., 2003). Thus, early identification and intervention can assist with achievement of functional outcomes and even reduce potential secondary behavioural challenges associated with developmental impairments (Gmmash et al., 2021; Guralnick, 1998; Majnemer, 1998).

1.1 Traditional Rehabilitation Strategies for Children with Developmental Delays

Current rehabilitation strategies for children with developmental delays vary and are based on a range of neurodevelopmental, pharmacological and biomechanical approaches in which the primary focus is on the child, and to improve functional outcomes by implementing motor, sensory, speech and language-based activities (McGibbon & Law, 2003). Such strategies are utilized differently as developmental delays stem from various aetiologies (Hong et al., 2017). For example, cerebral palsy is a common cause of developmental delay which may affect motor, sensory, cognitive and speech (Rosenbaum et al., 2007) in which physical, occupational, speech-language and neurodevelopment therapy are incorporated (Hong et al., 2017). To improve the functional development of children with developmental delays, rehabilitation therapy is also incorporated into the home setting (Gorgon, 2018).

1.2 Home Rehabilitation Programs

Home exercise programs include tasks that have been prescribed by a physical, occupational or speech-language therapist and are implemented by caregivers in the home setting (Gorgon, 2018; Johnson et al., 2018; Milton et al., 2019; Novak et al., 2009). These home exercises are seen as an opportunity for caregivers to deliver a higher and more

consistent dose of therapy, and as a result have been considered an essential part of the treatment process (Bazyk, 1989; Giller Gajdosik, 1991; Hinojosa & Anderson, 1991; Law & King, 1993; Palsili et al., 2014). The involvement of caregivers who deliver the home exercises has become even more crucial with the recent shift to telehealth during the COVID-19 pandemic (Gmmash et al., 2021). However, despite the positive effects of home practice on functional outcomes, many studies have shown families of children who have chronic health conditions are at risk of low levels of adherence to home exercises (Costello et al., 2004; Galil et al., 2001; Gmmash et al., 2021; Milton et al., 2019; Rapoff & Lindsley, 2007). Poor adherence to home practice can be attributed to factors such as parents' inability to perform such activities, and personal barriers such as lack of time (Rezaie & Kendi, 2020). This problem is compounded for children with long term health conditions such as cerebral palsy because of the extended duration of the prescribed home exercise regimen and lifelong involvement with healthcare providers and interventions (Galil et al., 2001; Santer et al., 2014).

1.3 Factors Affecting Adherence

Findings from several studies have shown adherence to home exercises among children with developmental delays is affected by a range of factors. A study by Taylor et al., (2004) concluded that adherence is affected broadly by environmental and personal factors. Specifically, environmental factors that affect adherence included social and physical support from family members and healthcare workers within the community, whereas personal factors related to the severity of the child's condition, motivation of the child, and the caregiver's daily schedule. Expanding on this, Lillo-Navarro et al., (2015) classified factors that affect adherence into two major categories: the characteristics of the home exercise program, and the therapist's teaching style. Combining and extending this work, Rezaie & Kendi (2020) documented four categories that affect overall adherence to home exercise programs: (1) child and family factors, (2) therapist factors, (3) environmental factors, and (4) therapy factors. Child and family factors consisted of features related to the child or family such as child behavioural status, family structure, and family emotional atmosphere. Therapist factors included skills of the therapist and their job satisfaction in relation to adherence. Environmental factors consisted of cultural view, physicians'

awareness, physical environment, access to therapy, etc. Therapy factors entailed features of the therapy program offered by the therapist such as assessment tools, type of intervention, and length of treatment.

Medina-Mirapeix et al., (2017) found that parental adherence to their children's home-based exercises was reduced compared to studies of adherence to home-based exercises for adults with chronic conditions (Medina-Mirapeix et al., 2009). Many studies suggest this difference may be because parental adherence is affected by both the caregiver and child instead of being solely influenced by the adult (Barton & Fettig, 2013; Gorgon, 2018; Medina-Mirapeix et al., 2017; Rezaie & Kendi, 2020). Examples of challenges faced by parent-child pairs include a mismatch between appropriate times for practice in parent and child's routines or schedules and child behavioural issues (McConnell et al., 2015; Rezaie & Kendi, 2020).

In much of the previous literature, sociodemographic background of caregivers such as caregiver age and socioeconomic status were not directly correlated with adherence to HEPs (Medina-Mirapeix et al., 2017; Rone-Adams et al., 2004). However, parental cognitive factors such as confidence, perception of barriers to adherence, and ability to perform HEPs were found to be associated with adherence levels (Giller Gajdosik, 1991; Law & King, 1993; Medina-Mirapeix et al., 2017). In contrast, studies by Rezaie & Kendi (2020) and Gmmash et al., (2021) found socioeconomic status to be a specific factor that influenced adherence rates as families with higher social wellbeing tended to have a better understanding of their responsibilities during treatment.

Some child factors related to adherence to HEPs include severity of the impairment, mood, and resistance to cooperate with caregivers (Medina-Mirapeix et al., 2017; Rezaie & Kendi, 2020). Numerous studies have found that an increased severity of the child's condition and functional limitation increased parental adherence to HEPs. Medina-Mirapeix et al., (2017), hypothesized that this could be due to the caregiver's strong perception of their role in their child's development. However, in the study by Rezaie & Kendi (2020), home adherence decreased when children had more severe conditions because their response to treatment was slow, which may have caused feelings of discouragement for the family and

decreased motivation to continue with HEPs. Behavioural status of the child is also a factor that strongly relates to levels of adherence as it has been reported to affect the caregiver's ability to support exercises in the home environment (Brossard-Racine et al., 2012; Herring et al., 2006; Rezaie & Kendi, 2020).

It was noted that therapist interaction with parents can play a crucial role in determining HEP adherence (Giller Gajdosik, 1991; Santer et al., 2014). A study by Medina-Mirapeix et al., (2017) aimed to determine whether certain behaviours and characteristics of health professionals affected parental adherence to HEPs. They found that when parents were provided with information about their child's progress and encouragement regarding the completion of HEPs, adherence significantly increased (Medina-Mirapeix et al., 2017). In other studies, caregivers had higher adherence rates when the therapist provided written instructions in addition to demonstrating the HEPs at home with their child (Hinojosa & Anderson, 1991; Taylor et al., 2004). However, this was not the case in the study by Medina-Mirapeix et al., (2017) which showed no association between therapists demonstrating the HEPs or providing written instructions and adherence.

Another important factor that determines adherence is the therapist-caregiver relationship. In the study by Medina-Mirapeix et al., (2017), parental adherence increased when the therapist frequently checked in and inquired about any issues regarding the child and the HEPs. This finding was supported in many other studies that have reported good parental adherence to HEPs when therapists demonstrated clinical competency, had good communication skills, were emotionally supportive, and provided consistent feedback and reassurance (Gmmash et al., 2021; Rezaie & Kendi, 2020).

1.4 Health Coaching

Families of children with chronic health conditions and developmental delays experience increased amounts of parental stress due to the extensive tasks required of caregiving (Raina et al., 2005). Rehabilitation therapists currently rely on theoretical models to develop activities and practices for their clients, many of which already align with the values of family-centered care (FCC) (King, 2009). Although FCC and other various models encourage a holistic view of health and promote a focus on quality of life, few

provide the explicit guidance needed regarding how to achieve this desired functional outcome (Baldwin et al., 2013). Therefore, health coaching may be a possible solution to address this issue.

Coaching originated within the sporting and self-help industries (Griffiths, 2005). Currently, such coaching interventions are prevalent in the behavioural sciences, business and organizational sectors. These interventions have also become more prevalent as a health intervention, especially within the realm of pediatric rehabilitation (Griffiths, 2005; Ogourtsova et al., 2019). Within health and rehabilitation, coaching attempts to move therapists and families towards a more proactive model, in which interventions provide the “how” and necessary steps for clients to feel empowered through their decisions and goal setting (Foster et al., 2013; Gillian King et al., 2019; Milton et al., 2019; Novak & Berry, 2014; Olsen, 2014). The benefits of coaching for caregivers and their children include improved goal setting skills, goal attainment, enhanced problem-solving ability, positive behavioural changes, and overall personal development. These benefits are believed to be due in part to the highly collaborative and participatory nature of coaching (Gmmash et al., 2021; Quick & Macik-Frey, 2004; Rush & Shelden, 2011).

Novak & Honan (2019) found that while occupational therapy-based home exercise programs can be beneficial towards the motor and functional outcomes of children, coaching provides more positive parental outcomes such as stress reduction. In support of this, previous literature also suggests that coaching, as an educational technique, could help improve caregiver self-efficacy and confidence, which could help increase parental adherence to HEPs (Gmmash et al., 2021; Medina-Mirapeix et al., 2017). Despite the budding literature on this topic, there is still yet to be a rehabilitative model that incorporates health coaching to address the facilitators and barriers to HEP adherence. Therefore, coaching and its application to parental adherence must be researched further (Gmmash et al., 2021).

1.5 The Applied Coaching Model

Despite extensive knowledge of the specific factors that affect adherence to home exercises, there is still a lack of transfer of this information to clinical practice in a standardized rehabilitation model. Such a model can help incorporate a holistic approach considering factors such as FCC, learning theory, and a strengths-based approach to help families reach their goals through home practice. Additionally, much of the existing research focuses on generalized behavioural strategies and teaching methods instead of a specific therapist to parent and child approach (Steiner, 2011). Debra Teitelbaum, a pediatric physical therapist at the Alberta's Children's Hospital in Calgary, AB, has developed the Applied Coaching Model (ACM) (Figure 1) based on her clinical experience and extensive review of the research related to health coaching in pediatric rehabilitation (Daviault, 2021).

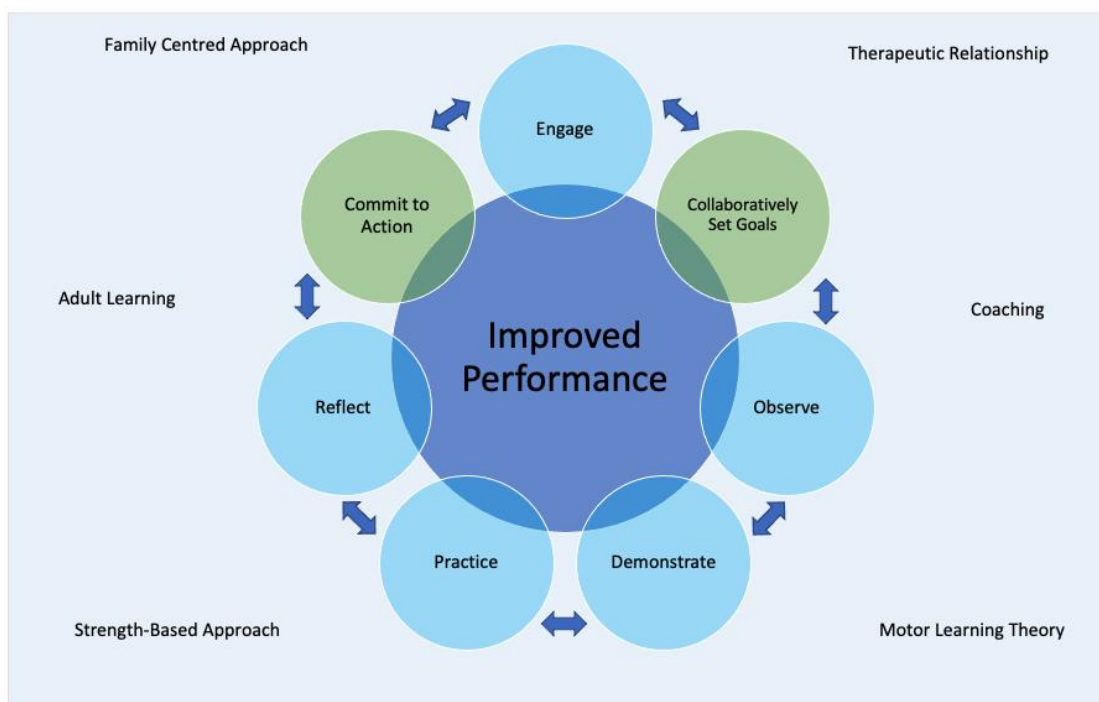


Figure 1: The Applied Coaching Model

The ACM integrates various theories, approaches, and evidence-based practices with the aim of providing well defined steps and concrete therapist actions to operationalize coaching in pediatric rehabilitation. There are six foundational principles that underpin the model including:

Family Centered Care

FCC as a theoretical framework necessitates health and rehabilitation professionals to communicate and negotiate with families actively (Shields, 2010). Although there is yet to be a clear-cut definition of FCC, many health organizations and therapists agree that it is underpinned by similar themes including: (1) the family is the expert on the child and their needs, (2) all families are acknowledged as diverse and unique, (3) children's optimal health outcomes stem from a supportive familial environment and community context, (4) services should be responsive and flexible to the familial environment, and parents can determine their level of participation and decision making regarding their child's health, and (5) healthcare services should take into consideration the needs of the entire family unit (Institute for Family-Centered Care, 2017; Rosenbaum et al., 1998; Shields, 2010). Recently, there has been substantial consideration of parental and caregiver perspectives as a necessity while implementing rehabilitation therapy, as many researchers and healthcare practitioners recognize the significance of the role of the family within the rehabilitative process (Bamm & Rosenbaum, 2008; Gmmash et al., 2021; G. King et al., 2017). Additionally, therapists' position as "expert" has been questioned by a number of communities in the healthcare sphere (Rosenbaum et al., 1998; Turnbull et al., 2000). Under a family-centred approach, therapeutic methods should endorse collaboration between the parents and therapists, where the therapist remains an expert regarding technical knowledge of child development and relevant health conditions and parents are acknowledged as experts on their child and the needs, assets, and values of the family (Rosenbaum et al., 1998). At a minimum, it is expected that therapists consider the context of the family when planning interventions, and that they support the family unit within multiple aspects of the broader community, for example, planning an intervention that can be done despite the parents' busy work schedules (Hanson & Carta, 1995).

