EXPLORING FACTORS ASSOCIATED WITH READINESS TO CHANGE DURING THE ACQUISITION OF MOTOR ABILITIES IN YOUNG CHILDREN WITH CEREBRAL PALSY

by

Karen Ann Sauve
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ABSTRACT

Purpose: The timing of physiotherapy intervention for optimal motor outcomes in children with cerebral palsy (CP) remains unknown. Dynamic Systems Theory (DST) suggests this timing is during transition periods when new motor behaviour is emerging; transition periods are identified by increased variability in motor performance. Additionally, factors within the child and environment are thought to influence motor acquisition. The aim of this study was to explore the relationships between these factors and motor acquisition in young children with CP. Specifically the following were examined:

1. a) Variability in motor abilities during a preceding time interval,
   b) Variability in motor performance during a preceding time interval,
2. Child factors, and
3. Environmental factors.

Methods: For this case series, the sample comprised five children with CP, aged three to five years, and classified in levels I to III of the Gross Motor Function Classification System. Each child's gross motor abilities and performance were assessed during ten home visits using the Gross Motor Function Measure and the Quality FM respectively. Mastery motivation and engagement in daily life were assessed through questionnaires. Environmental factors were described using field notes at each home visit.

Results: No associations were found between a) variability in motor abilities or b) variability in motor performance and subsequent motor acquisition in each child individually nor when data were pooled across children. Mastery motivation was inversely associated with motor change (r_s=-0.90, p=0.04) for the pooled data set. Child engagement and GMFM scores were not related nor were there trends in field note data with GMFM change scores.

Conclusions: Although this study failed to identify associations between the factors explored, the results were likely impacted by the inability of the measurement tools used to capture subtle changes in motor behaviour in this sample. Further investigation is warranted using a larger, diverse sample of children with CP using nonlinear tools designed to measure movement variability. Greater understanding of the implications of variability on the emergence of motor abilities in this population could offer critical insight into how children with CP acquire motor abilities and select optimal motor strategies under task constraints.

PREFACE

The master's candidate designed this study with invaluable guidance from the supervisory committee: Dr. Liisa Holsti, Dr. Doreen Bartlett, and Ms. Lori Roxborough. Additional input was provided by Dr. Virginia Wright related to the use of the Quality FM, training with this tool, and answering administrative questions throughout data collection and analysis. The master's candidate collected all data and performed analyses with guidance from Dr. Bartlett. Finally, the candidate wrote this thesis manuscript in full with ongoing editing contributions from all three committee members.

A version of the Dynamic Systems Theory information in Chapter Two has been published online. Sauve, K. & Bartlett, D. (2010). *Dynamic systems theory: A framework for exploring readiness to change in children with cerebral palsy*. From, http://canchild.ca/en/canchildresources/dynamic_systems_theory.asp

The developers of each outcome measure used in this study provided permission for the use and inclusion of their respective measure in this thesis. Copyright information is indicated on the required measures in the appendices.

The UBC C&W Behavioural Research Ethics Board approved this research project; the approval certificate number is H09-01386.

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LIST OF ABBREVIATIONS

AACPDM……American Academy for Cerebral Palsy and Developmental Medicine

APTA……American Physical Therapy Association

BREB……Behavioural Research Ethics Board

CP……..……Cerebral Palsy

CPA…….Canadian Physiotherapy Association

DMQ……...Dimension of Mastery Questionnaire

DST……..Dynamic Systems Theory

GMAE……..Gross Motor Ability Estimator

GMFCS……..Gross Motor Function Classification System

GMFM…….Gross Motor Function Measure

GMPM……...Gross Motor Performance Measure

ICC……...Intraclass Correlation Coefficient

ICF……International Classification of Functioning, Disability and Health

PT……..Physiotherapy or Physiotherapist

QFM……Quality FM

r_s……..Spearman Rank Correlation Coefficient or Spearman rho

WHO……..World Health Organization

GLOSSARY

Age-90

Age-90 refers to the age at which children with cerebral palsy are expected to achieve ninety percent of their motor acquisition as measured by the Gross Motor Function Measure (GMFM) (Rosenbaum et al., 2002). This age differs for children classified in each level of the Gross Motor Function Classification System (Rosenbaum et al., 2002).

Cerebral Palsy

Cerebral Palsy (CP) is a group of non-progressive conditions which affect movement and posture causing activity limitation (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Children with CP may present with impairments in body structures and functions including communication, cognition, behaviour, sensation and percption, among others (Rosenbaum et al., 2007). CP affects 2 to 2.5 per 1000 live births in Canada (Statistics Canada, 2004).

Gross Motor Function Classification System

The Gross Motor Function Classification System (GMFCS) is a valid and reliable classification system of children with CP according to their gross motor ability (Palisano et al., 1997). Developed by researchers at the *CanChild* Centre for Childhood Disability Research, the GMFCS describes five levels which range in abilities, from Level I "Walks without restrictions", to Level V "Self-mobility is severely limited" (Palisano et al., 1997)

Mastery Motivation

Mastery motivation is a quality inherent to a person which drives them to attempt to master a task that is moderately challenging (Morgan & Bartholomew, 1998).

Motor Growth Curves

The motor growth curves were initially developed by a group of researchers at *CanChild* Centre for Childhood Disability Research using a large sample of children with CP across Ontario, Canada (Palisano et al., 2000). The purpose of creation of the curves was to understand gross motor development in children with CP based on GMFM scores and offer prognostic information about motor development for children classified in each level of the GMFCS (Palisano et al., 2000). Further prognostic information from these curves was provided by work from Rosenbaum et al. (2002) and Hanna et al. (2009). The motor growth curves are referred to extensively in research and practice.

Physiotherapist

In Canada, physiotherapists are university educated, primary health care professionals (Canadian Physiotherapy Association [CPA], 2010). Physiotherapists possess comprehensive knowledge of how the body functions and moves (CPA, 2010). With this knowledge combined with specialized clinical training, physiotherapists work with people of all ages and diagnoses to assess and treat impairments in body structures and functions while promoting improved activity and participation (CPA, 2010).

ACKNOWLEDGEMENTS

What a journey! Over the past two years, I have learned a tremendous amount about the research process, the literature related to this thesis and the application of research to practice. How do I thank my committee members enough? Liisa, Doreen and Lori: I truly value all of the time you have dedicated to me and to this project throughout this experience. Thank you for all the timely and constructive feedback, guidance, support and encouragement. You all demonstrate such passion and commitment to your professions and to research; it is inspiring! Liisa, your words of wisdom and strong writing and organizational skills have been a huge asset to my learning. I hope they have rubbed off somewhat on me along the way! Doreen, your comprehensive knowledge of this field, ability to direct to me relevant literature and contacts at the drop of a dime, and willingness to work across time zones have been invaluable to me; thank you. Lori, I appreciate your open door policy and advice through recruitment challenges. To you and the rest of my colleagues at Sunny Hill Health Centre for Children, thank you for the flexibility in my work schedule and genuine interest in my project.

I would like to express a heartfelt thank you to my family, friends and fellow graduate students for always extending a listening ear, offering advice, sharing experiences and celebrating with me along the way. And when the mood was not so celebratory, thanks for the distractions with exercise or good food and drink!

Through recruitment and data collection, I was privileged to work with such wonderful community physiotherapists, children and their families. Thank you so much for your time and effort contributed to this project. You opened your homes to me over four months and participated in assessment after assessment; I truly value your role in this research.

Finally, I am grateful to the Canadian Institutes of Health Research and the University of British Columbia for funding this research project.

DEDICATION

Kyle,

Your patience, optimism and support never fail to amaze me! Thank you.

On to the next adventure together!

1. INTRODUCTION

Cerebral Palsy (CP) is a group of non-progressive conditions which affect movement and posture causing activity limitation (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). CP affects 2 to 2.5 per 1000 live births in Canada (Statistics Canada, 2004). Physiotherapists collaborate with children with CP and their families, providing intervention, consultation, education, and support (American Physical Therapy Association [APTA], 2001). Because of the chronic nature of their condition, children with CP often receive these services from birth until adulthood (Russell, 2005). The goals of pediatric rehabilitation are ultimately to facilitate the child's safe participation in meaningful activities, by helping families integrate their child into home, school, and community (Russell, 2005). More specifically, aspects of physiotherapy intervention are directed at the acquisition of motor abilities, defined as "the capacity to perform a movement" (Bartlett & Palisano, 2000, p599). This capacity to perform a movement and functional mobility are thought to be important outcomes for children with CP (Tieman, Palisano, Gracely, & Rosenbaum, 2007).

Although physiotherapists agree upon these common *goals* of intervention, debate exists regarding the optimal physiotherapy intervention delivery model. Dynamic Systems Theory (DST) suggests that the best time to intervene is during transition periods (Darrah & Bartlett, 1995) which are identified by increased variability in motor behaviour (Thelen, 1989b). Thus, this study explored the potential association between increased variability in motor behaviour at one time interval with subsequent motor ability acquisition.

Chapter Two of this thesis includes a literature review to outline and critique what is known currently about how CP is classified, when children with CP acquire gross motor abilities, what physiotherapy delivery model is used currently, what changes are being proposed,

and how these changes may be influenced by Dynamic Systems Theory (DST). This review of the literature will provide the rationale for the conducted research project.

Chapter Three presents a thorough description of the methods used for this study. This chapter focuses on the design, recruitment strategies, inclusion criteria and exclusion criteria of the sample. Additionally, the characteristics of the children in the sample and the study protocol are described in detail. Finally, this third chapter details the outcome measures used to collect the data for the study and the analyses used to investigate each of the three study aims.

Chapter Four outlines the results of the study; they are presented according to the study aims. Tables and figures are used for clarity and statistical significance is indicated where relevant. Results from descriptive data are reviewed separately from data used to calculate potential associations.

Finally, Chapter Five provides a discussion regarding the implications and potential explanation for the study results. The findings are compared to current and relevant literature while the strengths and limitations of the study are outlined. Lastly, recommendations for future research and for clinical practice are provided followed by concluding remarks.

1.1 Study Questions

This exploratory study was conducted to investigate three research questions.

1. Does a relationship exist between variability in a) motor function and b) motor performance in young children with CP and subsequent motor ability acquisition?
2. What is the association between child factors, such as mastery motivation and engagement in daily activities, and the acquisition of motor ability in young children with CP?