The Therapeutic Relationship

The term therapeutic relationship (TR) can be described as the connection between healthcare workers and their patients (McCabe & Priebe, 2004). Factors affecting TR include techniques of the therapist and level of client involvement (Hill, 2005). To cultivate

a strong TR, therapists should demonstrate clinical competency while exhibiting empathy, patience and appropriate communication within a rehabilitation setting (Epstein & Hundert, 2002). However, this alone cannot deepen the TR if the client lacks motivation; thus, client involvement may be considered the most important factor (Hill, 2005). Due to the collaborative nature of rehabilitation, a therapeutic relationship between the family and therapist is important for addressing functional rehabilitation outcomes of the child. Without a strong TR, clients might not trust the therapist's skills and feel uncomfortable going into therapy, which could diminish the treatment's overall effectiveness (Hill, 2005). The concept of TR is extremely important in a family-centred rehabilitation setting where the focus is on the interaction between families and therapists and should be explored when considering factors that affect adherence to home exercises.

Motor Learning Theory

Motor learning theory suggests that a set of actions that are practiced repetitively will contribute to long-lasting changes in movement (Kleynen et al., 2020; Schmidt et al., 2018; Zwicker & Harris, 2009). Related theories include the Closed Loop Theory which explains how motor skills can be acquired through continual practice of the same movement, while the Schema Theory assumes past practice and patterns can aid in the creation of new skills (Zwicker & Harris, 2009). Finally, the Dynamic Systems Theory emphasizes that interactions between both personal and external factors affect the child and parent's ability to reach the intended outcomes (Elman, 2003; Thelen, 1989). Thus, the environment, characteristics of the child and parent, and nature of task or therapeutic activity can serve as either a barrier or something that cultivates goal attainment (Aydin & Nur, 2012). Combining the elements of these theories of motor learning we can establish that for a child to successfully reach their goals all aspects of the individual(s), therapy, and environment must be carefully considered (Aydin & Nur, 2012; Bottos & Gericke, 2003; Morgan et al., 2016; Yang et al., 2013). Furthermore, general tenets of these motor learning theories emphasize the need for repetitive practice to make developmental and functional gains (Kleynen et al., 2020; Zwicker & Harris, 2009). This principle has been incorporated into The Applied Coaching Model as it relates to parent learning and repetition of practice to gain skills.

Strength-Based Approach

Many models of assessment and treatment in the rehabilitation sphere focus on a child's functional deficits. In contrast, the strengths-based approach views all interactions through a positive lens, working with the child and family to identify areas of competence that can be used to facilitate goal achievement in other areas (Steiner, 2011). Furthermore, there is evidence to suggest that caregivers who are coached to view their child's condition optimistically display success in mitigating negative outcomes such as feelings of anxiety and stress (Gray, 2006; Lawton et al., 1991; Steiner, 2011). Using such strength-based approaches can improve parents' quality of life as it provides an opportunity to voice any personal concerns or goals regarding their child's rehabilitation process (Steiner, 2011). This approach is especially useful for parents of children with chronic conditions such as autism spectrum disorder as related stressors are usually long lasting and difficult to overcome (Gray, 2006; Hastings et al., 2005; Steiner, 2011).

Adult Learning

Learning styles between adults and children differ due to factors such as maturity and life experiences. Specific to this study, adult learning is a useful concept as therapists need to engage adult family caregivers during rehabilitation sessions, specifically when prescribing therapy activities to complete independently with their child in the home setting. The concept of adult learning identifies specific qualities that should be considered when developing educational programs for adult learners including self-directed learning and readiness to learn (Cox, 2015; Wang, 2011). Self-directed learning refers to adults' ability to learn new concepts independently while readiness to learn relates to the idea that adults already have a reservoir of knowledge based on their past experiences which can be a strength when learning new concepts (Cox, 2015; Wang, 2011). Adult learning principles should also be considered when developing interventions aimed at changing parenting skills such as creating a healthy parent-child relationship. These relationship-focused interventions can be useful in alleviating feelings of caregiver burden and are therefore important to offer also in addition to

focusing on children's functional and developmental outcomes (Tétreault et al., 2003; Whittingham et al., 2011).

The ACM model is comprised of seven stages including Engage, Collaboratively Set Goals, Observe, Demonstrate, Practice, Reflect and Commit to Action. Therapists and families generally start at Engage on their first session but may enter the model at any other stage on subsequent sessions and focus on one or more stages within any given session. The seven stages are presented in more detail below.

1.5.1 Engage

Within Engage, the therapist initiates contact with the family and develops rapport. It is important to establish good rapport for the family to feel safe enough to articulate their concerns and identify the child's strengths and family goals regarding their child's development. The therapist engages in active listening where they acknowledge potential barriers in the rehabilitation process. Taking a family-centered and strengths-based approach is crucial as this stage involves establishing roles and expectations with the family in a collaborative and respectful way that helps to define the TR.

1.5.2 Collaboratively Set Goals

Goal setting is an essential step in the ACM where the therapist acknowledges the family as experts in their child's health, explores possible hopes and provides guidance for the family. Before any goals are set, an assessment of the child is completed, and parents are asked to summarize the child's skills. During this stage, principles such as coaching and adult learning are emphasized, with the duties of the therapist consisting of explaining the developmental sequence in relation to the child, providing clinical expertise, and assessing the family's capacity. Goals are then negotiated, shaped, and agreed upon by both parties, and formatted in accordance to SMART guidelines: Specific, Measurable, Achievable, Relevant, and Time-bound. Other key principles involved in this stage include FCC, strength-based approach, and therapeutic relationship.

1.5.3 Observe & Demonstrate (integrated)

The Observation and Demonstration stages are where the therapist observes the child and parents' skills, explains the context for and importance of learning new activities and demonstrates strategies to the family. The coaching principle underpins this stage as the therapist's responsibilities include narrating the environmental set-up required for different activities, such as identifying necessary tools and equipment and encouraging parents to be active participants in their child's care. FCC and adult learning principles are also incorporated as the family and therapist observe each other's actions, and performance of the demonstrations.

1.5.4 Practice & Reflect (integrated)

During the stages of Practice and Reflect, the therapist encourages the family to imitate the prescribed home exercises and practice any handling or specific activities during therapy sessions while providing supportive feedback towards the family and child's dedication. Families are encouraged to ask questions to solidify their understanding of the activities and the therapist's role is to provide support and encouragement to enable family members to reflect on their practice and identify their concerns to elicit relevant and helpful feedback. As such, coaching, adult learning, FCC, motor learning theory and strength-based approach all play an important role during these two stages.

1.5.5 Commit to Action

Commit to Action is the final step in the cyclical framework where the SMART goal(s) is summarized and together parents and the therapist create an actionable plan to achieve it, as a precise plan is more likely to provide opportunity for success. The therapist reviews the prescribed activities with the family and adjusts where needed. During this stage, the therapist cultivates the TR and demonstrates the values of FCC by offering options to support the family when they undergo the prescribed home exercises alone, such as providing photos, videos, diagrams, and handouts. As this is an ongoing journey, scheduling regular follow-up with the family is also recommended to document and celebrate improved child functional outcomes and set new goals as appropriate.

1.6 Purpose and Research Questions

To date, numerous barriers to adhering to home exercises for children with chronic health conditions have been identified including severity of the child's condition, family emotional atmosphere, clinical competency and type of intervention (Medina-Mirapeix et al., 2017; Rezaie & Kendi, 2020). Treatment effectiveness for children under the age of five is primarily determined by their caregivers' adherence to home exercise programs, which is affected by their knowledge and competence regarding the assigned tasks (Rezaie & Kendi, 2020). However, many studies fail to explore and challenge the intricacies surrounding barriers such as lack of time and family emotional atmosphere from the perspective of caregivers (Law & King, 1993; Palsili et al., 2014; Peplow & Carpenter, 2013; Rone-Adams et al., 2004). Despite the growing interest in promoting adherence to home exercises to maximize outcomes for children with developmental delays, there is limited literature on specific evidence-based and practical models that can support therapist delivery of health coaching and its effectiveness within pediatric rehabilitation (Ogourtsova et al., 2019). Therefore, it would be advantageous to explore the lived experiences of caregivers who are faced with the task of completing home practice suggested by therapists who practice using the ACM model. It is also prudent that potential barriers to adherence be identified so they can be addressed in future iterations and implementations of the ACM model.

This study aims to (1) explore and make meaning of caregivers' lived experiences surrounding adherence HEPs among children with developmental delays, including experience with the Applied Coaching Model and (2) measure parental adherence and factors related to it under the use of the Applied Coaching Model.

Therefore, two research questions are defined:

- (1) What are caregivers' lived experience adhering to HEPs focused on the rehabilitation goals of their children? (*Qualitative Component*)
- (2) Does the use of the ACM influence adherence outcomes for children with developmental delays? (*Quantitative Component*)

Chapter 2

2 Research Methods

A mixed methods triangulation design was used, such that qualitative data was the primary focus and quantitative data was used to support the qualitative findings (Creswell & Plano Clark, 2007). A phenomenology, from an interpretivist lens, was conducted in the qualitative portion of the study. Furthermore, hermeneutics, also known as the study of interpretation, was chosen within the phenomenological approach as it allows us to focus on the various methods people use to understand and view phenomena (Paterson & Higgs, 2015). This theory was chosen because our study aimed to interpret caregivers' experiences with the Applied Coaching Model (ACM) and their adherence to the prescribed home exercise programs. The convergent model (of triangulation mixed method designs) was used such that both qualitative and quantitative data were first analysed separately and then converged to validate results pertaining to understanding caregivers' experience and factors associated with adhering to HEPs. During participant recruitment, data collection, and analysis, strategies were put into place to ensure the study was conducted in an efficient and ethical manner, including the safeguard strategies discussed below in sections 2.3, 2.4, 2.5 and 2.6.

2.1 Participant Recruitment

Convenience sampling was used as a recruitment approach. To have been eligible for this study, caregivers must have been supporting a child with a developmental delay and have been engaged in a rehabilitative home exercise program using the ACM. We did not aim to seek representativeness when recruiting our participants (Wright-St Clair, 2014) for this mixed methods study. Instead, we invited all participants who expressed interest in participating and shared an understanding of being a caregiver while having diverse and unique experiences based on personal factors and events such as differences in family structure and children of different ages with varying developmental delays. Seven participants were recruited by a member of their circle of care at the Early Childhood Rehabilitation Program at the Alberta's Children's Hospital in Calgary, AB. More

specifically, therapists who were participating in an implementation evaluation of the ACM recruited caregivers and children from their active caseloads to participate in the study. The demographic distribution of the participants is summarized in Table 1 below.

Table 1: Participant Demographics

Variable	Number (%)
Caregiver Gender	
Female	7 (100%)
Caregiver Education	
No Diploma	1 (14.29%)
Bachelor's	5 (71.43%)
Not Stated	1 (14.29%)
Child Sex	
Male	5 (71.43%)
Female	2 (28.57%)
Mean Child Age in Months	14.67 (M; SD = 5.73)
Child Health Condition*	
Prematurity	3 (42.86%)
Global Developmental Delay	2 (28.57%)
Epilepsy	1 (14.29%)
Visual Impairment	2 (28.57%)
Chronic Lung Disease	3 (42.86%)
Chromosomal Deletion	1 (14.29%)
Agenesis of the corpus callosum	1 (14.29%)
Periventricular leukomalacia	1 (14.29%)
Ectrodactyly	1 (14.29%)
Relationship with Child	
Natural Mother	7 (100%)

Abbreviations: M, Mean; SD, Standard Deviation

***Note:** Children could have more than one health condition

2.2 Position of the Researcher

Pertaining to the qualitative portion of the study, an interpretivist paradigm considers multiple perspectives and views them as equally valuable rather than seeking a single truth (Ponterotto, 2005). Hence, a qualitative phenomenology informed by an interpretivist paradigmatic lens was conducted with caregivers who engaged in rehabilitative home exercises with their children with developmental delays. Such a methodology was ideal for this study because, it sought to understand core phenomenon through many individuals' lived experiences. Furthermore, ontology is the study of "the nature of reality and being" and is used to assess the meaning behind a phenomenon (Ponterotto, 2005, p.130). Thus, an ontological mode of inquiry was used to illuminate the taken-for-granted meaning of being a caregiver during the semi-structured interviews.

2.3 Data Collection

Qualitative data (interviews) were collected once during this study, after implementing the ACM for a period of one to three months.

Due to the COVID-19 pandemic, semi-structured interviews were conducted with caregivers individually using online video teleconferencing software (Western Zoom Corporate). Each interview lasted approximately 30 to 40 minutes. The interviews were audio-recorded and had live transcription service enabled so the researcher could participate in the moment but still facilitate transcription and analysis of the data. The semi-structured interview approach provided a guide but still allowed opportunities for further topics and questions to emerge during the interview process (Wright-St Clair, 2014). Interview questions were open-ended to ensure inclusiveness of data collection regarding the caregivers' description of their lived experiences, and information concerning lifestyle routines related to HEPs. For example, caregivers were able to describe their experience with their therapist, specifically how they affected adherence to their child's prescribed home exercises. The initial semi-structured interview guide was adapted from Peplow & Carpenter, (2013) and can be found in Appendix A.

To support the qualitative findings from the semi-structured interviews, a weekly quantitative electronic survey was sent out to participants. The surveys included: (1) a visual analogue scale where participants indicated the percentage of expected home practice sessions that were completed that week, and (2) questions pertaining to each of the four factors identified by Rezaie & Kendi (2020) to identify the barriers to adherence encountered while doing their child's prescribed home exercises: child and family factors, therapist factors, environmental factors, and therapy factors.

The student researcher conducted practice interviews and meetings with other members of the Child Health, Exercise and Rest (CHEaR) Lab, and consulted the advisory committee regarding potential interview questions and topics before beginning any dialogue with participants. The student researcher also consulted with their supervisor throughout the interview process. During interviews, the student researcher avoided controlling the conversation and refrained from exerting pressure on the participants as the aim was to invite the participants to share as much as possible regarding the research topic (DiCicco-Bloom & Crabtree, 2006). Instead, the student researcher took on the role of an active listener to encourage the rearticulation of caregivers' lived experiences of supporting their child during home exercise programs (HEPs).

2.4 Data Analysis

Specific to this study, a mixed methods triangulation design was chosen as it allows the comparison of qualitative and quantitative findings to attain unique but complementary data to better understand the caregiver perspectives on adhering to HEPs (Creswell & Plano Clark, 2007).

The interviews were transcribed verbatim using Western Zoom Corporate's live transcription function, with the student researcher reviewing and correcting as needed. Using coding software (NVivo 12, QSR International), transcripts were read and re-read by the researcher to generate relevant codes to group thoughts into corresponding categories. The anecdotes formed by these categories were then explicated and interpreted to highlight the everyday experiences of the caregivers with adhering to home exercises

during the use of a coaching model. This process involved selective reading by the researcher as she analysed the interviews and gathered all relevant ideas, experiences, and phrases to generate multiple broad themes that related to the meaning of the participants' experience. In keeping with the interpretivist approach, data collection and analysis occurred simultaneously as this qualitative phenomenological study was inductive, deductive, and iterative in nature.

Quantitatively, descriptive analysis was performed on the continuous data from the weekly questionnaires. A mixed effect regression model helped determine if adherence was associated with increased exposure to the ACM model (time), with fixed factors as time (week) and variable factors as therapist and parent's self-reported efficacy rating for confidence in performing the home exercise program at the onset of the study. To identify the best fitting model, two mixed models, one model including all the fixed and variable factors above, while the other only included time as a fixed factor, were run using SPSS software (IBM). The model with the lower Akaike's Information Criterion (AIC) value was chosen as it reflects how much error is left in the model (Lohse, 2021). Participants' individual survey responses were plotted as time series graphs to conduct visual analyses.

2.5 Strategies for Validating Findings

In line with an interpretivist paradigm, communicative validity becomes a significant factor to consider when determining the quality of research findings (Kvale, 1995). The hermeneutical approach considers valid knowledge to stem from conversations among participants specific to their discourse and argumentation (Sweeney, 1972). Hence, such communicative processes regarding social reality become the pinnacle of how knowledge is obtained and understood (Kvale, 1995).

Several strategies were utilized to ensure the validity and accuracy of the research findings. As an interpretivist approach was used, validation of data did not pertain to a single truth or reality (Tracy, 2010). Instead, member checking helped to reveal new perspectives and enlighten researchers and participants, and provided an opportunity to engage in more profound analyses (Miller & Dingwall, 1997). Thus, member checking was an occasion for reflexive discussion and collaboration (Tracy, 2010). Member checking was conducted

with all participants during the interview process, allowing participants to retract elements in their narrative that they no longer believed to be a true depiction of their caregiver experience (Birt et al., 2016).

In qualitative research, reflexivity is a highly essential skill that helps researchers embrace their role in co-constructing meaning (Morrow, 2005). In addition to member checking, the student researcher, engaged in bracketing to ensure they made their internal assumptions and biases explicit. Bracketing is a qualitative research method that can help reduce preconceptions concerning the research and may help to increase the rigour of the study (Tufford & Newman, 2012). To accomplish this, consultations with the advisory committee and research supervisor were conducted on a bi-weekly basis during the data collection and analysis phases (over a 4-month period) to encourage critical discussion regarding the research process. Such discussions involved exploring all possible interpretations of the data collected.

2.6 Anticipated Ethical Issues

When beginning this research, several safeguards were put in place to protect the participants involved in this study: (1) consent was provided both verbally and in written format only after participants had the study described to them and a chance to ask questions of the research team to ensure informed, voluntary consent, (2) confidentiality was enhanced by the use of pseudonyms when referring to the participants to protect their identities effectively in all stages of data analysis and reporting of research findings, (3) all participants were informed on the data collection process, including how data was incorporated into the study and how data will be stored and deleted after the study and (4) the rights and interests of the participants were prioritized during the entire research process before decisions were finalized. If unforeseen issues arose, participants were able to withdraw from the study and have segments removed from the transcript at any time.

Although participants were caregivers over the age of 18, their stories included experiences shared with young children up to the age of five. Children are considered a vulnerable population. Thus, all participating researchers completed human research ethics training

before beginning this study to ensure procedures related to protecting the privacy and confidentiality of participants were followed.

In addition to gaining consent and ensuring our participants' privacy and confidentiality, we also strived to protect their mental well-being during research interactions. During data collection, such issues are often difficult to distinguish due to their subtle nature and may not seemingly be recognized as ethical predicaments (Guillemin & Gillam, 2004). Potential harm towards participants in a qualitative study usually surface through interaction during the interview process. Thus, participating researchers must be sensitive to such "ethically important moments" and be able to effectively articulate themselves to successfully handle these issues if and when they arise (Guillemin & Gillam, 2004, p.262). Thus, the participating researchers must undergo the necessary ethics training and remain respectful towards the participants, especially when the content of what is being discussed may be considered sensitive. To ensure heightened sensitivity towards such capricious topics, the use of reflexivity as a skill may improve the researcher's awareness regarding their own preconceptions and assumptions about the caregiving process (Phelan & Kinsella, 2013). The student researcher accomplished this by keeping a reflexive memo to reflect on her thoughts throughout multiple stages of data collection and analysis, such as before and after conducting the interviews and during and after transcription.

It is important to note that the initiation of this project did not stem from the participants nor solely benefit them on an individual basis. Furthermore, the nature of the interview process required interrogation, as participants shared their lived experience within a social setting in an unnatural manner (Kellehear, 2019). As such, the circumstance of this research study could have been deemed ethically questionable (Guillemin & Gillam, 2004). However, the aim of this qualitative study was of good intention in which the results can benefit a particular group of individuals within the healthcare and rehabilitation community. Regarding participant recruitment, interaction with gatekeepers may be another anticipated ethical dilemma as researchers must obtain their consent and develop a good rapport before securing access to a safeguarded population (Reeves, 2010). As participant recruitment for this study was completed by therapists in the Early Childhood Rehabilitation Program at the Alberta Children's Hospital through their circle of care, the method of participant

selection raised some ethical barriers. It could have negatively affected the integrity of the sample because the therapists acted as gatekeepers, only providing referrals to their patients instead of allowing the researchers to actively invite whom they see fit (Abrams, 2010). To manage this, researchers strengthened their relationship with such gatekeepers and educated them regarding research integrity and their role in participant recruitment (Abrams, 2010). Through this, gatekeepers should have gained a better understanding of participant sampling specific to this research study. Recruiting therapists also used a “Consent to Be Contacted” script standardizing the way they invited potential participants to minimize coercion during participant recruitment. Invited caregivers were unaware of their healthcare provider’s participation in the study until consenting to be contacted by the research team, who ultimately obtained consent, reducing any coercion that may have been perceived by families and providing another opportunity to decide not to participate in the study. Finally, caregivers were told that their therapists would not see or analyze any data that they provided in the study (including their experience or adherence data).

Problems regarding the power balance between the researcher and participant during interviews also posed some ethical concerns (Nunokoosing, 2005). Due to the interview’s semi-structured format, the researchers maintained some degree of control over how knowledge was constructed (DiCicco-Bloom & Crabtree, 2006; Nunokoosing, 2005). However, as ethical and responsible researchers, we must possess the ability to extract valuable and meaningful information during our interactions with participants while abstaining from the exploitation of their person in the process (DiCicco-Bloom & Crabtree, 2006; Nunokoosing, 2005). To better manage this, each interview session began with an allotted time for rapport building between the researcher and participant to diffuse any tension and minimize the power imbalance. For example, some topics discussed before the interview included basic questions about the child, a background description of who the researcher was and the context for this study, in addition to allowing time for breaks or clarification and the use of member checking as previously mentioned. Additionally, open-ended questions allowed participants to take the lead; participants explored their stories through their own words and lived experiences, giving them a sense of control while distributing the power among both parties. (Phelan & Kinsella, 2013).

2.7 Role of the Researcher

As the student researcher who conducted this qualitative phenomenological study, my background knowledge as a recent graduate of the University of Western Ontario's undergraduate Rehabilitation Sciences Program proved relevant to this research topic. I wanted to understand other people's lived experiences as caregivers supporting young children with chronic health conditions to better understand if current rehabilitative care could be improved in relation to child functional outcomes and caregivers' adherence to HEPs.

I have previously worked with children under the age of six with chronic health conditions such as cerebral palsy and have worked closely with rehabilitation professionals and witnessed their interactions with the children. From my courses in my undergraduate career, I also understand that the therapists are only one piece of the puzzle in determining rehabilitation success, and the family and child also play a significant role. I wanted to pursue this interest even further while I worked towards my graduate degree and interacted with caregivers. Furthermore, this study's findings did not only add to my general knowledge but also helped discover new perspectives for improving pediatric rehabilitation for children with chronic conditions and developmental delays, which can potentially enhance service delivery for these families.

Ultimately, specific to a phenomenological study, my role as a researcher during interviews played an integral part in determining the quality of findings. My experiences with this specific population potentially affected this study's findings as I might have been inclined towards particular topics of conversation, which influenced me to actively seek out answers supportive of the caregivers' stories or came to favourable conclusions. However, as a responsible researcher, I took an interpretivist stance and transcended my current knowledge, opinions, and assumptions to effectively resonate with my participants. In other words, I became an interviewer worthy of eliciting true character to effectively communicate and create meaning to the stories of participants (Nunkoosing, 2005). To do so, I engaged in a pre-understandings interview with my research supervisor before beginning the study, to confront my own assumptions to gain a more profound

understanding of knowledge being shared (Wright-St Clair, 2014). Throughout the research process, I, as a novice researcher, wrote field notes after each interview, which I returned to and used to contextualize the analysis. I was also in regular contact with my advisory team to ensure the study progressed in a smooth and coherent manner with attention to quality criteria for qualitative research.

Chapter 3

3 Research Findings

3.1 Qualitative Findings

Five participants consented to be interviewed between February to April 2022. Member checking provided no changes to the data to be analyzed. After collecting, organizing, and analyzing the data, 10 specific themes were created through inductive coding. The 10 themes were then deductively organized into the four main themes based on the factors identified by Rezaie and Kendi (2020), 1) Child and Family factors, 2) Therapist factors, 3) Therapy factors, and 4) Environmental factors. No changes were made to the original coding structure and theme development through the process of bracketing, reflecting on the pre-understandings interview and discussions with the research team. Table 2 lists the main themes, subthemes (original 10 themes), and the number of mentions across all interviews.

Table 2: Extracted Themes and Subthemes

Themes	Number of Mentions Across All Interviews
Child and Family Factors	622
Caregiver Mindset	324
Child Status	189
Family Member Involvement	109
Therapist Factors	463
Clinical Competence	311
Communication Skills	152
Therapy Factors	143
Type of Intervention	87
Supportive Equipment	31
Flexibility of HEP	25
Environmental Factors	67
Physical Environment	40
Access to Therapy	27

Note: Subthemes flagged red, green, and black represent barriers, facilitators, and both, respectively.

3.1.1 Child and Family Factors

The most prevalent theme discussed in relation to adherence to home exercise programs (HEPs) included factors relating to the child and family. The following three subcategories are described below.

Caregiver Mindset

Data suggested that the mindset of the caregiver was an influential factor that determined adherence to HEPs. All participants shared their experiences and opinions regarding their ability to perform the prescribed exercises with their child at home. This included their perceived confidence level, skills in carrying out the HEP and their overall motivation to adhere. For example, while many caregivers admitted to challenges adhering to their HEPs, they also expressed their understanding of the role HEPs had on their child's development.

It takes a lot of patience because of what he's gone through [...] so it's just taking him a lot slower and a little bit more time, but he's proving that he can do it. Seeing him progress really turned things around and made me feel like, you know it. It is paying off, it is paying off and that he's gonna get there at his own pace. – 1002

With this understanding, caregivers shared their experiences and the need for creativity and patience to persuade their child to cooperate. One participant said:

[Regarding] some exercises that [are done] with her, I kind of have to be creative to get her to participate. I'll just pretend that [...] I'm feeding the doll, and then she'll like oh okay she wants to feed the doll now so she'll get the spoon and I'm like oh now we'll feed [child] and then she eats like that so I try to kind of make it seem like she's leading it all. - 1000

The participant also shared her experience of understanding her child's interests and using them as a way to engage the child and promote adherence:

[Regarding a strengthening HEP that involved stairs] I tried putting toys and whatever [on top of the staircase]. It didn't work so I actually grabbed the cat, because [child] loves the cat. I put him on top of the stairs, and she just jetted up the stairs, like she just crawled right up like no fear nothing. - 1000

Some caregivers expressed their struggles with completing certain exercises alone at home with their child, explaining how their confidence affected adherence. One participant said:

I remember [how to perform the HEP in therapy], then [...] I got home, and I kind of forgot [the] actual step. Sometimes when you are doing them at home, you think you're doing it properly but then sometimes you might not be doing it properly. But when we were [at therapy], when [the therapist] was doing it seems like "oh, it's so easy", and we go home sometimes it's like I thought it was that's how it works but that it just doesn't seem right. – 1007

Despite the challenges with HEP adherence, caregivers expressed their motivation and desire to continue adhering to see improvement in their child's functional outcome.