3. What is the influence of environmental factors on the acquisition of motor ability in young children with CP?

2. LITERATURE REVIEW[1]

2.1 Classification of Cerebral Palsy

Investigators at *CanChild* Centre for Childhood Disability Research at McMaster University developed a valid and reliable classification system of children with CP according to their gross motor ability (Palisano et al., 1997). The Gross Motor Function Classification System (GMFCS) describes five levels which range in abilities, from Level I "Walks without restrictions", to Level V "Self-mobility is severely limited" (Palisano et al., 1997). The differences between each level correspond to variations in gross motor function "that are thought to be meaningful in the daily lives of children with CP" (Palisano, Rosenbaum, Bartlett, & Livingston, 2008, p. 744). The GMFCS is an important communication tool for use among clinicians, researchers, and families to describe each child's gross motor function, and to assist in decision-making, in goal setting, and in the management of care (Palisano et al., 2008).

According to the GMFCS, children classified in level I will acquire functional independent walking abilities before their second birthday and may be able to run and jump by age six years (Palisano et al., 1997). Children classified in level II typically begin to walk with an assistive device by age four years, sit in a chair with hands-free by six years, and walk indoors without the assistive device by six years (Palisano et al., 1997). Similarly, children in level III may walk with an assistive device by four years and continue to use the assistive device for walking indoors and out (Palisano et al., 1997). Conversely, children classified in GMFCS levels IV and V usually do not achieve independent walking skills, rather may gain independent mobility using a power wheelchair, with or without adaptations (Palisano et al., 1997). Furthermore, the GMFCS and the motor growth curves (Rosenbaum et al., 2002), provide

[1] A version of the Dynamic Systems Theory information in Chapter Two has been published online. Sauve, K. & Bartlett, D. (2010). *Dynamic systems theory: A framework for exploring readiness to change in children with cerebral palsy*. From, http://canchild.ca/en/canchildresources/dynamic_systems_theory.asp

critical information regarding the trends and variability of development of motor abilities in children with CP. Evidence reveals that children with CP reach ninety percent of their motor function by five years of age in GMFCS levels I and II, and at progressively younger ages in levels III to V (Rosenbaum et al., 2002). To determine these reported attainment targets, motor function was assessed using the Gross Motor Function Measure (GMFM) (Russell, Rosenbaum, Avery, & Lane, 2002).

Although the GMFCS and motor growth curves provide critical prognostic information about *when* children with CP acquire motor abilities, they do not tell therapists *how* children with CP acquire these abilities. Knowing how they acquire motor abilities and how to identify the onset of that acquisition could provide important clues as to the timing of therapy so that optimal motor function is achieved.

2.2 Physiotherapy Delivery Models

Currently, physiotherapy intervention is not scheduled to match what is known about when children with CP acquire motor abilities. Indeed, a study by Kaminker, Chiarello, O'Neil, and Dichter (2004) surveyed physiotherapists providing services to children with motor impairments in the school setting, and found that the most common therapy schedule provided by therapists was one session per week for a period of thirty minutes, regardless of the child's phase of motor learning. This schedule is similar to therapy approaches used internationally; Bower, McLellan, Arnery, and Campbell (1996) reported that therapy in the UK is provided as a continuous process from birth until adulthood. These authors (Bower et al., 1996) thought that therapy is provided for its "presumed long term and cumulative effects" (p. 235). Evidence fails to support these presumed benefits using this once weekly therapy schedule. Rather, Piper (1990) recommended that to promote motor development, physiotherapy must be offered a minimum of twice per week.

2.3 Outcomes of Intensive Physiotherapy Delivery Models

A lack of consensus in the literature exists regarding the optimal therapy schedule for children with CP (Parette, Hendricks, & Rock, 1991). Several investigators have examined the effects of increased intensity of physiotherapy on motor outcomes in this population (Bower & McLellan, 1992; Bower et al., 1996; Bower, Mitchell, Burnett, Campbell, & McLellan, 2001; Christiansen & Lange, 2008; Schreiber, 2004; Trahan & Malouin, 2002; Tsorlakis, Evaggelinou, Grouios, & Tsorbatzoudis, 2004). In all studies, an increased intensity referred to providing children with therapy more frequently than conventional therapy, typically described as one session per week. Most studies defined intensive physiotherapy as a minimum of three sessions per week. In a randomized controlled trial, Bower and colleagues (2001) examined an intensive approach over the longest time frame by comparing intensive therapy to typical therapy over six months in a group of children aged three to twelve years, assessed at GMFCS levels III to V. Their intensive group received one hour of therapy daily, five days per week, for the six-month period. The authors monitored change in motor performance and function using the Gross Motor Performance Measure (GMPM) (Boyce et al., 1995) and GMFM. No statistically significant difference between groups was found. Importantly, the intensive group participants, family, and therapists reported fatigue from the demanding therapy schedule. However, it is not clear how much change in motor ability the authors expected out of this population with either therapy schedule. Evidence shows that children in GMFCS levels III to V attain approximately ninety percent of their motor function before four years of age (Rosenbaum et al., 2002). This limit is referred to as 'age-90' which is defined as the age at which children with CP are expected to achieve ninety percent of their motor acquisition as measured by the GMFM (Rosenbaum et al., 2002). Thus based on the outcome measures used in this study, further gains

in motor ability acquisition in children in this study were unlikely irrespective of changes in therapy regimes.

In contrast, more promising improvements were found in a case report examining shorter bursts of intensive therapy for a thirty-one month-old girl with a diagnosis of 18p- chromosomal abnormality (Schreiber, 2004). Schreiber (2004) studied the effects of increasing physiotherapy intervention for this young girl from one session every two weeks, to four sessions per week for four weeks. Improvements were noted on her GMFM and on Goal Attainment Scaling scores. Although these were not statistically significant results, the child's family noted functionally meaningful improvements in her motor abilities. Furthermore, the author found that the four-week time frame was well tolerated by the child and the family, and they remained committed and involved throughout the intensive period. Using a more rigorous study design and a larger sample, Bower et al. (1996) completed a randomized controlled trial looking at intensive versus conventional therapy, and aim- versus goal-directed therapy in a sample of forty-four children with a diagnosis of quadriplegic CP aged three to eleven years. Their intensive therapy regime consisted of one hour of physiotherapy daily, five days per week for two weeks. The children's motor function was assessed using the GMFM by an assessor blind to the amount and type of therapy received. The authors found that the greatest change in motor function was noted in the group receiving a combination of intensive therapy directed by parent- and therapist-identified goals. Although the results did not reach statistical significance, a clinical difference in scores was achieved. Bower and colleagues suggested that potentially more intensive physiotherapy targeted at specific goals could accelerate motor ability acquisition over a longer period of time. Perhaps repeating this study design with younger children classified in GMFCS levels I to III may have generated improved results.

Consequently, Tsorlakis and colleagues (2004) found that their results support the use of an intensive regimen of physiotherapy with a sample of thirty-four children with CP, classified in GMFCS levels I to III, aged three to fourteen years. Using a small randomized controlled trial, these authors stratified and matched their sample by age, sex and distribution of CP (i.e., hemiplegia, diplegia, quadriplegia). From the description of their sample, it appears the children were matched by GMFCS levels as well. The intensive group (group A) received physiotherapy intervention five times per week while the conventional group (group B) received therapy twice weekly; groups were seen for a total of sixteen weeks. Both groups demonstrated significant improvements in motor abilities as measured with the GMFM ($p<0.05$). The intensive group showed significantly greater improvements than the conventional group ($p=0.02$). Also, they found a significant difference between age groups from the first age group (three to five years) to the third age group (ten to fourteen years), with the younger children demonstrating greater change in GMFM scores ($p=0.05$). Further strengths of the study included blinded assessments of the children, achievement of a high power level, and ninety percent attendance for the intervention sessions with few dropouts; these findings show promise for the efficacy of an intensive therapy schedule.

2.4 Outcomes of Matching Intensive Physiotherapy With Stages of Motor Learning

Considerable discussion in pediatric rehabilitation regarding optimal service delivery models for children with CP is taking place. This debate is fueled by the desire to improve motor outcomes by matching therapy timing with the readiness of the child. Indeed, this issue was discussed at the American Academy of Cerebral Palsy and Developmental Medicine's (AACPDM) 2008 annual meeting in Atlanta, Georgia. Dr. Robert Palisano, Professor in the Physical Therapy and Rehabilitation Sciences Programs at Drexel University (Philadelphia) and Susan Murr, Cerebral Palsy Program Manager at Gillette Children's Specialty Healthcare Centre

(Burnsville, Minnesota) participated in the Point-Counter-Point discussion, "PT for Children with CP: Intensive or Intermittent". Palisano and Murr debated service delivery models for children with CP. They explained that there are stages of response competence (Alberto & Troutman, 1999) which are useful in the application of motor learning principles to children with movement disorders. According to Palisano and Murr, each stage is subsequently linked to a recommended service delivery model.

These presenters explained that the initial stage of motor learning is the *acquisition phase*, during which the new motor ability is emerging (Alberto & Troutman, 1999). During this phase, direct intervention should be provided for best outcomes. However, several questions remain unanswered: *What should that episode of care consist of, related to frequency and intensity of therapy? What schedule approach would optimize outcomes for children with CP while acquiring a new motor ability?* According to the Guide to Physical Therapist Practice (APTA, 2001), an episode of care is an "unbroken sequence of intervention…consisting of a set number of visits…provided for a given problem or related to a request from the client and family" (p. 40).

The acquisition phase is followed by the *fluency phase*, which relates to the rate of performance of the newly acquired motor ability (Alberto & Troutman, 1999). Palisano debated that direct intervention, either using an individual or small group approach, is best for this phase of motor learning. During the *maintenance* and *generalization phases*, children learn to use that new motor ability repeatedly without requiring re-teaching, and in multiple settings and environments (Alberto & Troutman, 1999). Consultative therapy services were suggested for these phases which may resemble an episode of physiotherapy maintenance (APTA, 2001). Physiotherapy maintenance consists of a series of occasional visits addressing clinical,

educational, or administrative needs (APTA, 2001). The approach proposed by Palisano and Murr is to match the child's stage of motor learning with corresponding episodes of care.