[Regarding goal setting] this is what I want him to achieve and then [therapist] guiding me. It was on me because I'm like well - I want, I set these goals. So, in order for [child] to

achieve that, and shape the goal that I've set, I need to do these exercises, no matter what
– 1002

Child Status

Some participants shared that the extent of their child's condition affected their ability to adhere to prescribed HEPs. Such conditions included motor limitations, speech limitations and developmental delays that caused behavioural outbursts. In most participating families, children's behaviour occasionally made them either uncooperative or unresponsive to treatment at home. One participant said:

Sometimes [child's] behavior would make it harder to do such exercises. When we first started, she doesn't like being told what to do, even when I touch her arms or legs and I tried to put her in a certain way, she does not like that. I had to actually physically hold her so that she wouldn't squirm away. - 1000

Another participant said:

Sometimes [the reason for lack of adherence] was behavioral because he was having tantrums so I couldn't push some of the exercises. Sit-ups worked for a while, but then he didn't want to do them correctly anymore, no matter what I did. He [...] thought it was a game so he wouldn't come up anymore. He just laid like a dead body, so you know it wasn't really doing anything anymore, so I had to give up on that exercise. – 1003

Family Member Involvement

Some participants shared that adherence to HEPs was easier when there were other members of the family present. Specifically, when the main caregiver was busy with work and could not be present either at home or at therapy. Other instances included the need for multiple persons to persuade the child to cooperate with home exercises.

There were a lot of those exercises where I had to hold her down and she would initially be upset but then we [other family members] would just distract her. - 1000

Another participant said:

It's a combination [doing HEP with the child among different family members]. The reason why my mom helps me is because my husband and I are both working [...] from home. But

like in the evenings if it's just my husband and I then we'll like play with him together, or we kind of mix it up, and I think that's what is beneficial for him to have change right as well. - 1002

Although participants expressed other family members aided in completing HEPs with their child, it was also noted that some exercises were not completed as members were not as familiar with the home exercise regimen compared to the main caregiver.

I hear all the exercises firsthand. I communicate it to either my husband or to my mother, but sometimes, like they forget some of the exercises to work on, and sometimes some things aren't worked on as much. - 1002

3.1.2 Therapist Factors

Another related main theme that was formed from the data was therapist factors. This main theme was made up of two other subcategories which are discussed in detail below.

Clinical Competence

Clinical competence included the therapist's overall knowledge and experience in the health and rehabilitation field regarding effective planning and case management, evaluations and treatment (Rezaie & Kendi, 2020). Study participants often shared how their perception of their therapist's clinical competence influenced their motivation to complete the prescribed exercises with their child at home. Some participants expressed their worries with their child's condition, specifically the uncertainty regarding their child's development and functional outcomes. However, they were able to overcome this with the help of their therapist who was able to shift their mindset. One participant stated:

Ever since changing that perspective [of understanding child's developmental delay] and getting that kind of feedback from our team, I found it [was a] more positive experience. It makes me that much more want to do the exercises, it's not that I wasn't doing it before but it just it's very reassuring to hear that you know, all this hard work all this time that I am putting into with my child, you know, how like it's paying off. - 1002

Data also suggested that the therapist's clinical competence regarding children's treatment cultivated trust with their client, which motivated families to comply with home exercises.

Anytime [therapist] tells me to do something or like exercises I like I feel like I have faith in her that excites me, that okay, I get to try something new and move on from there. - 1000

Many of the participants spoke about their interaction with their therapist, specifically when explaining how to perform such exercises at home with their child. Therapists would encourage caregivers to reflect and practice on the newly learned exercises while in session, making sure they understood how to complete the exercise regimens at home by themselves with their child. One participant said:

The great thing I love about our therapist is she explains it. Everything, and the reason behind it. She tests me too. She'll [therapist] actually make me do that exercise right there and say, "So what did you just do there? What did you focus on?" She's not just doing it on my kid. She's actually guiding me and taking my hand and saying, "Place your hands here. Do you feel it here? Do you see the difference between how you originally did it"? She would actually show me with my child. - 1002

By encouraging the family to imitate the home exercises and practice handling during therapy sessions, caregivers were able to reflect on their practice which reassured them that they were “on the right path” to seeing developmental and functional improvement in their child. Another participant shared:

I really appreciate it because it makes me stop and think that, okay, I think it should be this way and then [therapist]'s there to tell me that “this is how you should do it” and then that tells me [...] I'm on the right path. - 1002

Communication Skills

While clinical competency involved possessing up-to-date knowledge and clinical skills, communication included demonstrating empathy and patience when engaging with families. Participants shared their experiences of therapist's communication skills by showing empathy towards the family and their child. For instance, one caregiver said:

[Therapist]'s very in tuned with [child], and myself as the caregiver. They're not here to basically say like this is what your kids should be doing. They're like “What are your goals?” and “What can I do to help you achieve those goals”? What I liked about it is they weren't just going off a checklist. - 1002

Another caregiver stated:

They sincerely seemed like they really care, and so it helps me that to [hear] that I'm doing the right thing, because they're the ones that can see the progress, and sometimes I don't because I'm seeing him every day. - 1003

Having a strong therapeutic relationship between the therapist and family may also help increase adherence to HEPs. Participants shared how their therapist was able to incorporate their child's interests when planning a home regimen, which made it easier for the family to incorporate into their daily schedule.

I think [communicating with therapists, therapists recognizing child's interests] make it very easy for all of us as caregivers to incorporate the exercises into his [playtime]. It's so adaptable to what he does right, and I think that's where communicating to our therapists and our therapists recognizing "Okay, so what is your kid interested in? What does he like to do? Oh, he likes to read. Oh, he likes to play with these blocks. Why not play with the blocks on this little [...] table that we've created"? - 1002

Another participant shared her struggles of getting her child to cooperate with the prescribed HEP and how her therapist had helped her overcome it:

In terms of how you can incorporate it into like daily activities like we had a hard time doing sit ups. So then she showed me like you know, we could make it a game. - 1003

Most study participants also spoke about their experiences with their therapist when they did not have the equipment needed to complete their prescribed exercises at home. All participants stated their therapists suggested simple items that could act as substitutes for the missing equipment, which allowed them to perform their HEPs. One participant said:

I've never had to go out of my way to buy equipment. That's the great thing about these sessions too, and that therapist [...] tries to accommodate you know like, "What do you have at home"? - 1002

Another participant shared:

[Therapist] suggested a few things, she definitely suggested certain things that would work at home like even certain companies that had certain things. So she would sometimes send me links to things. - 1003

3.1.3 Therapy Factors

Factors related to therapy also influence parental adherence to home exercises. This theme encompassed three relevant sub-categories: type of intervention, supporting equipment, and the flexibility of HEP, which are described below:

Type of Intervention

While participating caregivers had multiple and different types of exercise interventions to be done in the home setting, they all shared their experiences of how each type of intervention affected their adherence. Home interventions were individualized to cater to the child's condition and would include exercises targeting strengthening, flexibility, and speech. Participants expressed that while they tried to complete all the prescribed exercises in their child's regimen, the nature of some exercises were more difficult than others in terms of adherence. One participant said:

Some [HEP] are inherent and you're doing it every day anyway because you know he's running or he's jumping. So, it depends on what the activity is. The harder one [to adhere to] is the speech, having to always get him to choose and the fine motors, some of it were I mean, we're trying to work on it. But it's not it's not as intuitive. You're not always having to get him to pull his pants down, [...] but like the feeding and stuff every day is easy. So some of them are easier and some of them are harder. - 1003

Supporting Equipment

Some exercises required the use of special equipment such as wooden platforms. It was suggested that adherence to home exercises may also be affected by the type and availability of equipment. Many participants shared their experiences of not having the equipment at home. While some caregivers were able to find substitutes, others stopped performing exercises that needed a certain apparatus to complete. One participant said:

I didn't have this platform and so [therapists] mentioned a few different ways to kind of use a cardboard box or whatnot. We started using the cardboard box and stuff, but I would say

that would be one thing I didn't really continue with. The cardboard box [was] a little flimsy, we tried to modify it a little bit it wasn't doing too much for us. - 1004

Flexibility of HEP

Another subcategory that could have influenced adherence was the flexibility of the HEP. Several caregiver participants shared when they were not able to continue with a certain exercise, they were still able to see their child's progress because the therapist gave them multiple exercises to pick from that would achieve the same developmental or functional outcome. One participant said:

We also did a few different sitting exercises instead of that [HEP that required wooden platform] so it wasn't like we were neglecting that exercise, it was more like we kind of just modified it at home. - 1004

The flexibility of the HEP did not only pertain to the type of interventions but also how they were delivered. By having a flexible HEP, families were able to keep their child cooperative and entertained. Another participant shared:

If you're constantly doing the same thing over with the same person, I'm sure it would get boring for [child] and to the point where he's like I don't want to do this, like we already did this. So, to have someone else do maybe that same exercise with him it's exciting, it's new, it's different. - 1002

3.1.4 Environmental Factors

Another main theme extracted from the data was environmental factors. Study participants reported that the physical/home environment and their access to therapy influenced their ability to perform their HEPs.

Physical Environment

The physical environment is the setting in which the child and caregiver perform their prescribed exercises. One participant shared their experience of her child being able to cooperate in the exercises in-therapy versus at home.

I actually found just recently that I have moved [child] from one area to another area of the room with different blankets to lie on and I think maybe he recognizes one blanket as the “tummy time” [HEP] blanket so I kind of moved him and shifted him over. And I think he is more interested in the fabric of the new blanket that he, he is okay with being on his stomach little longer, kind of a distraction so that might be something that's maybe easier. He actually performed pretty well for the physio funny enough, so maybe they have a softer mat that might be easier there. - 1004

Access to Therapy

All participating caregivers touched upon COVID-19's influence when sharing their experiences regarding their HEPs. Due to the recent COVID-19 pandemic, some caregivers had to conduct their therapy sessions online instead of in-person, which affected their understanding of new exercises that were prescribed by the therapist. Although most caregivers stated that they continued to adhere to their prescribed exercises, they believed that having in-person sessions with their therapist to be more effective in treating their child.

I never had a problem over zoom with the communication and her getting [...] what she wanted across, it was just, it's always easier if you take advantage of that time that you have like the 60 or 90 minutes, and really take advantage of that full 60 or 90 minutes versus, you know, spending that extra 5 or 10 minutes to figure out, okay, where do I place my hand kind of thing, you're like, I can see it on the doll but you know, is that right? Does that look right while trying to hold your kid and trying to hold your phone. - 1002

For some families, therapists encouraged exercising large muscles through gross motor activities during playtime as part of their HEP. However, their ability to do this exercise was also affected due to the recent COVID-19 pandemic. One participant said:

Now that the [COVID] mandates have eased up, [...] we probably can do a little bit more so that was the biggest challenge, not [being] able to [go out] cause it was during the winter where he needed [gross motor exercise] the most, and we couldn't go anywhere, because the playgrounds were closed so we really couldn't get the gross [motor] play in. - 1003

3.2 Quantitative Findings

A total of seven participants consented to participate in the online surveys between October 2021 to April 2022. Out of the seven participants, two only recently joined the program at Alberta Children’s Hospital and thus their data collection began in February 2022.

To measure the association between time and adherence in the Applied Coaching Model (ACM), a mixed effects model was used to analyze quantitative data collected from the weekly adherence surveys. Two mixed models were run using statistical analysis software (SPSS) and the second model with the lower Akaike’s Information Criterion (AIC) value was chosen, as shown in Table 4. A diagonal covariance structure was used for both models with time (week) being a fixed effect, which assumes that there are no other factors that affect the outcome and is measured without error. However, the second model also included therapist and pre-efficacy score as random effects in addition to the fixed effect in the first model, which assumes there are other factors of the independent variable (time exposed to the ACM) that are from a larger group of possibilities that can affect the outcome. A diagonal covariance structure was chosen as it indicates that variance of the repeated measures is different at each time point, while the correlation (covariance) between measurement times is constant. Details of the chosen model are included in the tables below in Tables 3.2.1 and 3.2.2. Table 3.2.3 demonstrates that both the intercept and week duration have significant influence on adherence level.