Some studies support Palisano and Murr's suggested therapy schedule and framework of motor development (Bower & McLellan, 1992; Christiansen & Lange, 2008; Schreiber, 2004; Trahan & Malouin, 2002; Tsorlakis et al., 2004). Benefits were found when pairing short bursts of intensive therapy with subsequent rest periods, or return to conventional therapy. In a multiple baseline pilot study, Trahan and Malouin (2002) posited that combining intensive periods with rest periods has the potential to optimize the effects of therapy in younger children. They examined a regime of intensive therapy offered four sessions weekly, for four weeks, followed by eight weeks of rest (no therapy provided). This cycle was repeated twice over six months. Theoretically, the sample recruited in this study had potential to change on the GMFM according to the motor growth curves (Rosenbaum et al., 2002); the five children were aged ten to thirty-seven months, and classified in GMFCS levels IV and V. Significant improvements were noted in GMFM scores for three out of five children during the intensive periods, as assessed by a blind evaluator. Both children who did not show significant improvements were close to the average age-90 for their GMFCS levels. All children maintained their motor abilities during the rest periods; no deterioration in motor abilities was found over the eight weeks of rest. The authors clearly outlined the treatment protocol provided and reported a compliance rate of 93.1% once the intensive period began. However, the authors suggested that intensive episodes of physiotherapy should not be provided for longer than four weeks at a time as some participants were reporting fatigue by the end of the fourth week.

Although providing a lower level of evidence, Bower and McLellan (1992) found that increasing the intensity of physiotherapy can accelerate the acquisition of motor abilities. They assessed change in motor function in seven children with quadriplegic CP and severe learning

difficulties, aged two to twelve years. Acting as their own control group, these children received three weeks of conventional therapy followed by three weeks of intensive therapy (five hours/week), with a subsequent return to conventional therapy for three weeks. Before the study protocol began, the physiotherapists set two measurable, short-term goals for each child. These goals were then categorized; all motor-related goals could be linked to items on the GMFM. All seven children demonstrated significant improvement in these goal-linked items on the GMFM and improved scores on other non-goal-linked GMFM items (which did not reach significance). Further, thirteen out of fourteen parents and teachers involved expressed preference for the intensive therapy regime. When the tasks were associated with functional daily activities, some motor abilities were maintained and even improved during the final (conventional) therapy phase of this study. For children with severe CP, such as those in this sample, the maintenance of motor function (i.e., GMFM score) is a desirable outcome of intervention (Weindling, Cunningham, Glenn, Edwards, & Reeves, 2007).

Finally, using a small prospective randomized controlled trial, Christiansen and Lange (2008) compared the effects of an intensive therapy schedule - four times per week for four weeks, alternating with a six week pause in treatment, repeated three times, to thirty weeks of continuous twice-weekly therapy. Prior to randomization, the twenty-four children in the sample were stratified by: age group (one to three years, four to ten years) and GMFCS levels (I and II combined, III alone, IV and V combined). Significant improvements in GMFM scores were found for both groups over the thirty weeks ($p=0.03$ for intensive group; $p=0.04$ for the continuous group). The results indicated no significant correlation between GMFM change score and age. Perhaps more narrow age bands would have revealed different findings. However, a significant correlation between GMFM change score and GMFCS level was found for the entire group combined ($p=0.01$). The authors concluded that their study did not support the use of

intensive therapy over continuous therapy for children with CP. Similarly, the authors of a small meta-analysis concluded that there is insufficient evidence to support an intensive therapy approach definitively; nevertheless, trends demonstrate support of this approach, particularly with children younger than two years of age (Arpino, Fenicia Vescio, De Luca & Curatolo, 2010).

It seems that critical to the efficacy of the treatments is that the intensive episodes of care are provided as a child is *acquiring* new motor abilities (Schreiber, 2004). As Palisano and Murr suggested at the AACPDM, direct episodes of therapy are recommended during the *acquisition phase* of motor development. This matching process has the potential to accelerate the acquisition of these new motor abilities (Bower & McLellan, 1992). Evidence has suggested the critical need to allow the child opportunity for independent practice of those new motor abilities in various settings throughout the *fluency* to *generalization phases* of motor development (Schreiber, 2004). Schreiber (2004) emphasized that reduced or no therapy should be provided during these phases to allow the child to work on *fluency and generalization*. Trahan and Malouin (2002) found that some of the children's motor function actually continued to increase during the rest periods, suggesting that practice of the new motor abilities in the child's natural environment through daily activities, or generalization of their abilities, promoted consolidation of the motor abilities learned in therapy. Bower and McLellan (1992) also found that gains were maintained during the return to conventional therapy following intense therapy. The new motor abilities must be implemented into the child's daily functional activities with the opportunity for practice without increased assistance from caregivers (Bower & McLellan, 1992). This finding suggests that meaningful motor activities that can be practiced and generalized by the child can continue to develop even when physiotherapy treatment is reduced or stopped temporarily. These findings support the claim that intervention to improve specific motor abilities must

consider the generalization of those abilities into daily life in order to be effective (Hanft & Feinberg, 1997). A survey of physiotherapists working in early intervention demonstrated that therapists agree that it is "very to extremely important" to emphasize functional activities and to ensure gains are generalized to other settings during intervention (O'Neil & Palisano, 2000).

This promising evidence suggests many benefits of providing goal-directed episodes of care, or bursts of physiotherapy, followed by rest breaks or conventional therapy. Aside from acceleration of motor acquisition, investigators agree that this therapy approach is cost-effective (Schreiber, 2004; Trahan & Malouin, 2002), improves communication between therapists and families (Trahan & Malouin, 2002), and promotes family-centred care (Hanft & Feinberg, 1997; O'Neil & Palisano, 2000; Trahan & Malouin, 2002). Trahan and Malouin (2002) found that families enjoyed the rest periods as they felt that they could have a more normal family life during that time.

Although evidence supports intensive therapy during the acquisition phase, followed by reduced therapy to allow for generalization, it remains unclear *when* the child is most ready to benefit from intensive therapy. There is a lack of literature regarding how to identify a child's readiness to change. Schreiber (2004) suggested that the readiness of the child encompasses the child's endurance to participate in frequent therapy, along with cognitive and behavioural factors, such as motivation and willingness. Schreiber (2004) explained further that if a child begins to maintain a certain posture for longer durations, requires less support from the therapist or caregiver, or begins to initiate weight-shifting independently, that these signs may indicate a readiness of the child (p. 66). Similarly, Bower and her colleagues (1996) alluded to readiness of the child as they explained that intensive episodes of care should be provided to change a motor behaviour "when the child displays the wish to do so" (p. 234). They also reported that the child must "demonstrate the appropriate behaviours" to change from "could do" to "does do"

(p. 235). The therapists surveyed by O'Neil and Palisano (2000) agreed that the child's characteristics are the most important factor when determining frequency and duration of services. Further work is required to explore the theoretical basis of readiness to change and to determine which characteristics impact readiness to change in a child, such as motivation and behaviour.

2.5 Assessment of Children with Cerebral Palsy

Before determining how to implement this new "intensive burst" physiotherapy service delivery model, a thorough assessment of the child is critical. The International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2007) provides a framework to guide physiotherapy assessment, goals, and intervention (Wright, Rosenbaum, Goldsmith, Law, & Fehlings, 2008a). When setting goals related to function, the ICF highlights the need to evaluate aspects of the child's body functions and body structures along with environmental and personal factors (Bartlett et al., 2006). In providing a framework for this broader evaluation, the ICF has prompted a shift in physiotherapy, from "minimizing deficits to enhancing functional success and participation in spite of persisting deficits" (Majnemer et al., 2008, p. 751). It emphasizes that function is the "positive outcome", produced by the "interaction among body structures, body functions, activity and participation" (Bartlett et al., 2006, p. 1170). To optimize motor outcomes in treatment, the impact of personal and environmental factors, and the interaction among those factors, can be examined as well (Bartlett et al., 2006). There is a need for physiotherapy to evaluate and to address those factors of the child's personality, such as motivation, which are thought to influence mobility (Tieman et al., 2007).

Despite the ICF's use as a classification tool and framework for thorough assessment of children with CP, it fails to provide information about when the child is most ready for

intervention. A review of Dynamic Systems Theory (DST) may provide insight into when to implement the proposed changes to the way in which physiotherapists assess and deliver treatment to children with CP.

2.6 Dynamic Systems Theory

DST is a theoretical framework of motor development applied in the management of children with CP (Darrah & Bartlett, 1995) which highlights that motor solutions result from the interaction of developing subsystems (Thelen, 1989a). Specifically, the most efficient motor solution evolves from the *self-organization* of subsystems within the child, task and environment (Thelen, 1989a; Thelen, Kelso, & Fogel, 1987). No subsystem is thought to have greater influence than the others in determining the resulting motor outcome (Thelen et al., 1987). The principle of self-organization suggests that a child's motor performance for a specific task should be assessed within the desired functional context (Darrah & Bartlett, 1995).

This framework can provide insight into identifying when a child is ready to develop new motor abilities. DST provides strong theoretical assumptions about behavioural organization and change, particularly related to the concept of *transition states* (Smith & Thelen, 1993). Transition states are periods of destabilization; they are the most likely periods to observe new motor behaviours (Darrah & Bartlett, 1995). During this time, a small change in one critical parameter can cause the whole system to self-organize leading to a new motor option (Thelen et al., 1987). This concept demonstrates the nonlinearity of motor development (Thelen, 1989a). Theoretically, transition periods represent a clinical "window of opportunity" or the optimal time to intervene (Heriza, 1991; Law et al., 1998) as a result of the pending change and associated new movement solutions. These periods can act as an indicator of developmental readiness for change in motor abilities (Law et al., 1998), begging the question, *how are transition periods identified clinically to capitalize on that "window of opportunity"?*

Thelen (1989b) suggested that transition periods are identified by increased behavioural variability or decreased stability. This variability was noted while studying reaching in infants (Thelen & Spencer, 1998); they observed variable performance indicated by poor targeting and increased shakiness prior to the onset of a stable, consistently targeted movement in their sample. This increase in variability is thought to elicit a phase shift driving the system to change (Harbourne & Stergiou, 2009). However, the identification of variability and transition periods in a clinical context continues to present a challenge. Darrah and Bartlett (1995) stressed the importance of this issue over a decade ago urging that "transition" needs to be defined in a way that captures the multitude of patterns through which children demonstrate this concept. The authors highlighted further that therapists possess specific observational skills which can contribute to the clinical identification of indicators of transition. Using these observational skills while assessing children repeatedly over time with developmental outcome measures is key to identifying this variability in performance clinically and observing how children explore new movement options (Case-Smith, 1996). Other researchers suggest that parents possess observational skills to identify transition periods, such that goals identified by parents were accurate in determining readiness to change (Law et al., 1998). For example, with respect to indicators for readiness to learn to walk, parents indicating that their child was letting go more and cruising more were more valid identifiers than impairment factors, such as balance reactions at the ankles.