Table 3.2.1: Model Dimension

		Number of Levels	Covariance Structure	Number of Parameters	Subject Variables
Fixed Effects	Intercept	1		1	
	Week	21		20	
Repeated Effects	Week	21	Diagonal	21	Study Id
Total		43		42	

Table 3.2.2: Information Criteria

-2 Log Likelihood	258.550
Akaike's Information Criterion (AIC)	342.550
Hurvich and Tsai's Criterion (AICC)	493.050
Bozdogan's Criterion (CAIC)	477.147
Schwarz's Bayesian Criterion (BIC)	435.147

Dependent Variable: Adherence by Time (21 Levels/ Weeks)

Table 3.2.3: Type III Tests of Fixed Effects

Source	Numerator df	Denominator df	F	Sig.
Intercept	1	3.270	1655.766	0.000
Week	17	2.141	803.730	0.001

Table 3.2.4: Estimates of Fixed Effects

Parameter	Estimate	Std. Error	df	t	Sig.
Intercept	2.062500
[Week=1]	1.929348
[Week=2]	86.333333	5.584370	3.425	15.460	0.000
[Week=3]	42.500000	30.052038	2.009	1.414	0.292
[Week=4]	84.750000	2.381570	9.373	35.586	0.000
[Week=5]	79.000000	3.577709	7.005	22.081	0.000
[Week=6]	92.600000	1.734359	34.173	53.391	0.000
[Week=7]	80.750000	6.158074	4.457	13.113	0.000
[Week=8]	73.666667	2.596294	6.016	28.374	0.000
[Week=9]	83.333333	9.813068	3.129	8.492	0.003
[Week=10]	60.000000	24.494897	3.020	2.449	0.091
[Week=11]	49.333333	21.193989	3.027	2.328	0.102
[Week=12]	78.333333	4.906534	3.567	15.965	0.000
[Week=13]	87.666667	2.325383	7.437	37.700	0.000
[Week=14]	88.333333	1.360828	49.793	64.911	0.000
[Week=15]	80.000000	4.714045	3.621	16.971	0.000
[Week=16]	79.000000	7.788881	3.208	10.143	0.002
[Week=17]	87.000000	2.867442	5.214	30.341	0.000
[Week=18]	91.000000	3.858612	3.999	23.584	0.000
[Week=19]	100.000000	0.000000	0.000	593164160	0.000
[Week=20]	90.000000	0.000001	0.000	129477096	0.000
[Week=21]	0	0	.	.	.

As seen from Table 3.2.4, all weeks excluding week one, three, ten and eleven, have significant fixed effects.

Figures 2 through 8 showcase the adherence level based on time exposure to the ACM for the individual participants. Results for participants 1001 and 1006 were not presented in the form of time series graphs as they did not contain enough data to plot. Additionally, participant 1005 did not complete the consent form as they decided not to participate in the study. Due to the limited data collection from survey responses, this quantitative portion is exploratory, and aimed to shed light on possible factors that affect adherence levels for caregivers using the ACM.

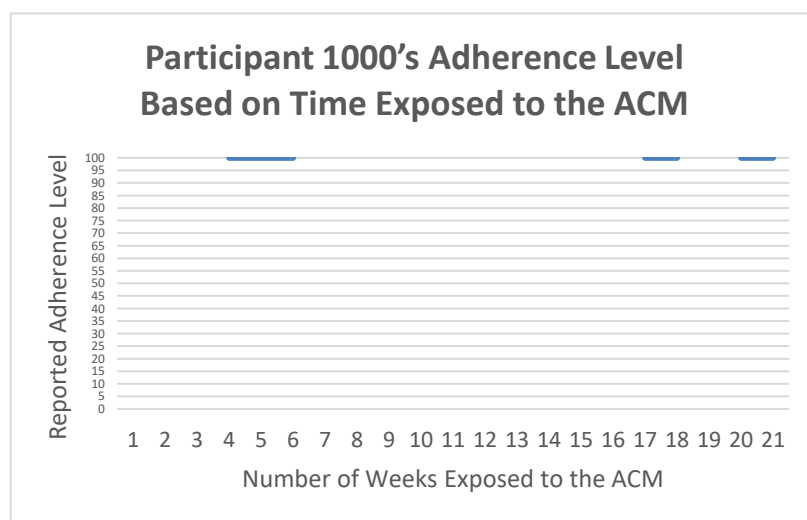


Figure 2: Participant 1000's Adherence Level Based on Time Exposed to the ACM

For this participant adherence level was reported at 100 percent each time the participant completed the survey. This score was supported with reports from the barrier/facilitator questions on the survey noting that the participant's family had both sets of grandparents at home to help with performing the child's HEPs.

Table 3.2.5: Participant 1000's Survey Responses

*Week Exposed to the ACM	Reported Adherence Percentage	Selected Factor for Adherence Percentage	Additional Comments Regarding HEP Completion
4	100	None	Our whole family (both set of grandparents) are committed to help with the exercises. Helps complete these with all their support.
5	100		
6	100		
17	100		
18	100		
20	100		
21	100		

**Note: Only the weeks with recorded responses were shown*

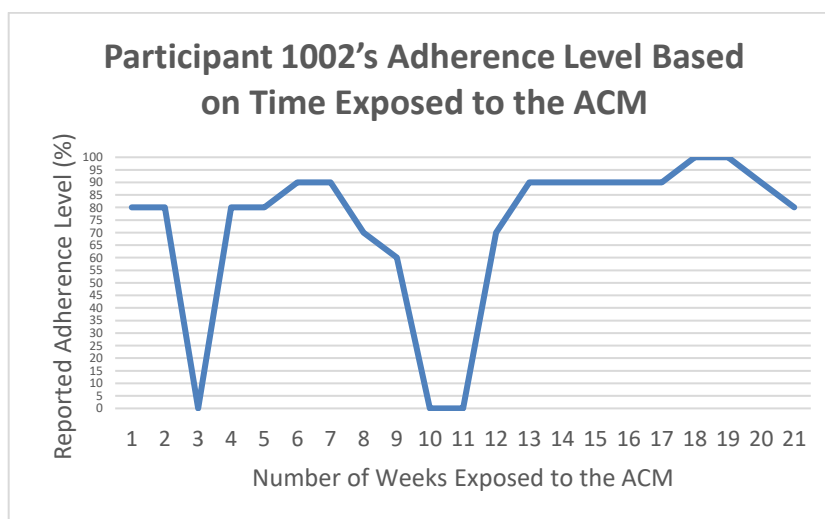


Figure 3: Participant 1002's Adherence Level Based on Time Exposed to the ACM

For participant 1002 there were some weeks where adherence level was reported as zero; however, overall, there was great variability in adherence to HEPs (Figure 3). Survey responses from this participant state that low adherence was due to child and family factors, specifically, child behaviour or when the caregiver was busy with work.

Table 3.2.6: Participant 1002's Survey Responses

*Week Exposed to the ACM	Reported Adherence Percentage	Selected Factor for Adherence Percentage	Additional Comments Regarding HEP Completion
1	80	Caregiver behavioural status	Our in-laws arrived last week, and it changed our routine.
2	80	Other	Working full time
3	0		
4	80	Caregiver behavioural status	
6	80	Caregiver behavioural status	work
7	90	Caregiver behavioural status	
8	90	Other	Holiday plans and work
10	70	Other	Caregiver feeling unwell
11	60	Caregiver behavioural status	Parents are sick
12	0		

14	0		
15	70	Child and caregiver behavioural status	Child was teething and parents were working
16	90	Caregiver behavioural status	
18	90	Caregiver behavioural status	
19	90	Caregiver behavioural status	
20	90	Caregiver behavioural status	

**Note: Only the weeks with recorded responses were shown*

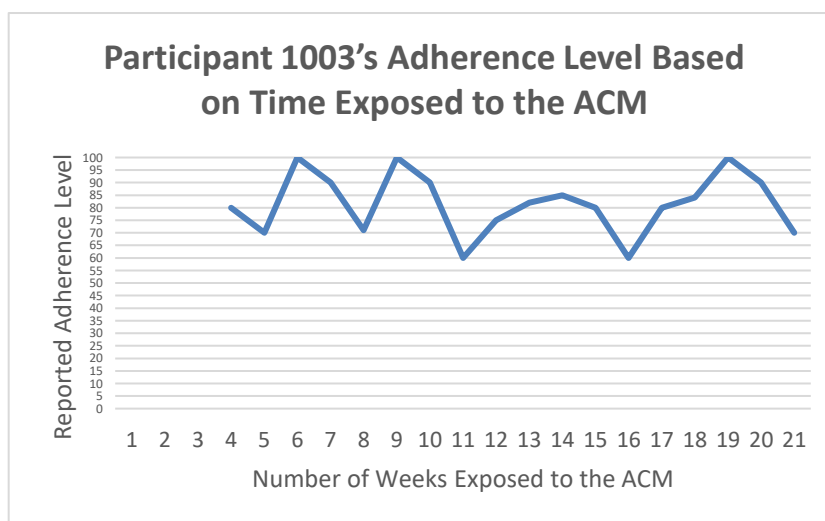


Figure 4: Participant 1003's Adherence Level Based on Time Exposed to the ACM

Table 3.2.7: Participant 1003's Survey Responses

*Week Exposed to the ACM	Reported Adherence Percentage	Selected Factor for Adherence Percentage	Additional Comments Regarding HEP Completion
4	80	Child and caregiver behavioural status	[Child] started fighting [their] naps, so wasn't able to accomplish our chores, and my spouse was especially more busy so I had more to do to compensate
5	70	Other	Got distracted with Christmas planning and activities
7	100	None	
8	90	Child behavioural status	My child is still refusing to eat very much at the table even though [they are]

			hungry and even though we stopped giving snacks in between.
10	71	Caregiver behavioural status	We were away on vacation visiting so was not able to complete all the exercises
11	100	None	My older [child] was home all week so, it made it easier to get [child's] gross motor exercises done since [they] helped me.
12	90	Child behavioural status	[Child] starting [their] tantrums so been a bit more difficult to get [them] to do something as [they] start to throw a tantrum.
14	60	Caregiver behavioural status	Some unforeseen events took a lot of time out of the last week that we had to deal with
15	75	Child behavioural status	
16	82	Child behavioural status	
18	85	Child behavioural status	
19	80	Child and caregiver behavioural status	Child was teething and parents were working
20	60	Caregiver behavioural status	

**Note: Only the weeks with recorded responses were shown*

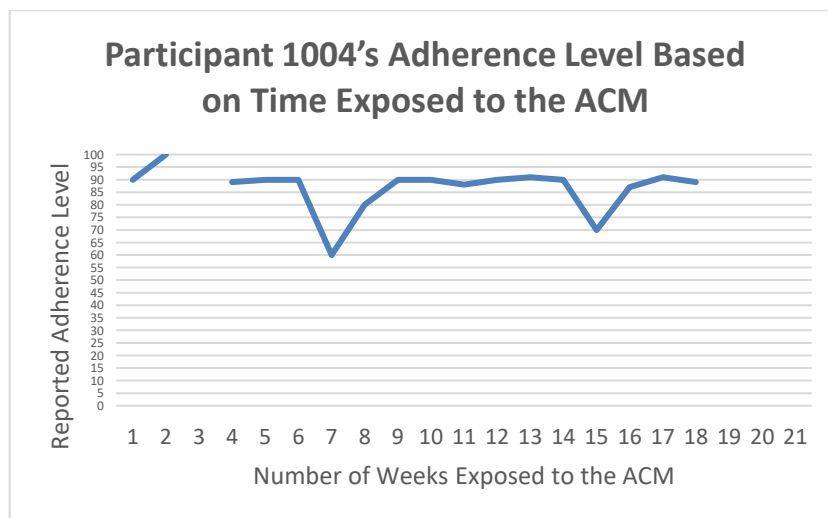


Figure 5: Participant 1004's Adherence Level Based on Time Exposed to the ACM

Survey data for participant's 1003 and 1004 show no overall trend, rather that adherence was variable. Survey responses from participant 1003 and 1004 stated low adherence was mostly due to their child's behavioural status and irregular personal events such as travelling and visiting family, respectively.

Table 3.2.8: Participant 1004's Survey Responses

*Week Exposed to the ACM	Reported Adherence Percentage	Selected Factor for Adherence Percentage	Additional Comments Regarding HEP Completion
1	90	Environmental, other	Lack of equipment at home. Fussy baby. I usually do an exercise at least once a day, but I feel like it's not a completed exercise unless it's done at least twice a day
2	100	None	We created a new tool to mimic what was used by the physio
4	89	Other	Family visiting over the holidays
5	90	None	
7	60	None	
8	80	Other	Visiting and outings
9	90	None	
10	90	None	
11	88	None	
12	90	None	
13	91	None	Always struggle with one as baby doesn't like it
14	90	None	
15	70	Other	Travel this week
16	87	None	
17	91	None	
18	89	None	

**Note: Only the weeks with recorded responses were shown*

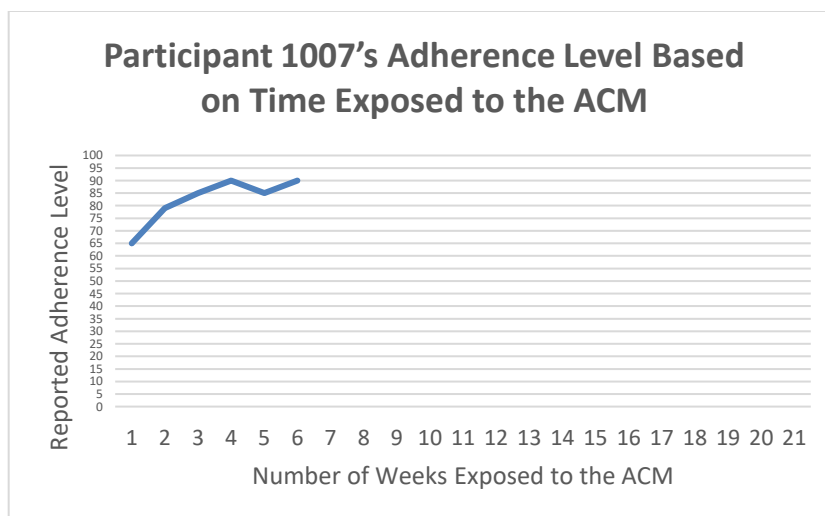


Figure 8: Participant 1007's Adherence Level Based on Time Exposed to the ACM

Participant 1007 only recently began treatment guided by the ACM, therefore only the first six weeks were recorded. The preliminary data suggest an increasing trend showing increased adherence with increased exposure to the ACM.

Table 3.2.9: Participant 1007's Survey Responses

*Week Exposed to the ACM	Reported Adherence Percentage	Selected Factor for Adherence Percentage	Additional Comments Regarding HEP Completion
1	65	Child behavioural status	None
2	79	Other	
3	85	None	
4	90	Child behavioural status	
5	85	None	
6	90	None	

**Note: Only the weeks with recorded responses were shown*

Chapter 4

4 Discussion

The purpose of the study was to explore the lived experiences of caregivers of children with developmental delays regarding factors that influence adherence to home exercise programs (HEPs) in relation to the Applied Coaching Model (ACM).

4.1 Qualitative Discussion

The data from this study supports four main themes: 1) child and family factors, 2) therapist factors, 3) therapy factors, and 4) environmental factors documented in the previous literature surrounding this topic (Johnson et al., 2018; Lillo-Navarro et al., 2015; Rezaie & Kendi, 2020) and can provide useful information for current rehabilitative care.

Child and family factors was a main theme that emphasized how the status of the child and caregiver directly affected adherence to exercises in the home setting. Regarding this category, the child's emotional and behavioural outbursts made adherence less likely. Many caregivers expressed their struggle to perform their HEP when their child was uncooperative and, in some cases, even gave up doing the exercises until their child was in a better state. The results from the quantitative adherence survey provided support to these findings, such that lower adherence rates were reported alongside barriers related to their child's behavioural difficulties. These findings corroborate previous literature stating behavioural problems are common in children with developmental delays and can cause non-compliance to treatment in the home setting (Brossard-Racine et al., 2012; Herring et al., 2006; Rezaie & Kendi, 2020). The mindset of the caregiver was also a sub-category that was shown to affect adherence to HEPs. Caregivers' mindset affected adherence, including level of confidence and skill level in carrying out exercises at home with their child. Such perceptions acted as either a barrier or facilitator to adherence to HEPs. For example, the interviews revealed that when a caregiver was not confident in performing a certain exercise at home, adherence level decreased, and vice versa. Although such perceptions could negatively impact adherence, it seems that caregiver motivation did not decrease adherence to HEPs. In the current study, all interviewed participants expressed

their desire and motivation to adhere to the exercises because they felt a sense of duty toward their child and believed it would help improve their child's quality of life. This is evidenced by key actions undertaken in the Engage and Goal-Setting stages of the ACM as many participants expressed their gratitude and trust they had in their therapist who helped them establish roles and expectations to view their child's condition more positively. From the qualitative findings, most instances of not being able to adhere to the HEP due to caregiver barriers appeared to be when caregivers were physically away or unavailable. This finding was supported by the responses in the quantitative adherence survey where low adherence rates were reported alongside reports of caregivers being away at work, travelling or sick. Furthermore, most caregivers were able to overcome this barrier by developing a sense of routine and incorporating their child's HEP into their daily schedule. This suggests that addressing caregiver confidence and skill level during therapist and caregiver interactions, as emphasized in the ACM, may help to increase adherence rates, which supports previous literature from Gmmash et al. (2021) and Rezaie & Kendi (2020). Family involvement was another subtheme that influenced adherence to HEP in a positive way. Having additional family members involved with the child's rehabilitative care and HEP can increase adherence rates. Supportive family members can help ease caregiver burden and perform HEPs in place of the main caregiver when they are busy or away or can be involved consistently to share the burden of acting as a "therapist" to the child. Another role for additional family members included keeping the child entertained and cooperative during home therapy by having multiple members involved in the exercises or rotating who was performing them. These findings were supported by responses on the quantitative survey such that caregivers reported higher adherence rates when other family members such as grandparents or siblings were present to help. The role of the family was also discussed in studies by Bamm & Rosenbaum, (2008), G. King et al. (2017), and Rezaie & Kendi, (2020). The study by Rezaie & Kendi (2020) specifically discussed how the family makeup and emotional atmosphere could affect adherence to HEPs. Implications for practice include incorporating voices from all family members rather than solely the caregiver when planning future pediatric rehabilitation interventions.

The therapist factors theme encompassed how adherence was affected by the role and responsibilities of the therapist. Findings from this theme suggest that therapists should

have the necessary skills to encourage the family to become actively involved in their child's rehabilitation journey. Such skills include empathy, patience, communication, technical skills, clinical reasoning, which cultivate the therapeutic relationship and personalized care (Epstein & Hundert, 2002) and contributed to the development of the subthemes relevant to HEP adherence. Clinical competency involved possessing up-to-date knowledge and clinical skills, while communication included demonstrating empathy and patience when engaging with families. The findings from the current study demonstrated that clinical competency and communication skills are pivotal in determining adherence to HEPs. Most findings from the qualitative interviews showed therapist factors as facilitators rather than barriers, as many caregivers shared their positive experiences with their therapist regarding adherence to their exercise regimen. These findings may also suggest that the ACM training played a key role in improving adherence to HEPs as this model is theorized to improve care by targeting the interaction between the therapist and client. For example, caregivers had positive reflections on strategies that therapists use to operationalize the Observation and Demonstration, Practice and Reflection, and Commit to Action stages of the ACM. Using the strategies and actions suggested with ACM, therapists were able to effectively plan individualized goals with the family, communicate reasoning behind choice of specific exercises, and display empathy by offering alternative treatment methods when aspects of treatment did not meet developmental or functional expectations.

Factors related to therapy was the third theme associated with parental adherence to HEPs. The type of home intervention was shown to influence adherence as caregivers found some exercises more difficult to complete. In addition, results suggest that children also preferred certain exercises over others. The nature of the exercise also played a role in adherence as some were more inherent in a child's play routine, which makes it easier to fit into the family's daily schedule. A HEP is made up of multiple exercises that the family completes with their child in the home setting. The results of the current study suggest that the more flexible the exercise regimen, the more likely families will adhere to home treatment, this includes being creative with equipment in the home environment. In many cases, caregivers who were given multiple exercises that targeted the same developmental or functional goal could maintain adherence because there were more options when their child

did not enjoy or became bored of or resisted a particular exercise. The Commit to Action stage of the ACM may be particularly relevant for this theme as through the planning process caregivers received multiple supports and suggestions from their therapist to assist the family at home, for example, when equipment was required or when the child became uncooperative about a certain exercise.

The final theme created from the data was environmental factors. The Commit to Action stage of the ACM informed this theme as the ability for therapists to create an actionable plan for the family in the home setting played a crucial role in determining adherence. Data from the current study suggests that the physical environment where the HEP takes place influences adherence. Both qualitative and quantitative findings revealed the environment to have more negative components regarding adherence to HEPs among participants in this study. Supplemental data from the weekly adherence surveys demonstrated low adherence when families were not able to find an ideal space to perform their HEPs. This theme was also evident in the interview data where some families found certain areas in the home influenced adherence, such that their children were familiar with particular aspects of the environment, causing them to be more or less cooperative. Access to therapy affected adherence rates such that caregivers were able to reach out to their therapists outside the times of their specific appointments with questions concerning their HEP, allowing them to continue adhering to their exercise regimen until their next in-person session. Some participants also conducted some therapy sessions online through Zoom (video conferencing software) due to the recent COVID-19 pandemic. While some parents thought it to be more convenient for their schedule, many expressed a perceived ineffectiveness in this method of treatment delivery. Therefore, researching the methods of treatment delivery and its effect on adhering to HEPs may also be beneficial for future research.

4.2 Quantitative Discussion

The preliminary quantitative data suggests that adherence rates are associated with increased exposure (time) to the ACM. A few weeks of data had insignificant values in the mixed model in addition to significant variability within participants over time, potentially demonstrating that adherence is cyclical. The drop in adherence level in the graphs may be

explained by any of the four factors that were found to affect adherence rates: child and family factors, therapist factors, therapy factors and environmental factors. Adherence is not linear as it fluctuates over time, in which the previously identified factors most likely play a role. The most consistent barriers reported during the drops in adherence included child and family factors, specifically child and caregiver behavioural status. Survey responses from participant 1001 showed high adherence. However, this may also have been the result of response bias as the caregiver may have felt pressured to provide a socially desirable response. Missing data may also have been related to adherence. For example, weeks without reports from caregivers could have been due to lower adherence (little or no HEP practice), supporting the concept of adherence's cyclical nature. The ACM is not a form of acute treatment, but rather a type of model that elicits therapist and client interaction. Therefore, external factors will affect adherence rate which could also have resulted in the dips seen in Figure 3 as the most frequent barrier given by participant 1002 were due to travel or family events. As seen in Figures 4 and 5, adherence level drops every three to four weeks. While all participating families see their therapist on a regular basis, the time in between in-person sessions vary. The data in Figures 4 and 5 could be explained by the nature of the child's rehabilitation journey. As the child completes their developmental goals, new ones are then set by the caregiver and therapist. With new developmental milestones, new exercises get incorporated into the child's HEP which may affect the caregiver's confidence in performing the new exercises alone at home for the first time or getting the child to cooperate when familiarizing them to the new exercise routine. Caregiver mindset also relates to the pre-efficacy score of participants that were recorded before exposure to the ACM as it reflected the caregivers' confidence at the start of the program in adhering to their child's HEP. While much of the existing literature discusses the relation between caregiver confidence and adherence (Giller Gajdosik, 1991; Gmmash et al., 2021; Law & King, 1993; Medina-Mirapeix et al., 2017), few provide specific explanations to help mitigate barriers that cause uncertainty in caregivers regarding adherence to HEPs within a pediatric rehabilitation setting. Findings from this study shed light on specific causes of uncertainty and other factors that affect adherence among caregivers of children with developmental delays and provide suggestions on how to mitigate them.

5 Conclusion

While this study's findings cannot be generalized to all families of children with developmental delays, it has provided insight on the lived experiences of caregivers regarding the experience of adhering to HEPs focused on the rehabilitative goals of their children with developmental delays. Additionally, the study explored adherence outcomes using the Applied Coaching Model (ACM). Factors that contribute to HEP adherence rates were classified based on themes identified by Rezaie & Kendi (2020): 1) child and family factors, 2) therapist factors, 3) therapy factors, and 4) environmental factors, all of which can positively or negatively impact adherence. By identifying the factors that influence adherence to HEPs among families of children with developmental delays, clinicians and families can minimize the barriers and promote the facilitators discussed in this study when planning future rehabilitative interventions.

5.1 Expected Impact and Significance of the Study

The aims of this study were to document the lived experiences of caregivers who participated in therapy sessions guided by the ACM and to identify the factors that affected adherence to home rehabilitation exercises for children with developmental delays. This study has implications that are both theoretical and practical in nature. Theoretically, the findings contributed new knowledge to the growing body of literature regarding factors that affect adherence to exercise programs in the home environment. Such advancements in research may also further encourage improvements in current therapeutic approaches available for children with developmental delays and their families. Practical implications of this study include shedding light on the perspectives of key stakeholders in children's rehabilitation journeys while proposing holistic theories and aspects from the ACM that can be incorporated into future rehabilitation practices to improve adherence to HEPs. Such theories include health coaching and Family Centered Care (FCC) which are used within the stages of the ACM to help tackle the barriers or act as facilitators in improving adherence to HEPs. Using concrete actions within the model stages provides a tangible way for caregivers to gain skills which may make adherence to HEPs more likely. For example, the ACM engage stage encourages therapists to cultivate a strong therapeutic

relationship that creates trust and security, giving parents the ability to be honest and discuss barriers to adherence in between sessions. Another example can be found in the ACM practice and reflect stages, where therapists are encouraged to use reflexive questioning with parents to confirm understanding and promote adherence through development of self-efficacy. Finally, through this experience, the participating caregivers may have gained personal revelation regarding their role and how their voices contributed to potential changes in rehabilitative care.

5.2 Limitations and Recommendations

This study explored caregiver perspectives of adhering to HEPs among children with developmental delays in a rehabilitative setting using the ACM. While this study provides useful information regarding pediatric rehabilitative care, it also has its limitations. Due to the COVID-19 pandemic, qualitative interviews were conducted online through teleconferencing software (Western Zoom Corporate). Therefore, non-verbal cues may not have been detected which may have affected research findings to a certain degree. The COVID-19 pandemic also significantly affected participant recruitment, resulting in a smaller sample size than initially desired. While the small participant pool does not affect the quality of the results regarding caregiver perspectives, as we recognize each caregiver's unique experiences through a phenomenological interpretivist lens, more participants could have been recruited for the quantitative component which may shed light on more factors that affect adherence to HEPs. Additionally, a mixed effects regression model may not have been ideal due to the variable nature of adherence. For future research regarding this topic, a non-linear model or single subject approach (case series) is proposed to better capture how different factors affect HEP adherence and describe the pattern of adherence overtime. This study also only focuses on the experiences of caregivers. Therefore, as a future recommendation, studying multiple population samples such as clinicians, therapists, therapy students, and other healthcare workers may help to better understand the different factors that affect adherence to HEPs.

5.3 Budget

This research project has received funding from the Child Health, Exercise and Rest (CHEaR) Lab at the University of Western Ontario and is also funded by an in-kind contribution from the Alberta Health Services, which donated the time of participating therapists to support the project. Specifically, the intervention was conducted during the participants' usual rehabilitation sessions with their therapist.