2.7 Variability

In the literature, many different types of variability are associated with motor development. Two phases of variability in motor development have been proposed, with the first phase beginning during early fetal life (Hadders-Algra, 2000). The author suggested that *primary variability* is illustrated by general exploratory movements. Features of these

movements include variable speed and amplitude, lack of sequence and the involvement of all body parts (Hadders-Algra, 2000). Abnormal general movements, specifically those that lack variation, are strong indicators of CP (Hadders-Algra, 2000). *Secondary or adaptive variability* emerges with function-specific behaviours and exposure to a variety of experiences (Hadders-Algra, 2000). Consistent with DST, the most efficient adaptive motor strategies are thought to develop through practice, reducing secondary variability (Hadders-Algra, 2000; Thelen, 1989a). In her discussion of variability, Hadders-Algra (2000) explained that the movement of the mature, healthy adult is characterized by the ability to adapt each movement efficiently to task conditions or to produce multiple solutions for a specific task. This description of movement highlights the presence of variability in typical motor development and the importance of adaptability as a feature of a healthy system.

Stergiou, Harbourne, and Cavanaugh (2006) supported this link between variability and adaptability within a healthy system. These authors suggested that in motor development, there is an *optimal variability*. Harbourne and Stergiou (2009) described that this optimal variability is necessary for health, functional movement, and adaptive change. Human movement variability is described as the "normal variations that occur in motor performance across multiple repetitions of a task" (Stergiou et al., 2006, p. 120), in other words, the normal changes in performance that are observed when a movement is repeated under exactly the same situation. They contended that greater than optimal variability is reflected by a noisy and unstable system, while less than optimal variability indicates a rigid system that is unchanging and characteristic of abnormal development. Both of these conditions result in a system that is less adaptable to changes in the environment or context. Consistent with the tenants of DST, the authors reported that increased variability is indicative of changing behavioural states. The implication of these observations for therapists is that new motor abilities will initially be unorganized as they

emerge (Harbourne & Stergiou, 2009). The authors suggested that, through intervention, therapists should attempt to promote the development of motor abilities featuring this optimal variability. This strategy would ensure that children could adapt and generalize these movements across settings. As motor development is related to the active engagement of the child in their environment (Stergiou et al., 2006), it seems that optimal movement variability can be fostered by facilitating exploration of multiple movement strategies in multiple environments. Smith and Thelen (1993) explained that variability is an essential feature to this active exploration process rather than being considered error in movement strategies. The literature fails to indicate how much variability is considered optimal or healthy, or how much predicts change. Although the authors proposed nonlinear measures of variability (Harbourne & Stergiou, 2009; Stergiou et al., 2006), no nonlinear clinical tools to measure this construct as it relates to motor acquisition have been published.

Darrah and her colleagues provided further insight into the nonlinearity and variability of typical development in infants (Darrah, Hodge, Magill-Evans, & Kembhavi, 2003; Darrah, Redfern, Maguire, Beualne, & Watt, 1998). Through this work, they identified *intra-* and *inter-individual variability* in typical motor development. The gross motor development of forty typical infants was assessed monthly using the Alberta Infant Motor Scale; the individual infant's monthly percentile ranks demonstrated considerable variability while lacking any systematic pattern of change across infants (Darrah et al., 1998). This intra-individual variability in motor ability acquisition demonstrates the nonlinearity of typical development, consistent with DST (Darrah et al., 1998). Thus, according to these results, there are periods of development when no change in abilities was observed and other times when numerous abilities were acquired simultaneously. This developmental trend of "peaks and valleys" is reflective of a systems approach in which multiple factors within the infant, environment, and task interact to produce a

new movement (Darrah et al., 1998, p. 177). To further support the premise that typical development is nonlinear, Darrah and colleagues (2003) found considerable intra-individual variability, along with variability inter-individually (among infants) and across developmental domains. They found variable developmental trajectories and unstable patterns in the assessment of fine motor, gross motor, and communication scores longitudinally in 102 typically developing Canadian infants. Consequently, the authors highlighted that the rate of development fluctuates, reminding clinicians that there is no "gold standard" of typical development. In a more recent study, this variability in development was not unique to infants; intra- and inter-individual variability was observed in infants and preschool children up to the age of five and a half years (Darrah, Senthilselvan & Magill-Evans, 2009). These findings of intra-individual variability can be critical in identifying a child's readiness to change. If typical development features a series of peaks and valleys in motor acquisition, it is critical to determine if therapists can observe these clinically. Currently no work has been published examining this trend in children with motor impairment.

Tieman et al. (2007) published data exploring the variability in performance of children with CP. They found that children with similar gross motor capability demonstrated differences in performance of mobility methods across settings. These results show that environmental setting has an effect on the performance of mobility methods used by children with CP. The authors found that variability within each classification level captured the inter-individual variability between children related to their gross motor performance. The authors proposed that personal and environmental factors are related to that variability, as they are determinants of motor performance. Further work is needed to explore these personal and environmental factors; however, Tieman et al. (2007) indicated that perhaps the child's motivation, preferences, and personality influence their mobility.

As demonstrated, DST provides valuable information related to a child's readiness for intervention through transition periods, marked by variability. Further evidence substantiates the impact of multiple systems on the motor acquisition of children with CP. The developmental literature provides insight into how environmental factors are thought to influence motor ability acquisition.

2.8 Perception of Affordances

For decades, developmental research has explored this link between the child and the environment. Similar to DST, this work also examines the impact of multiple systems within the child and environment which contribute to motor development. Gibson (1988) explained "affordance links perception to action and links a child to its environment" (p. 4). Adolph, Eppler, and Gibson (1993a) defined affordances as "the reciprocal fit between physical properties of actor and environment that is required to perform a given action" (p. 1159). This refers to the opportunities the environment provides the child related to movement, or the "objective relationship between the child and the environment" (Adolph, Eppler, & Gibson, 1993b, p. 52). Thus, learning about affordances in the environment is an active process and entails exploration (Gibson, 1988). This process is cyclical in nature; as new information about the environment is perceived, adjustments occur in the sensory system and new action systems develop (Thelen, 1989a). New affordances are then available for further exploration and experimentation by the child (Gibson, 1988). Paralleling a systems approach to development, one small adjustment, or change in a subsystem (i.e., sensory system) causes a phase shift, or transition to the emergence of new motor abilities. Furthermore, perception of affordances can become more efficient with practice resulting in an increased "readiness for action" (Adolph et al., 1993b, p. 53).

Adolph and colleagues (1993a) found children's exploratory behaviours of the properties of a ramp changed when the affordances for walking were unclear and when risk of fall was greater. Toddlers in the study explored different mobility options for safe and efficient descent when they perceived walking to be unsafe. The authors explained that children "learn by doing" (p. 1159), and as their motor abilities change, they are capable of exploring the environment in new ways. A critical piece in perception of affordances highlighted by Adolph et al. (1993b) is that the "features of the environment must be suited to the child's capabilities in order to be exploited for action" (p. 52). Setting up the environment to match the child's current abilities allows the child to guide the activity and use the environment functionally, while learning about their own capabilities (Adolph et al., 1993b).

The impact of active exploration on motor ability acquisition has been suggested elsewhere in the literature. Bartlett and Palisano (2000) proposed that children who take pleasure from the task of active exploration might acquire motor abilities more readily. This proposition suggests that the exploration of the environment potentially has a huge impact on a child's motor ability acquisition. Furthermore, a child who takes pleasure from this process demonstrates an expressive aspect of mastery motivation (Morgan & Bartholomew, 1998). Mastery motivation is a quality inherent to a person which drives them to attempt to master a task that is moderately challenging (Morgan & Bartholomew, 1998). This quality was found to predict social-emotional adaptation and to influence the involvement in leisure activities of children with CP (Majnemer et al., 2008; Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007). A child's motivation was found to be an important factor for achieving satisfying life and their persistence in performing tasks correlated with better physical functioning (Majnemer et al., 2007). Majnemer and colleagues (2008) stressed the importance of identifying attributes of the child that may be modified, such as motivation, to promote participation and engagement of

children with CP. Similarly, Smith & Thelen (1993) suggested that motivation is a determinant of developmental change.

2.9 Summary

Through review of the literature, changes have been proposed to the current physiotherapy delivery model for children with CP. Evidence promotes the implementation of intensive bursts of physiotherapy followed by a rest break or a return to conventional therapy. However, it remains unknown when children with CP are most ready to benefit from this intensive delivery model. Throughout this paper, several factors have been proposed which are thought to be associated with the readiness to change during motor ability acquisition of young children with CP. Using DST as a theoretical framework, it is evident that increased variability can indicate transition periods, during which emergence of new motor abilities is expected (Darrah & Bartlett, 1995; Thelen, 1989b). Variability is inherent in motor development and provides meaningful information regarding the health, adaptability, and propensity to change a system (Darrah et al., 1998; Stergiou et al., 2006). Although the measurement of variability with nonlinear tools is recommended, this strategy presents a challenge to clinicians who use linear clinical measures (Harbourne & Stergiou, 2009; Stergiou et al., 2006). Further, there remain several unanswered questions regarding the identification of optimal variability in children with CP. Finally, the active exploration of the environment, the ability to perceive affordances, and the motivation of the child to do so, also seem to play an important role in motor ability acquisition.

The nature of the influence of these factors remains unknown; however, it is upon these factors that this research was conducted to investigate the following study aims:

1. To explore the relationship between variability in a) motor function and b) motor performance in young children with CP with subsequent motor ability acquisition

2. To explore the association between child factors, such as mastery motivation and engagement in daily activities, and the acquisition of motor ability in young children with CP, and

3. To explore the association between environmental factors and the acquisition of motor ability in young children with CP.

3. METHODS

3.1 Design and Rationale

A descriptive case series was used to meet the aims of this study. Currently there is a lack of research exploring the factors that are thought to be associated with the readiness to change during the acquisition of motor abilities in young children with CP; thus, this exploratory design served as a logical and acceptable starting point (Backman & Harris, 1999; Rothstein, 1993). This non-experimental design was used to capture descriptive information about each child and measure his or her gross motor function and performance over time. This method allowed for exploration of trends in data to generate hypotheses, testable using experimental designs in future research projects (Backman & Harris, 1999; Rothstein, 1993). The case series design differed from a single-subject experimental design in that there was no intervention provided (Backman & Harris, 1999).

3.2 Participants

3.2.1 Ethics and Recruitment

Ethics approval was obtained through the UBC C&W Behavioural Research Ethics Board. Recruitment occurred through: The Centre For Ability (CFA) in Vancouver, The Centre for Child Development in Surrey, Reach Child and Youth Development Society in Delta and The North Shore Pediatric Resource Team in North Vancouver. Purposive sampling was used to select participants based on specific desired criteria (Portney & Watkins, 2000). All recruitment and data collection was performed by the master's candidate. Physiotherapists were visited or contacted at each recruitment site; the research project and desired sample were discussed. Those physiotherapists approached appropriate families on their caseloads using a study pamphlet (**Appendix A**) and consent form (**Appendix B**) to describe the project and to gain a release of information consent to be contacted about the study. The family was given a period of

forty-eight hours to review the study consent form then they were contacted to provide further information, obtain informed consent and schedule the first study visit for those who consented.

3.2.2 Participant Inclusion Criteria

The targeted sample size for this study included six children with a diagnosis of CP. If a diagnosis of CP was not yet confirmed, and as recommended by Dr. Rosenbaum, the child was eligible to participate in the study if his/her physiotherapist or occupational therapist had observed a "delay in gross motor development and impairments in the following body functions and structures:

- Muscle tone,
- Righting and equilibrium reactions,
- Anticipatory postural movements of the head, trunk or legs during movement,
- Active range of motion during movement,

such that the therapist was able to answer the question 'does this child look like they have CP?'' (Bartlett, personal communication, 2009). Furthermore, the children had to be between three to four years of age (after 3rd birthday, before 5th birthday) at the time of recruitment. This criterion ensured that they had not yet reached their peak motor ability acquisition potential according to the motor growth curves (Rosenbaum et al., 2002). Recruitment was aimed at including two children classified in each of GMFCS levels I to III. These children were expected to demonstrate the greatest potential for motor change before age five years, according to the GMFCS and motor growth curves (Rosenbaum et al., 2002). Children classified within these three levels of the GMFCS are a heterogeneous sample, based on CP subtype (Beckung, Carlsson, Carlsdotter, & Uvebrant, 2007). Children in levels I and II can be diagnosed with diplegia or hemiplegia (Beckung et al., 2007), while children in level III can present with diplegia, triplegia or quadriplegia.

Children who participated in the study had to demonstrate adequate endurance to tolerate gross motor assessments using the GMFM and Quality FM (QFM), indicating an ability to

engage in forty-five minutes of gross motor play. Consequently, he or she had to be able to follow sequential two-step commands in English, consistent with the game "Simon says". The child's parents had to have fluent English skills (spoken and comprehension) in order to participate in the interviews. The family had to have adequate space (10ft x 12ft) in their home for the child's gross motor assessment for study purposes.

3.2.3. Participant Exclusion Criteria

Children were excluded from this study if they had undergone surgical intervention in the six months before the study, or had planned surgical intervention scheduled during the duration of the study. These surgeries included dorsal rhizotomy, bony, and/or soft tissue procedures which would have impact the child's motor abilities (Tieman et al., 2007). Children were also excluded if they had intra-thecal baclofen (Tieman et al., 2007), or visual or hearing impairments, which precluded their ability to undergo standardized gross motor assessment. Children receiving botox injections for the first time during the study duration were excluded, as this may have had unknown effects on their motor function. Children receiving scheduled routine injections during the study duration were eligible for participation, although this was not an issue with the recruited sample.

3.2.4 Sample

A total of seven children were recruited for this study: three from CFA, two from The Centre for Child Development, one from Reach and one from the North Shore Pediatric Resource Team. Although all seven children appeared to meet the inclusion and exclusion criteria initially, two children had a very difficult time participating in the gross motor assessments. Throughout the course of the study, it was unclear if two of the children truly understood the instructions provided to complete the items on the gross motor assessments. The parents of both children indicated that their child did not perform well with structured play and

instructions in the home setting. Often these two children would not attempt more than one trial of each item on the assessments and refused to attempt multiple items. Consequently, the data from these two children were excluded from all data analyses. One of these children was a four year-old male, diagnosed with CP (spastic diplegia) and was classified in GMFCS level II. Additionally, he had a confirmed diagnosis of Pervasive Developmental Disorder. The other child, turned five years within weeks after recruitment, was male, diagnosed with CP (right hemiplegia) and classified in GMFCS level I. His mother indicated that he was also diagnosed with severe hemophelia and a seizure disorder. During the duration of the study, he had undergone two assessments by a team of pediatricians and psychologists at Sunny Hill Health Centre for Children and they thought he had a diagnosis of Autism Spectrum Disorder. He was scheduled for a follow-up assessment to confirm the diagnosis at a date after his participation in this study.

The remaining five children met the inclusion and exclusion of the study and their data were included in all data analyses for this study. The descriptive information of each of these five children is listed in **Table 3.1**.

Table 3.1 Description of Study Participants and Their Families

Study ID	Age at Recruitment	Gender	GMFCS Level	CP Sub-type	Family Composition	Parent Employment
1	3 yrs, 4 mths	Female	I	Right Hemiplegia	Lives with mother and 2 sisters (7 yrs and newborn during study) Visits father on weekends	Mother (33 yrs) unemployed Father (36 yrs) self-employed
2	4 yrs, 11 mths	Male	I	Right Hemiplegia	Lives with foster parents and 4 siblings (13 y.o. sister, 11 y.o. sister, 9 y.o. brother, 8 y.o. sister) Supervised visits with biological mother	Foster mother (43 yrs) unemployed Foster father (45 yrs) meat cutter
3	3 yrs, 11 mths	Female	III	Diplegia	Lives with parents and brother (17 mths)	Mother (38 yrs) works midnights at liquor store Father (39 yrs) fibreglasser
4	3 yrs, 2 mths	Male	I	Diplegia	Lives with parents	Mother (24 yrs) student Father (24 yrs) stone mason
5	3 yrs, 9 mths	Male	I	Diplegia	Lives with mother, grandparents, uncle, aunt and aunt's boyfriend No contact with biological father	Mother (22 yrs) works at winery

yrs = years; mths = months; y.o. = years old

The services each child was receiving as they commenced the study were recorded as part of the detailed description of each participant. **Table 3.2** outlines the details regarding the

type and frequency of physiotherapy (PT), occupational therapy (OT), speech-language pathology (SLP) and other community services received by each participant. For the community services, parents were asked if the child participated in community recreational programs including: horseback riding, aquatics, gym programs, dance/movement programs, sports programs, or other (and whether a therapist was involved in each program). This information was captured from the Services Questionnaire (See Measures Section) completed with the parent at the initial home visit.

Table 3.2 Type and Frequency of Services Received By Each Participant At Recruitment

Study ID	PT	OT	SLP	Community
1	60 min every 2 wks	60 min every 2 wks	60 min x 1 ax	None
2	Consultation (not in mths)	60 min mthly	60 min every 2 wks	None
3	60 min wkly	60 min every 2 wks	60 min every 2 wks	Horseback riding (with PT) Gymnastics
4	30-45 min mthly	30-45 min mthly	60 min every 2 wks	Aquatics Skating
5	60 min wkly	60 min mthly (or less)	None (on wait list)	Swimming in backyard

PT = physiotherapy; OT = occupational therapy; SLP = Speech-language pathology; min = minutes; wks = weeks; wkly = weekly; mths = months; mthly = monthly; ax = assessment

When reporting the types and frequencies of services, parents were also asked to rate the focus of therapy services categorized as targeting primary or secondary impairments, limitations in activity, environment factors or restrictions in participation, using the Services Questionnaire (see Measures Section). The foci of therapy services for the participants varied from child to child, as perceived and reported by their parents (**Appendix C**).

3.3 Measures

Several measures were used in this study to describe each child systematically. Demographic information was collected, including the age, gender, and GMFCS level of each child, along with family composition information (parents ages and employment status, number

and ages of siblings). The first three measures were *parent-report descriptive* measures which were completed with the parent during the initial visit. Additionally, two *evaluative outcome* measures were administered during the bi-weekly home visits to assess gross motor function and performance of each child.

3.3.1 The Dimension of Mastery Questionnaire (DMQ)

The DMQ is a 45-item measure used to assess aspects of an adult's perception of a child's mastery motivation (**Appendix D**). For this questionnaire, mastery motivation relates to the quality inherent to a person which drives them to attempt to master a task that is moderately challenging (Morgan & Bartholomew, 1998). The parent rates how typical each statement is relative to their child, using a five-point Likert scale, from 1 (not at all typical) to 5 (very typical). For this project, the preschool DMQ (ages 1½ to 5 years) was used. Reliability estimates for the DMQ are a Cronbach alpha for the parents' ratings for the preschool age group of 0.81, and test-retest reliability > 0.7 (Morgan, Busch-Rossnagel, Barrett, & Harmon, 2008). Scoring of the DMQ component scores for this study was consistent with the scoring guidelines indicated on page two of the measure (**Appendix D**). Although the scoring guidelines indicate how to calculate each dimension score and not a total DMQ score, for this study, a total DMQ score was calculated for each child by adding each of the seven component scores to provide a description of each child's overall motivation as reported by the parent. The DMQ total score and Gross Motor Persistence (GMP) score for each child were included in the data analysis.

3.3.2 The Child Engagement in Daily Life Measure

This measure is a 30-item questionnaire divided into four sections which all use five-point Likert scales for response options (**Appendix E**). Parts A and B include questions to determine how often a child participates in various family, community, and recreational activities, and their degree of enjoyment from these activities. These sections offer response

options to capture the frequency of participation (very often to never) and enjoyment (a great deal to not at all). Part C of this measure examines the child's level of independence in self-care activities, as indicated by the parent (yes, does the activity independently to no, unable). Finally in Part D, the parent provides responses related to the ease of care-giving (no help is needed to very difficult).

The test-retest reliability intra-class correlation coefficients (ICC) for this measure are 0.70 for both participation and enjoyment, 0.96 for self-care and 0.76 for ease of care-giving (Chiarello, personal communication, 2010). For this study, the standard scoring guidelines were followed: a score of five was assigned for responses indicating 'very often', 'a great deal', 'yes, does the activity independently' or 'no help is needed' and a score of one for 'never', 'not at all', 'no, unable' or 'very difficult'. A separate mean score for each section was then calculated yielding scores for: participation, enjoyment, self-care, and ease of care-giving.

3.3.3 The Services Questionnaire

This measure provides information related to "Types and Intensity of Programs and Services Your Child Receives" and "Focus of Therapy Services" (**Appendix F**). Psychometric data on the Services Questionnaire are not yet available.