References

- Abrams, L. S. (2010). Sampling 'Hard to Reach' Populations in Qualitative Research. *Qualitative Social Work: Research and Practice*, 9(4), 536–550.
<https://doi.org/10.1177/1473325010367821>
- Aydin, R., & Nur, H. (2012). Family-centered approach in the management of children with cerebral palsy. In *Turkiye Fiziksel Tip ve Rehabilitasyon Dergisi* (Vol. 58, Issue 3, pp. 229–235). Turkish Society of Physical Medicine and Rehabilitation.
<https://doi.org/10.4274/tftr.84429>
- Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M. A., & Servais, M. (2013). Solution-Focused Coaching in Pediatric Rehabilitation: An Integrated Model for Practice. *Physical & Occupational Therapy In Pediatrics*, 33(4), 467–483.
<https://doi.org/10.3109/01942638.2013.784718>
- Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, 89(8), 1618–1624.
<https://doi.org/10.1016/j.apmr.2007.12.034>
- Barton, E. E., & Fetting, A. (2013). Parent-Implemented Interventions for Young Children With Disabilities: A Review of Fidelity Features. *Journal of Early Intervention*, 35(2), 194–219. <https://doi.org/10.1177/1053815113504625>
- Bazyk, S. (1989). Changes in attitudes and beliefs regarding parent participation and home programs: an update. *The American Journal of Occupational Therapy. : Official Publication of the American Occupational Therapy Association*, 43(11), 723–728. <https://doi.org/10.5014/ajot.43.11.723>
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, 26(13), 1802–1811. <https://doi.org/10.1177/1049732316654870>
- Bottos, M., & Gericke, C. (2003). Ambulatory capacity in cerebral palsy: prognostic criteria and consequences for intervention. *Developmental Medicine and Child Neurology*, 45(11), 786–790. <https://doi.org/10.1017/S0012162203001452>
- Brossard-Racine, M., Hall, N., Majnemer, A., Shevell, M. I., Law, M., Poulin, C., & Rosenbaum, P. (2012). Behavioural problems in school age children with cerebral

- palsy. *European Journal of Paediatric Neurology : EJPN : Official Journal of the European Paediatric Neurology Society*, 16(1), 35–41.
<https://doi.org/10.1016/J.EJPN.2011.10.001>
- Costello, I., Wong, I. C. K., & Nunn, A. J. (2004). A literature review to identify interventions to improve the use of medicines in children. *Child: Care, Health and Development*, 30(6), 647–665. <https://doi.org/10.1111/j.1365-2214.2004.00478.x>
- Cox, E. (2015). Coaching and Adult Learning: Theory and Practice. *New Directions for Adult and Continuing Education*, 2015(148), 27–38.
<https://doi.org/10.1002/ace.20149>
- Creswell, J. W., & Plano Clark, V. L. (2007). Designing and conducting mixed methods research. In J. W. Creswell & V. L. Plano Clark (Eds.), *Thousand Oaks, Calif. : SAGE Publications*. SAGE Publications.
- Daviault, Z. (2021). Collaborative Coaching in Pediatric Rehabilitation: An Effectiveness-Implementation Study of the Applied Coaching Model. *Electronic Thesis and Dissertation Repository*. <https://ir.lib.uwo.ca/etd/7945>
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. In *Medical Education* (Vol. 40, Issue 4, pp. 314–321). John Wiley & Sons, Ltd.
<https://doi.org/10.1111/j.1365-2929.2006.02418.x>
- Elman, J. (2003). Development: it's about time. *Developmental Science*, 6(4), 430–433.
<https://doi.org/10.1111/1467-7687.00297>
- Epstein, R. M., & Hundert, E. M. (2002). Defining and Assessing Professional Competence. *JAMA*, 287(2), 226–235. <https://doi.org/10.1001/JAMA.287.2.226>
- Foster, L., Dunn, W., & Lawson, L. M. (2013). Coaching mothers of children with autism: A qualitative study for occupational therapy practice. In *Physical and Occupational Therapy in Pediatrics* (Vol. 33, Issue 2, pp. 253–263). Phys Occup Ther Pediatr. <https://doi.org/10.3109/01942638.2012.747581>
- Galil, A., Carmel, S., Lubetzky, H., Vered, S., & Heiman, N. (2001). Compliance with home rehabilitation therapy by parents of children with disabilities in Jews and Bedouin in Israel. *Developmental Medicine and Child Neurology*, 43(04), 261.
<https://doi.org/10.1017/s0012162201000494>
- Giller Gajdosik, C. (1991). Issues of parent compliance: What the clinician and

- researcher should know. *Physical and Occupational Therapy in Pediatrics*, 11(3), 73–87. https://doi.org/10.1080/J006v11n03_05
- Gmmash, A. S., Effgen, S. K., Skubik-Peplaski, C., Faota, / L, & Lane, J. D. (2021). Parental Adherence to Home Activities in Early Intervention for Young Children With Delayed Motor Development. *PTJ: Physical Therapy & Rehabilitation Journal | Physical Therapy*, 101, 1–11. <https://doi.org/10.1093/ptj/pzab023>
- Gorgon, E. J. R. (2018). Caregiver-Provided Physical Therapy Home Programs for Children with Motor Delay: A Scoping Review. *Physical Therapy*, 98(6), 480–493. <https://doi.org/10.1093/PTJ/PZY009>
- Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970–976. <https://doi.org/10.1111/J.1365-2788.2006.00933.X>
- Griffiths, K. (2005). Personal coaching: A model for effective learning. *Journal of Learning Design*, 1(2). <https://doi.org/10.5204/jld.v1i2.17>
- Guillemin, M., & Gillam, L. (2004). Ethics, Reflexivity, and “Ethically Important Moments” in Research. *Qualitative Inquiry*, 10(2), 261–280. <https://doi.org/10.1177/1077800403262360>
- Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. In *American Journal on Mental Retardation* (Vol. 102, Issue 4, pp. 319–345). Am J Ment Retard. [https://doi.org/10.1352/0895-8017\(1998\)102<0319:EOEIFV>2.0.CO;2](https://doi.org/10.1352/0895-8017(1998)102<0319:EOEIFV>2.0.CO;2)
- Hanson, M. J., & Carta, J. J. (1995). Addressing the challenges of families with multiple risks. In *Exceptional Children* (Vol. 62). Council for Exceptional Children. <https://kuscholarworks.ku.edu/handle/1808/10955>
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism : The International Journal of Research and Practice*, 9(4), 377–391. <https://doi.org/10.1177/1362361305056078>
- Herring, S., Gray, K. M., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and

- family functioning. *Journal of Intellectual Disability Research*, 50(12), 874–882.
<https://doi.org/10.1111/j.1365-2788.2006.00904.x>
- Hill, C. E. (2005). Therapist techniques, client involvement, and the therapeutic relationship: Inextricably intertwined in the therapy process. In *Psychotherapy* (Vol. 42, Issue 4, pp. 431–442). <https://doi.org/10.1037/0033-3204.42.4.431>
- Hinojosa, J., & Anderson, J. (1991). Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *The American Journal of Occupational Therapy. : Official Publication of the American Occupational Therapy Association*, 45(3), 273–279. <https://doi.org/10.5014/ajot.45.3.273>
- Hong, B. Y., Jo, L., Kim, J. S., Lim, S. H., & Bae, J. M. (2017). Factors Influencing the Gross Motor Outcome of Intensive Therapy in Children with Cerebral Palsy and Developmental Delay. *Journal of Korean Medical Science*, 32(5), 873–879.
<https://doi.org/10.3346/JKMS.2017.32.5.873>
- Institute for Family-Centered Care. (2017). *Patient- and Family-Centered Care*.
<https://www.ipfcc.org/about/pfcc.html>
- Johnson, R. W., Williams, S. A., Gucciardi, D. F., Bear, N., & Gibson, N. (2018). Evaluating the effectiveness of home exercise programmes using an online exercise prescription tool in children with cerebral palsy: Protocol for a randomised controlled trial. *BMJ Open*, 8(1). <https://doi.org/10.1136/bmjopen-2017-018316>
- Kellehear, A. (2019). Unobtrusive methods in delicate situations. In *Ethical Intersections: Health Research, Methods and Researcher Responsibility* (pp. 97–105). Taylor and Francis. <https://doi.org/10.4324/9780429039591-13>
- King, G., Williams, L., & Hahn Goldberg, S. (2017). Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child: Care, Health and Development*, 43(3), 334–347.
<https://doi.org/10.1111/CCH.12435>
- King, Gillian. (2009). A framework of personal and environmental learning-based strategies to foster therapist expertise. *Learning in Health and Social Care*, 8(3), 185–199. <https://doi.org/10.1111/j.1473-6861.2008.00210.x>
- King, Gillian, Schwellnus, H., Servais, M., & Baldwin, P. (2019). Solution-Focused Coaching in Pediatric Rehabilitation: Investigating Transformative Experiences and

- Outcomes for Families. *Physical and Occupational Therapy in Pediatrics*, 39(1), 16–32. <https://doi.org/10.1080/01942638.2017.1379457>
- Kleynen, M., Beurskens, A., Olijve, H., Kamphuis, J., & Braun, S. (2020). Application of motor learning in neurorehabilitation: a framework for health-care professionals. *Physiotherapy Theory and Practice*, 36(1), 1–20. <https://doi.org/10.1080/09593985.2018.1483987>
- Kvale, S. (1995). The Social Construction of Validity. *Qualitative Inquiry*, 1(1), 19–40. <https://doi.org/10.1177/107780049500100103>
- Law, M., & King, G. (1993). Parent Compliance with Therapeutic Interventions for Children with Cerebral Palsy. *Developmental Medicine & Child Neurology*, 35(11), 983–990. <https://doi.org/10.1111/j.1469-8749.1993.tb11580.x>
- Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journals of Gerontology*, 46(4). <https://doi.org/10.1093/GERONJ/46.4.P181>
- Lillo-Navarro, C., Medina-Mirapeix, F., Escolar-Reina, P., Montilla-Herrador, J., Gomez-Arnaldos, F., & Oliveira-Sousa, S. L. (2015). Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: A qualitative study. *Journal of Physiotherapy*, 61(2), 81–86. <https://doi.org/10.1016/j.jphys.2015.02.014>
- Lohse, K. (2021, June 9). *Chapter 3: Mixed-Effects Models for Longitudinal Data*. https://keithlohse.github.io/mixed_effects_models/lohse_MER_chapter_03.html
- Majnemer, A. (1998). Benefits of early intervention for children with developmental disabilities. *Seminars in Pediatric Neurology*, 5(1), 62–69. [https://doi.org/10.1016/S1071-9091\(98\)80020-X](https://doi.org/10.1016/S1071-9091(98)80020-X)
- McCabe, R., & Priebe, S. (2004). The therapeutic relationship in the treatment of severe mental illness: A review of methods and findings. In *International Journal of Social Psychiatry* (Vol. 50, Issue 2, pp. 115–128). Sage Publications London, Thousand Oaks and New Delhi. <https://doi.org/10.1177/0020764004040959>
- McConnell, D., Parakkal, M., Savage, A., & Rempel, G. (2015). Parent-mediated intervention: adherence and adverse effects. *Disability and Rehabilitation*, 37(10), 864–872. <https://doi.org/10.3109/09638288.2014.946157>

- McGibbon, L. B., & Law, M. (2003). The effects of Family-Centred Functional Therapy on the occupational performance of children with cerebral palsy. *Canadian Journal of Occupational Therapy, 70*(5), 285–297.
<https://doi.org/10.1177/000841740307000505>
- Medina-Mirapeix, F., Escolar-Reina, P., Gascán-Cnovas, J. J., Montilla-Herrador, J., Jimeno-Serrano, F. J., & Collins, S. M. (2009). Predictive factors of adherence to frequency and duration components in home exercise programs for neck and low back pain: an observational study. *BMC Musculoskeletal Disorders, 10*(1).
<https://doi.org/10.1186/1471-2474-10-155>
- Medina-Mirapeix, F., Lillo-Navarro, C., Montilla-Herrador, J., Gacto-Sánchez, M., Franco-Sierra, M. A., & Escolar-Reina, P. (2017). Predictors of parents' adherence to home exercise programs for children with developmental disabilities, regarding both exercise frequency and duration: A survey design. *European Journal of Physical and Rehabilitation Medicine, 53*(4), 545–555.
<https://doi.org/10.23736/S1973-9087.17.04464-1>
- Miller, G., & Dingwall, R. (1997). *Context and method in qualitative research*. 226.
- Milton, Y. M., Dunford, C., & Newby, K. V. (2019). Occupational therapy home programmes for children with cerebral palsy: A national survey of United Kingdom paediatric occupational therapy practice. *British Journal of Occupational Therapy, 82*(7), 443–451. <https://doi.org/10.1177/0308022619830263>
- Morgan, C., Novak, I., Dale, R. C., Guzzetta, A., & Badawi, N. (2016). Single blind randomised controlled trial of GAME (Goals - Activity - Motor Enrichment) in infants at high risk of cerebral palsy. *Research in Developmental Disabilities, 55*, 256–267. <https://doi.org/10.1016/J.RIDD.2016.04.005>
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250–260.
<https://doi.org/10.1037/0022-0167.52.2.250>
- Novak, I., & Berry, J. (2014). Home program intervention effectiveness evidence. *Physical & Occupational Therapy in Pediatrics, 34*(4), 384–389.
<https://doi.org/10.3109/01942638.2014.964020>
- Novak, I., Cusick, A., & Lannin, N. (2009). Occupational therapy home programs for