Parents reported the services (with frequencies) their child was receiving at the time of the study. These descriptive data were used to characterize the current therapy schedules of each child participant. Subsequently, the parent reviewed a series of thirteen statements outlining different foci of intervention. According to the scoring guidelines, the foci are categorized using ICF terminology: primary impairments, secondary impairments, activity, environment, and participation (self-care and play). Using a five-point Likert scale (all the time to not at all), the parent rated each statement indicating the extent to which his or her child's physiotherapist and/or occupational therapist provide the intervention. A score of five was given to responses of

'all the time', while a score of one was assigned to responses 'not at all'. A mean score was calculated for each of the ICF categories; these data were used descriptively.

3.3.4 Gross Motor Function Measure (GMFM)

Gross motor function is defined as the achievement of motor activities, or how much a child does, testable in a standardized way (Boyce et al., 1995). The GMFM evaluates gross motor function, and change in motor ability over time, in children with CP (Russell et al., 2002). An abbreviated version of this measure, the GMFM Basal and Ceiling (GMFM-66-B&C) (Brunton & Bartlett, in press), has been developed and tested for research and clinical use; thus, was used for this study (**Appendix G**).

The GMFM demonstrates high levels of validity, reliability, and responsiveness (Russell et al., 2002). Total GMFM change scores correlated with judgments of change made by the video-based evaluations at r=0.82, and with the therapists' judgments at r=0.65 (Russell et al., 2002). Intra-class correlations (ICC) were 0.99 for intra- and inter-rater reliability (Russell et al., 2002). There was significant difference between stable and responsive groups, at $p<0.01$ (Russell et al., 2002). Work by Brunton and Bartlett (in press) indicated strong psychometric properties of the GMFM-66-B&C and decreased administration time: ICC (and 95% confidence interval) for concurrent validity of 0.99 (0.97-0.99), and 0.99 (0.99-1.00) for test-retest reliability. A criterion score of 96% agreement on the GMFM criterion-tapes was achieved prior to data collection to enhance rigor.

The following equipment was required for administration of the GMFM and was taken to each home visit:

- Stop watch
- Yoga mat
- Measuring tape
- 24" Circle
- Ruler
- Soccer ball

- 24” Stick
- Small interesting toy < 4” height
- Height-adjustable bench

During each assessment, the child was provided with verbal commands to perform each item, and was scored in person in real-time using an ordinal scale (0-3). A demonstration and practice trial was provided for items as needed. For the GMFM-66 B&C, a basal level is determined by a score of three consecutive ‘3s’; a ceiling is achieved with three consecutive ‘0s’. For this study, a basal and ceiling level was determined for each child at the initial assessment. Upon subsequent visits, the assessment would begin with the items from that initial basal level and proceed until a ceiling was achieved. A true basal and ceiling (i.e., three consecutive ‘3s’ and ‘0s’) were not always achieved if the child began refusing to attempt items. Additionally for the GMFM-66-B&C, a minimum of 15 items must be tested and scored. This guideline was met consistently for all five children whose data were included in the analyses. For this study, each child was asked to repeat each item for three trials in order to calculate variability scores (see Data Synthesis and Analysis).

The Gross Motor Ability Estimator (GMAE) Software was used to calculate a GMFM-66 score based on the smaller number of items collected with the GMFM-66-B&C. This calculation is possible through Rasch analysis. The child was given credit for the highest score of his or her three trials of each item; this highest score was input into the GMAE Software to calculate the GMFM-66 score, which has a scale from 0 to 100 (Russell et al., 2002). The GMAE Software indicated the number of items scored for each assessment, the standard error of measurement and the 95% confidence intervals.

3.3.5 Quality FM (QFM)

Boyce and colleagues (1995) defined gross motor performance as the quality of motor activities, or how well the child is able to execute the movement. Their definition of

performance includes five attributes which characterize quality of movement: "alignment, stability, coordination, weight shift, and dissociation" (p. 612). They developed the GMPM as the sister-measure to the GMFM. Wright and colleagues expanded on the GMPM when developing the QFM as a thorough measure of quality of movement (Wright, personal communication, 2009). The QFM features 39 items from the GMFM Standing and Walking/Running/Jumping Dimensions which are scored on an ordinal scale of 0 (a lot of difficulty) to 3 (no difficulty); samples of the questions and scoring criteria for the QFM are outlined in **Appendix H**. Each item assesses three (of the five) attributes of quality of movement determined by international expert consensus (Wright & Breuer, 2008b). The QFM is used as a clinical research tool to assess ambulatory children with CP, classified in GMFCS levels I to III, aged four years and older.

The initial psychometric data for the QFM revealed excellent test-retest reliability with the GMFM Standing Dimension (ICC = 0.96) and GMFM Walking, Running, & Jumping Dimension (ICC = 0.95) (Wright, 2009). Furthermore, the inter-rater reliability ICC for each attribute of the QFM are as follows: alignment (0.84), co-ordination (0.90), weight-shift (0.92), stability (0.96), and dissociated movement (0.95) (Wright, 2009). A score of 78% agreement was achieved on the QFM criterion-tapes prior to data collection. This is reportedly a 'good score' according to Dr. Wright (Wright, personal communication, 2009).

For typical QFM administration, the child is cued verbally to perform the item from the GMFM. The assessment is videotaped and scoring of the QFM is completed from reviewing the video. If the child scores greater than '0' on the GMFM (indicating they can at least initiate the task), the child's performance on that item is later scored with the QFM (from the videotape). The child is asked to repeat the task for three trials. According to QFM administration protocol, the assessor can provide cueing and modeling of the task between trials. This prompting is

thought to facilitate the child's optimal performance for the task (Wright & Breuer, 2008b). The equipment required to administer the QFM is identical to that of the GMFM with addition of a video camera and tripod. For this study, a Canon Vixia HFS10 digital high-definition camera was used.

With approval from Dr. Wright, several modifications were made to the administration protocol for this study. The QFM was used to assess children with CP as young as three years of age who could follow sequential commands in English. During assessment, the child did not receive additional verbal cueing or modeling of each task between trials unless he or she failed to understand the initial commands. Verbal commands were repeated; however, cues to facilitate *optimal performance* were omitted. This omission of prompts allowed for assessment of the child's natural performance over three trials. All attempted GMFM items were assigned a QFM score, even for those on which the child scored '0' on the GMFM. This strategy was used to measure if the child modified his or her performance (or attempt) over the three trials despite not being able to achieve a higher score on the GMFM. From the three trials a variability score was calculated and used for data analysis (see Data Synthesis and Analysis). Finally with recommendation from Dr. Wright, the 'alignment' attribute was omitted from assessment due to weaker initial psychometric data (Wright, personal communication, 2009). Consistent with typical administration and scoring, all QFM scoring for this study was completed from the videotapes while the GMFM scoring was completed while assessing the child in person during the home visit. The GMFM items were administered once (and repeated for three trials) at each home visit; that same administration of GMFM items was videotaped and later assigned a QFM score.

3.3.6 Field Notes

Field notes were documented immediately after each home visit. These notes consisted of clinical observations of each child, the set-up of their environment, whether they explored their environment and how, the preferred toys played with during the visit, behaviours they displayed during the assessments and any comments made by the parent regarding the child's status and progress for the time interval since the previous assessment.

3.4 Procedures

The data collection phase included ten home visits scheduled at the family's convenience. Typically, each family had a preferred day of the week and time of day for the home visits and this schedule was maintained for all ten visits (with occasional changes to the schedule). The home visits were scheduled at two-week intervals; however, on a few occasions, the visits occurred within ten days of each other or three weeks apart depending on the family's availability. All children completed the data collection phase within a four to four-and-a-half month period.

The first visit involved a parent interview for completion of the DMQ, the Child Engagement in Daily Life Measure and the Services Questionnaire to gather descriptive information about each child. This visit lasted approximately ninety minutes; the questionnaires were all completed by the child's mother. The child's gross motor abilities were assessed during all ten home visits using the GMFM. These assessments were video taped for subsequent scoring of the QFM to assess motor performance. Visits two through nine lasted forty-five minutes to one hour typically. At each initial visit, the parent was asked if he or she was interested in operating the video camera to video tape each assessment. All parents declined this

role; thus, the video camera was set up on the tripod in the corner of the room for every visit and turned on to record for the duration of each assessment.

Parents, siblings and extended family members were present for assessments at times. Most often, they would sit and observe the assessment. Occasionally, they were asked to participate in motivating the child if the child responded well to this or requested it (i.e., the older sister or mother of child 1 would follow behind child 1 during some walking tasks and pretend that child 1 was teaching them how to complete the task). For most children, the parents preferred to leave the room during the assessment and tend to other household responsibilities (particularly children 2, 3, and 4). The parents indicated that their child's participation would be negatively impacted if they were present for the assessment. Each family had a preferred room in which all ten assessments took place: consistently the family living room. Furniture (i.e., coffee tables) was moved out of the way as needed to ensure adequate space for the assessment and toys or obstacles were cleaned up from the floor to prevent tripping hazards. During the motor assessments, the child was given rest breaks as needed. A collection of puzzles, bubbles, stickers and toy cars were brought to each visit for the child to play with throughout the assessment as a means to engage the child in testing. All children requested to play with these toys during assessments, with the occasional addition of his or her toys as well.

Prior to the commencement of data collection, it was decided that if a child received routine botox injections with lower extremity casting during the course of data collection, the motor assessments would be stopped until the cast was removed. The data collection time period would then be extended to ensure a total of ten home visits were completed. If a child received botox without casting, motor assessments would continue. Additional home visits would be scheduled, with the families' consent, if the child's motor scores appeared to be changing

significantly in the month after botox injections. However, none of the five children with data included in data analysis received botox injections during the study duration.

3.4.1 Confidentiality

All collected data were labeled with non-identifying information to ensure accurate tracking and confidentiality. Video files are stored on password-protected external hard drives. Upon completion of this thesis, original and back-up files (paper and video) will be stored in a locked cabinet, in a locked office at BC Children's Hospital and will remain there for five years, in accordance with the ethics approval requirements. After five years, the data will be destroyed.

3.4.2 Participant Remuneration

The children each received a small token of appreciation for their participation in the study. At the initial home visit, each child received his or her own one-piece sun suit to wear during all study-related gross motor assessments. Child 4 and Child 5 both lost their sun suits mid-way through the data collection phase and wore pants or shorts instead (pants were rolled at the ankle). All other children wore the sun suits for assessments. After completion of the project, each child kept his or her sun suit and the parents were provided with a copy of two GMFM and QFM assessment score sheets and video clips.

3.5 Data Synthesis and Analysis

3.5.1 Calculating Variability Scores

To prepare the data to address the first study aim, variability scores were calculated for each QFM and GMFM item tested. Upon commencement of data collection, the intention was to calculate variability scores for the QFM only to subsequently measure the potential correlation between variability in QFM scores with change in GMFM scores between time intervals. However, during data collection children were demonstrating variability in their GMFM scores

across the three trials at each visit thus prompting the exploration of potential correlations between variability in GMFM scores and change in GMFM scores between time intervals. The QFM and GMFM scores for each item were assigned a variability score using the ranking system outlined in **Table 3.3**.

Table 3.3 Ranking System Used to Assign Variability Scores for QFM and GMFM Items

QFM or GMFM Score	Variability Score
If all three trials are the same (i.e., 1, 1, 1)	0
If two trials result in the same score, but the other trial results in a different score (i.e., 1, 1, 2)	1
If all three trials result in three different scores (i.e., 1, 3, 2)	2

A mean variability score for each attribute of the QFM was calculated (i.e., mean weight shift variability score, mean stability variability score, etc.) for each child for visits one through nine. Similarly, a mean GMFM variability score was calculated for each child for visits one through nine. Variability scores for visit ten were not required as it was the final visit; correlations between variability at one time point with GMFM change during the proceeding time interval were assessed. To achieve a greater number of data points, these data for all five children were pooled for the analyses of associations addressing the first study aim (See Statistical Analysis Section).

3.5.2 Video Quality and Scoring

Several issues arose with video taping the assessments. Specifically, the children moved outside of the field of view of the camera on several occasions. Two different video cameras were trialed initially before deciding on the Canon camera (with wide-angle lens) used for the remainder of the visits. Also, on a couple of occasions, a parent or sibling would walk in front of the camera during the assessment blocking the view of the child completing the task. Finally,

during one visit the battery of the camera stopped; thus, the camera failed to record the child completing the final two items on the assessment.

To address these issues, the child, parent and siblings were reminded of the location of the camera and onset of recording at each visit and throughout the assessment as needed. The assessment items were set up within the field of view of the camera at the start of the assessment and the position of the camera was re-adjusted as needed when the position of the child shifted during the assessment. The video camera was charged fully prior to each home visit and plugged into a power outlet during assessments if the battery appeared low when the camera was first turned on. This was required only on a couple of occasions when two children were assessed consecutively in the same day.

The video issues did not impact the scoring of the GMFM as it was scored in person; however, after the home visit, the video files were transferred to an external hard-drive for subsequent scoring of the QFM. If the child was outside of the camera field of view for a task, this was noted on the QFM score sheet and no score was assigned. However, if the child could be seen on the video for the majority of the task, this was noted on the score form and a QFM score was assigned.

Similarly, for some of the items requiring the child to walk ten steps, the child would run out of physical space to complete the item. When this occurred, the obstacles were moved if possible and the child was cued to re-attempt the item and start from a different position or take smaller steps. If this re-occurred for items on which the child demonstrated good stability, had otherwise demonstrated the ability to complete the task with ease, and appeared to simply run out of room to complete the final one to two steps, then the child was given credit for all ten steps and this was noted on the score sheet. Otherwise, the scoring occurred in accordance with

the guidelines outlined in the GMFM Manual (Russell et al., 2002) and QFM Scoring Criteria (**Appendix H**).

3.5.3 Missing Data

One video was deleted accidentally when transferring the video file from the initial video camera to a laptop (in order to transfer it to an external hard-drive). Consequently, there are no QFM scores for first visit for Child 1. All other videos were transferred successfully and all other data are accounted for.

3.5.4 Statistical Analyses

Data analyses were conducted using descriptive and correlation statistics using Microsoft Excel for Macs and SPSS for Macs (PASW Statistics version 18.0). Consistent with a case series approach, the data were organized and presented below using tables and graphs (Backman & Harris, 1999). Data from the first measures were compiled to provide rich descriptions of each child participant including their mastery motivation, engagement in daily activities, and current therapy services received.

To address the first study aim, non-parametric correlation statistics, Spearman Rank Correlation Coefficients (Spearman rho or r_s), were calculated to assess for associations between 1) the mean variability in QFM scores (for each attribute) at one time point with subsequent change in GMFM scores in the following time interval, and 2) mean variability in GMFM scores at one time point with subsequent change in GMFM scores in the following time interval. As mentioned previously, the scores for all five children were pooled for these analyses. Additional bivariate correlation analyses were conducted with the data for each child individually for comparison with the pooled data. Subsequently, these variability data were analyzed visually using scatter plots; this is the most common approach to data analysis for case series (Backman & Harris, 1999; Gonnella, 1989). Scatter plots were created for the pooled data as well as for

each child's data individually. Although visual analysis focuses on determining clinical significance, statistical significance cannot be tested (Zhan & Ottenbacker, 2001). This approach to analysis is descriptive and is used to identify patterns or trends, to support theory, and to generate testable hypotheses (Backman & Harris, 1999; Gonnella, 1989; McEwan, 1996).

To address the second study aim, Spearman Rank Correlation Coefficients were calculated to identify bivariate associations between the overall GMFM change score over time and 1) DMQ score, and 2) The Child Engagement in Daily Life Measure score. As there were only five data sets addressing this aim, the data for all five children were pooled for these analyses.

For this small sample, exploratory study, the level of significance was set at alpha=0.10. The strength of the correlation coefficient was interpreted using the following guidelines: correlation coefficients ranging from 0 to 0.25 were classified as 'no relationship'; those ranging from 0.25 to 0.50 were considered a 'fair relationship'; those from 0.50 to 0.75 were 'moderate to good'; finally, those from 0.75 to 1.0 were classified as 'good to excellent' (Portney & Watkins, 2000, p. 494).

Finally to address the third study aim, the information documented in the field notes was reviewed to provide additional descriptions of each child throughout the study duration. Any comments reflecting variability or a change for the child were highlighted with orange, while comments reflecting stability or lack of change for the child were highlighted green. The dates of these comments were compared with the GMFM change scores between assessment intervals in an attempt to subjectively note trends in impending change in motor ability acquisition.

4. RESULTS

4.1 Participant Characteristics

Participant characteristics are outlined in **Table 3.1**. Nine children and their families were informed about the study during recruitment; two families declined as they felt they did not have the time to commit. As mentioned previously, seven children were recruited initially and completed all data analysis; however, the data from two children were excluded from data analysis as it was questioned whether the children actually met all inclusion criteria (i.e., they did not appear to understand and be able to follow sequential commands in English). Thus, data for the remaining five children were analyzed and are reported in this chapter.

Of the five children, four were classified in GMFCS level I while one was classified in level III. In a large sample of 657 children with CP across Ontario, the largest proportion of children recruited were classified in GMFCS level I as well (Rosenbaum et al., 2002). Two of the children in the current sample presented with spastic right hemiplegia and three presented with spastic diplegia; these CP subtypes are appropriate presentations for children classified in GMFCS levels I to III according to other samples (Beckung et al., 2007). Two children were females and three were males with a mean age for the sample of three years ten months (range three years two months to four years eleven months) at the time of recruitment.

4.2 Descriptive Data

Table 4.1 outlines the descriptive data for each of the five participants. These data include the initial DMQ (total score) and GMP score, the mean Participation, Enjoyment, Self-Care and Ease of Care-giving scores from the Child Engagement in Daily Life Measure.

Table 4.1 Descriptive Data From the DMQ and Child Engagement in Daily Life Measures for the Five Participants

Study ID	DMQ	GMP	Participation	Enjoyment	Self-Care	Ease of Care-giving
1	23.4	2.8	3.9	4.3	3.7	2.8
2	26.1	3.5	3.6	4.3	5.0	4.4
3	25.2	4.4	4.1	4.3	3.3	3.6
4	27.9	4.5	4.5	4.9	4.4	3.8
5	29.2	3.6	3.8	4.7	3.4	3.7

4.2.1 DMQ Scores

The highest possible total DMQ score is 35; children in this sample scored from 23.4 (Child 1) to 29.2 (Child 5). The range of GMP scores were from 2.8 (Child 1) to 4.5 (Child 4); whereas, the highest score for each domain is 5.0 with a higher score indicating greater gross motor persistence. Normative data were provided for each domain of the DMQ from a sample of typically developing preschoolers (Morgan et al., 2008). The mean GMP score for parent's ratings of preschoolers from this sample (n=244) was 3.9, with a standard deviation (SD) of 0.7. Only Child 1 from the current study's sample falls below the value within one standard deviation away from the mean. Morgan et al. (2008) do not calculate total DMQ scores in the scoring guidelines; thus, they do not provide mean total DMQ scores. However, from adding the mean score for each dimension from the normative data, the total DMQ score was 26.2. This score is higher than three of the five participants from this study (i.e., Children 1, 2, 3). When examining the gender normative data, the mean parent-rated GMP score for preschool boys (n=122) was 3.9 (SD=0.7) and for girls (n=125) was 3.8 (SD=0.7). The boys in the current sample scored from 3.5 to 4.5 (within one standard deviation from the normative mean value), while the girls scored from 2.7 to 4.4 (within two standard deviations below the normative mean value and within one standard deviation above the mean).

4.2.2 Child Engagement in Daily Life Scores

The highest mean score for each category is 5.0. A higher score in Participation, Enjoyment and Self-Care indicate greater participation, greater enjoyment, and greater independence in self-care as reported by the parent. As such, Child 4 was reported to have the highest participation and enjoyment by his parent. Conversely, Child 2 scored the lowest for Participation, while children 1, 2, and 3 tied for the lowest scores in Enjoyment; although, the range of Enjoyment scores were quite close (within 0.6 points). Child 2 scored a perfect 5.0 for Self-Care indicating a high level of independence; he was the oldest participant and classified in GMFCS level I. Child 3 scored lowest on Self-Care with a mean score of 3.3. She was classified in GMFCS level III, having the greatest motor impairments of the children in the sample.

A higher score in Ease of Care-giving indicates that the parent perceives it to be easier to safely help their child to do activities of daily living. Conversely, a lower Ease of Care-giving score indicates that the parent perceives it to be more difficult to safely help their child based on issues of: safety, the physical demands on the parent, the parent's confidence in providing help, and the time required to complete the task, according to the Child Engagement in Daily Life Measure (**Appendix E**). Again, Child 2 scored highest with a mean Ease of Care-giving score of 4.4 and Child 1 scored lowest at 2.8.