- cerebral palsy: double-blind, randomized, controlled trial. *Pediatrics*, 124(4).
<https://doi.org/10.1542/PEDS.2009-0288>
- Novak, I., & Honan, I. (2019). Effectiveness of paediatric occupational therapy for children with disabilities: A systematic review. *Australian Occupational Therapy Journal*, 66(3), 258–273. <https://doi.org/10.1111/1440-1630.12573>
- Nunokoosing, K. (2005). The problems with interviews. *Qualitative Health Research*, 15(5), 698–706. <https://doi.org/10.1177/1049732304273903>
- Ogourtsova, T., O'Donnell, M., & Majnemer, A. (2019). Coach, Care Coordinator, Navigator or Keyworker? Review of Emergent Terms in Childhood Disability. *Physical & Occupational Therapy In Pediatrics*, 39(2), 119–123.
<https://doi.org/10.1080/01942638.2018.1521891>
- Olsen, J. M. (2014). Health Coaching: A Concept Analysis. *Nursing Forum*, 49(1), 18–29. <https://doi.org/10.1111/nuf.12042>
- Palsili, S., Bakıcılarının, Ç., Egzersiz, E., Uyumları, P., Başaran, A., Karadavut, K. İ., Üneri, Ş. Ö., Balbaloğlu, Ö., & Atasoy, N. (2014). Adherence to Home Exercise Program among Caregivers of Children with Cerebral Palsy. *Türk Fiz Tıp Rehab Derg*, 60, 85–91. <https://doi.org/10.5152/tftrd.2014.60973>
- Paterson, M., & Higgs, J. (2015). Using Hermeneutics as a Qualitative Research Approach in Professional Practice. *The Qualitative Report*.
<https://doi.org/10.46743/2160-3715/2005.1853>
- Peplow, U. C., & Carpenter, C. (2013). Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: A qualitative study. *Physical and Occupational Therapy in Pediatrics*, 33(3), 285–299.
<https://doi.org/10.3109/01942638.2013.773954>
- Phelan, S. K., & Kinsella, E. A. (2013). Picture This... Safety, Dignity, and Voice-Ethical Research With Children: Practical Considerations for the Reflexive Researcher. *Qualitative Inquiry*, 19(2), 81–90. <https://doi.org/10.1177/1077800412462987>
- Ponterotto, J. G. (2005). *Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science*. <https://doi.org/10.1037/0022-0167.52.2.126>
- Quick, J. C., & Macik-Frey, M. (2004). Behind the mask coaching through deep

- interpersonal communication. In *Consulting Psychology Journal* (Vol. 56, Issue 2, pp. 67–74). <https://doi.org/10.1037/1061-4087.56.2.67>
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, *115*(6). <https://doi.org/10.1542/peds.2004-1689>
- Rapoff, M. A., & Lindsley, C. B. (2007). Improving adherence to medical regimens for juvenile rheumatoid arthritis. *Pediatric Rheumatology*, *5*, 10. <https://doi.org/10.1186/1546-0096-5-10>
- Reeves, C. L. (2010). A difficult negotiation: fieldwork relations with gatekeepers. *Qualitative Research*, *10*(3), 315–331. <https://doi.org/10.1177/1468794109360150>
- Rezaie, L., & Kendi, S. (2020). <p>Exploration of the Influential Factors on Adherence to Occupational Therapy in Parents of Children with Cerebral Palsy: A Qualitative Study</p>. *Patient Preference and Adherence*, *Volume 14*, 63–72. <https://doi.org/10.2147/PPA.S229535>
- Rone-Adams, S. A., Stern, D. F., & Walker, V. (2004). Stress and compliance with a home exercise program among caregivers of children with disabilities. *Pediatric Physical Therapy : The Official Publication of the Section on Pediatrics of the American Physical Therapy Association*, *16*(3), 140–148. <https://doi.org/10.1097/01.PEP.0000136006.13449.DC>
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: A conceptual framework and research review. In *Physical and Occupational Therapy in Pediatrics* (Vol. 18, Issue 1, pp. 1–20). Informa Healthcare. https://doi.org/10.1080/J006v18n01_01
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology*, *49*(SUPPL. 2), 8–14. <https://doi.org/10.1111/j.1469-8749.2007.tb12610.x>
- Rush, D. D., & Shelden, M. L. (2011). *The Early Childhood Coaching Handbook*. Brookes Publishing Company, 220.
- Santer, M., Ring, N., Yardley, L., Geraghty, A. W. A., & Wyke, S. (2014). Treatment

- non-adherence in pediatric long-term medical conditions: Systematic review and synthesis of qualitative studies of caregivers' views. *BMC Pediatrics*, *14*(1), 63. <https://doi.org/10.1186/1471-2431-14-63>
- Schmidt, R., Lee, T., Winstein, C., Wulf, G., & Zelaznik, H. (2018). *Motor control and learning: A behavioral emphasis*. [https://books.google.com/books?hl=en&lr=&id=EvJ6DwAAQBAJ&oi=fnd&pg=PR1&dq=Schmidt,+R.+A.,+%26+Lee,+T.+D.+\(2005\).+Motor+control+and+learning:+A+behavioral+emphasis+\(4th+ed&ots=k5ErhJkaNH&sig=aYtR5HmJQUBLFyJddRThmWGBkkg](https://books.google.com/books?hl=en&lr=&id=EvJ6DwAAQBAJ&oi=fnd&pg=PR1&dq=Schmidt,+R.+A.,+%26+Lee,+T.+D.+(2005).+Motor+control+and+learning:+A+behavioral+emphasis+(4th+ed&ots=k5ErhJkaNH&sig=aYtR5HmJQUBLFyJddRThmWGBkkg)
- Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing*, *19*(17–18), 2629–2638. <https://doi.org/10.1111/j.1365-2702.2010.03214.x>
- Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2003). How do primary care physicians identify young children with developmental delays? A national survey. *Journal of Developmental and Behavioral Pediatrics*, *24*(6), 409–417. <https://doi.org/10.1097/00004703-200312000-00002>
- Steiner, A. M. (2011). A Strength-Based Approach to Parent Education for Children With Autism. *Journal of Positive Behavior Interventions*, *13*(3), 178–190. <https://doi.org/10.1177/1098300710384134>
- Sweeney, R. D. (1972). Hermeneutic Phenomenology: The Philosophy of Paul Ricoeur. *International Philosophical Quarterly*, *12*(1), 140–142. <https://doi.org/10.5840/IPQ197212124>
- Taylor, N. F., Dodd, K. J., McBurney, H., & Graham, H. K. (2004). Factors influencing adherence to a home-based strength-training programme for young people with cerebral palsy. *Physiotherapy*, *90*(2), 57–63. <https://doi.org/10.1016/j.physio.2003.09.001>
- Tétreault, S., Parrot, A., & Trahan, J. (2003). Home activity programs in families with children presenting with global developmental delays: evaluation and parental perceptions. *International Journal of Rehabilitation Research*, *26*(3), 165–173. <https://doi.org/10.1097/01.mrr.0000088441.78481.56>
- Thelen, E. (1989). The (Re)Discovery of Motor Development: Learning New Things From an Old Field. *Developmental Psychology*, *25*(6), 946–949.

- <https://doi.org/10.1037/0012-1649.25.6.946>
- Tracy, S. J. (2010). Qualitative Quality: Eight “Big-Tent” Criteria for Excellent Qualitative Research. *Qualitative Inquiry*, *16*(10), 837–851.
<https://doi.org/10.1177/1077800410383121>
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, *11*(1), 80–96. <https://doi.org/10.1177/1473325010368316>
- Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of Family–Professional Partnerships: Collective Empowerment as the Model for the Early Twenty-First Century. In *Handbook of Early Childhood Intervention* (pp. 630–650). Cambridge University Press. <https://doi.org/10.1017/cbo9780511529320.029>
- Wang, E. E. (2011). Simulation and Adult Learning. *Disease-a-Month*, *57*(11), 664–678. <https://doi.org/10.1016/j.disamonth.2011.08.017>
- Whittingham, K., Wee, D., & Boyd, R. (2011). Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child: Care, Health and Development*, *37*(4), 475–483. <https://doi.org/10.1111/J.1365-2214.2011.01212.X>
- Wright-St Clair, V. (2014). *Doing (interpretive) phenomenology*. Routledge.
<https://doi.org/10.4324/9780203383216-14>
- Yang, J. F., Livingstone, D., Brunton, K., Kim, D., Lopetinsky, B., Roy, F., Zewdie, E., Patrick, S. K., Andersen, J., Kirton, A., Watt, J. M., Yager, J., & Gorassini, M. (2013). Training to enhance walking in children with cerebral palsy: are we missing the window of opportunity? *Seminars in Pediatric Neurology*, *20*(2), 106–115.
<https://doi.org/10.1016/J.SPEN.2013.06.011>
- Zwicker, J. G., & Harris, S. R. (2009). A reflection on motor learning theory in pediatric occupational therapy practice. In *Canadian Journal of Occupational Therapy* (Vol. 76, Issue 1, pp. 29–37). Canadian Association of Occupational Therapists.
<https://doi.org/10.1177/000841740907600108>

Appendices

Appendix A: List of Semi-structured Interview Questions

The initial semi-structured interview guide is listed below (Peplow & Carpenter, 2013):

- Tell me in your own words about your experience helping your child do their exercise program.
- Who do you think should be involved in helping your child with their exercises?
- What motivates you to help your child with the program?
- What makes it hard for you to help your child follow the program?
- What has made it easier for you to help your child with the program?
- What involvement did you have in deciding which exercises were appropriate for your child to do at home?
- What would you do differently or change about your child's exercise program?
- What impact/effect do you think the exercise program has on your child's life?
- Does it have any impact on your life?

The following questionnaire is adapted from (Lillo-Navarro et al., 2015):

Regarding your experience with the home exercise program:

1. Does the home program fit your daily routine?
2. Do understand your child's home program?
3. Do you feel skilful in carrying out the home program?
4. How confident are you about performing the home program?
5. Do you have any supports at home to help complete your child's program?
6. Do you have the equipment you need to do the exercises at home?

Regarding the therapist's involvement:

7. Does your therapist give you information regarding your child's progress?
8. Does your therapist explain the usefulness of the exercises?
9. Does your therapist give you written instructions or another method of explaining and remembering the exercises?
10. How does your therapist explain the exercises to you?
11. Does your therapist give you advice on how to include exercises into daily routines?

12. Does your therapist regularly check your skills at performing the exercises?
13. Does your therapist ask you about my adherence to the exercises at home?
14. If you had to mark from 1 to 10 your overall satisfaction with the attention from your therapist, what would your score be?

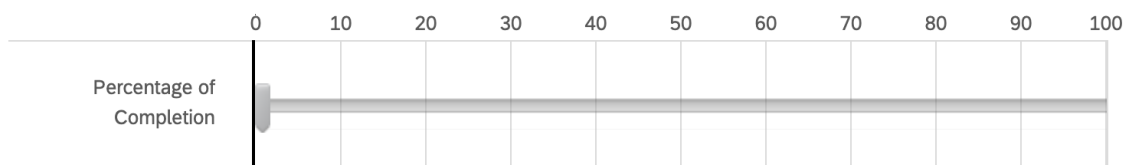
Appendix B: Weekly Electronic Survey Measuring Level of Adherence to Prescribed Home Exercises

1. Did you complete the assigned home exercises with your child this week?

Yes

No

2. What percentage of the home exercises were you able to complete this week?



Percentage of Completion

3. What, if any, were some reasons that made it difficult to complete the home exercises this week? Please select all that apply:

Child and Family Related Factors

Therapist Related Factors

Environmental Factors

Therapy Related Factors

Other

None

4. Among child and family related factors, please select the reasons that might have affected your ability to complete the home exercises

My child's behavioural status

My child's physical response to home exercises (couldn't complete activity due to physical reasons)

Parental or caregiver behavioural status (e.g. couldn't complete activity due to feeling under the weather, etc.)

5. Among the therapist related factors, please select the reasons that might have affected your ability to complete the home exercises. Select all that apply.

Clinical competency (knowledge and skills) of your therapist

Therapist's communication skills

Other:

6. Among the environmental factors, please select the reasons that might have affected your ability to complete the home exercises. Select all that apply.
 - Lack of equipment at home
 - No ideal space to perform home exercises
 - Other:
7. Among therapy related factors, please select the reasons that might have affected your ability to complete the home exercises. Select all that apply.
 - Length and/or amount of home exercises
 - Difficulty and/or complexity of home exercise
 - Other:
8. Please share any other reason(s) that made it difficult to complete the home exercises that was not previously mentioned
9. If any, please share any additional comments regarding your ability to complete this week's home exercises

Appendix C: Ethics Approval Notice



Date: 27 May 2021

To: Dr. Laura Brunton

Project ID: 115539

Study Title: The Effectiveness of Joint Planning in Pediatric Rehabilitation Parent and Child related Outcomes

Reference Number/ID: Version 4 - Version Date Feb 24 2021

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 08/June/2021

Date Approval Issued: 27/May/2021

REB Approval Expiry Date: 26/Aug/2021

Dear Dr. Laura Brunton ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Protocol Joint Planning V4 Apr 22 2021	Protocol	22/Apr/2021	4
Adherence Qualtrics Survey	Online Survey	22/Apr/2021	1
Semi-Structured Interview Questions	Interview Guide	22/Apr/2021	1
Consent form for ParentChild V9	Consent Form	13/May/2021	9

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Karen Gopaul , Ethics Officer on behalf of Dr. Joseph Gilbert, HSREB Vice-Chair

Note: *This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*

Curriculum Vitae

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Post-secondary Education and Degrees: University of Western
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