4.3 Associations Between Variability Scores and GMFM Interval Change Scores

To address the first study aim, the GMFM-66 visit scores were needed to analyze the associations between a) GMFM variability scores and GMFM change scores, and b) QFM variability scores and GMFM interval change scores. **Table 4.2** outlines the GMFM-66 scores for all five participants across all ten visits and the overall GMFM change score (visit 10 minus visit 1) for each participant. Each visit score was calculated using the GMAE Software. All ten

assessments were completed for each of the five children. There were no missing data unless a child refused to attempt a task in which the item was noted as "Not Tested" and it was not included in the GMFM-66 score.

Table 4.2 GMFM-66 Scores For Each Visit and Overall Change Score

Study ID	Visit 1	Visit 2	Visit 3	Visit 4	Visit 5	Visit 6	Visit 7	Visit 8	Visit 9	Visit 10	Overall GMFM Change
1	56.4	64.6	64.3	66.7	65.0	65.3	65.0	64.6	63.6	65.3	8.9
2	75.3	76.8	74.8	76.0	76.8	78.3	80.0	83.0	71.7	80.9	5.6
3	53.9	54.2	54.4	55.9	55.9	56.2	56.2	55.9	54.2	56.2	2.3
4	65.3	65.6	66.3	68.5	68.1	65.0	68.1	68.5	65.3	66.3	1.0
5	68.5	68.1	69.2	68.9	67.4	68.1	68.1	68.9	68.9	68.9	0.4

4.3.1 GMFM-66 Scores

Children 1, 2, 4 and 5 were all classified in GMFCS level I, with their ages ranging from three years two months to four years eleven months. Over the four to four-and-a-half months of serial assessments (ten visits), Child 1's scores ranged from 56.4 to 66.7; Child 2 had a range of scores from 71.7 to 83.0; Child 4's scores ranged from 65.0 to 68.5; and Child 5's scores ranged from 67.4 to 69.2. As expected, Child 2 was the oldest child participant in level I and demonstrated the highest GMFM-66 score out of all assessments (83.0). Child 1, who was the second youngest participant, scored the lowest GMFM-66 score for children in level I at 56.4. These scores are all within the typical, expected range of scores for children classified in GMFCS level I within the age range of three to five years, according to the motor growth curves (Rosenbaum et al., 2002). The mean GMFM-66 limit - the limit of the child's motor potential on the GMFM-66 – for GMFCS level I is 87.7 (Rosenbaum et al., 2002).

Child 3 was classified in GMFCS level III and aged three years eleven months at recruitment. Over four months of bi-weekly assessments, her GMFM-66 scores ranged from 53.9 to 56.2, which also appears within expected ranges for her age and GMFCS level

(Rosenbaum et al., 2002). The reported mean GMFM-66 limit score for level III is 54.3 (Rosenbaum et al., 2002).

4.3.3 GMFM and QFM Variability Scores with GMFM Interval Change Scores

Table 4.3 outlines the Spearman Rank Correlation Coefficient values for the correlation analyses exploring associations between variability scores and GMFM interval change scores for the entire data set combined (i.e., all visits of all five participants combined). There were forty-five scores for the GMFM interval change scores and GMFM variability scores (five children with nine intervals each) and forty-four scores for the QFM variability scores for each attribute, due to the missing first video data for Child 1.

Table 4.3 Spearman Rank Correlation Coefficients for GMFM Interval Change Scores and GMFM and QFM Variability Scores for All Five Participants Combined

	GMFM Interval Change Scores (n=45)
GMFM Variability (n=45)	-0.11 (p=0.47)
QFM Weight Shift Variability (n=44)	-0.12 (p=0.45)
QFM Coordination Variability (n=44)	-0.05 (p=0.75)
QFM Stability Variability (n=44)	0.05 (p=0.75)
QFM Dissociation Variability (n=44)	0.07 (p=0.66)

No significant correlations were found between GMFM interval change scores with GMFM variability scores or any QFM variability scores (i.e., for the attributes of weight shift, coordination, stability or dissociation) when the data for all five children were combined. The values of all correlation coefficients ranged from 0 to – 0.12 indicating 'no relationship' (Portney & Watkins, 2000). The directions of the correlation coefficients (i.e., + or -) varied; only the Spearman rho for the (lack of) relationship between GMFM interval change score and 1) QFM stability variability, and 2) QFM dissociation variability were positive. When the data were analyzed for each child separately, three statistically significant results were found: a moderate inverse association between GMFM interval change scores and mean QFM coordination variability scores (r_s=-0.61; p=0.08) for child 2, a similar moderate inverse association between

GMFM interval change scores and mean QFM dissociation variability (r_s=-0.60; p=0.09) for child 2, and a strong inverse association between GMFM interval change scores and mean GMFM variability scores (r_s=-0.84; p=0.01) for child 3 (**Appendix I**). Otherwise, the results for each child individually were similar to those for the entire sample combined (**Appendix I**).

4.3.4 Trends in Visual Analysis of Variability Data

The following figures show the scatter plots for the data for each set of variability scores plotted with GMFM interval change scores for all five children combined.

Figure 4.1 GMFM Variability Scores with GMFM Interval Change Scores

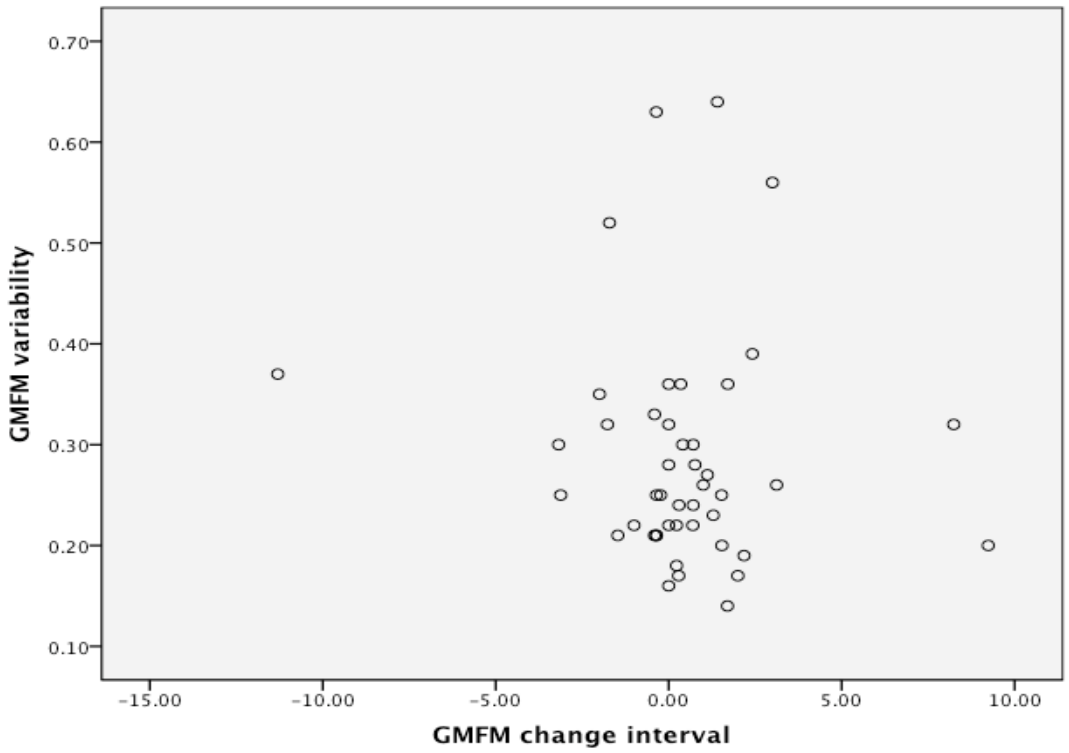


Figure 4.2 QFM Weight Shift Variability Scores with GMFM Interval Change Scores

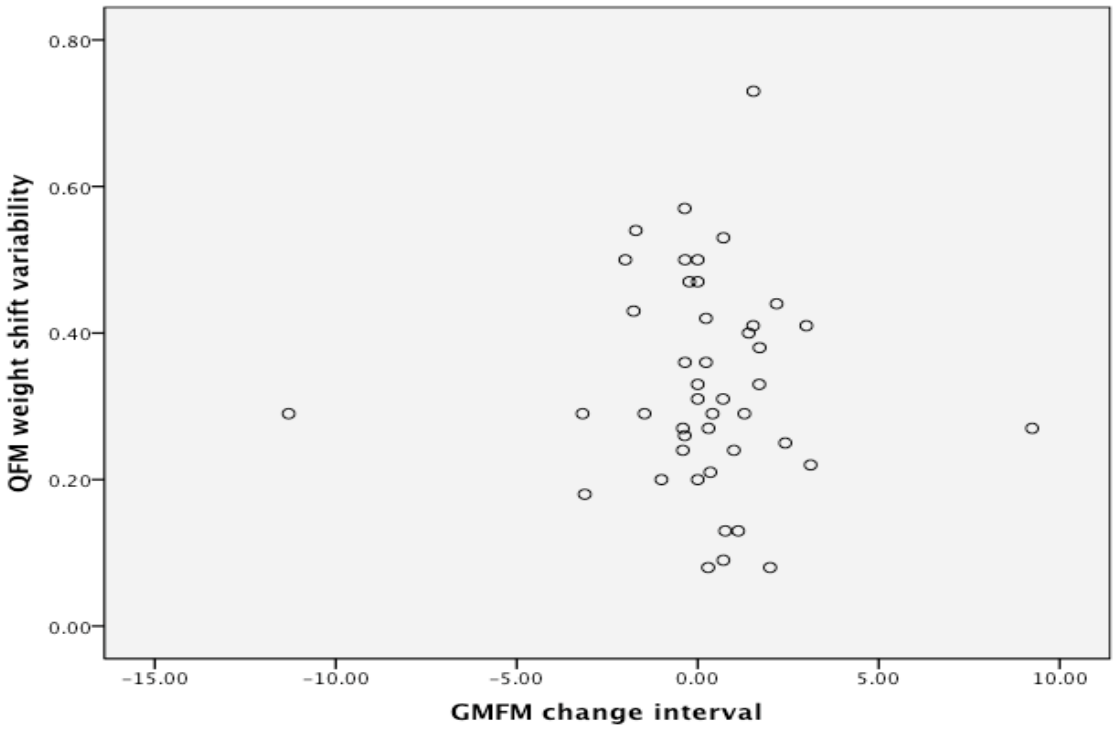


Figure 4.3 QFM Coordination Variability Scores with GMFM Interval Change Scores

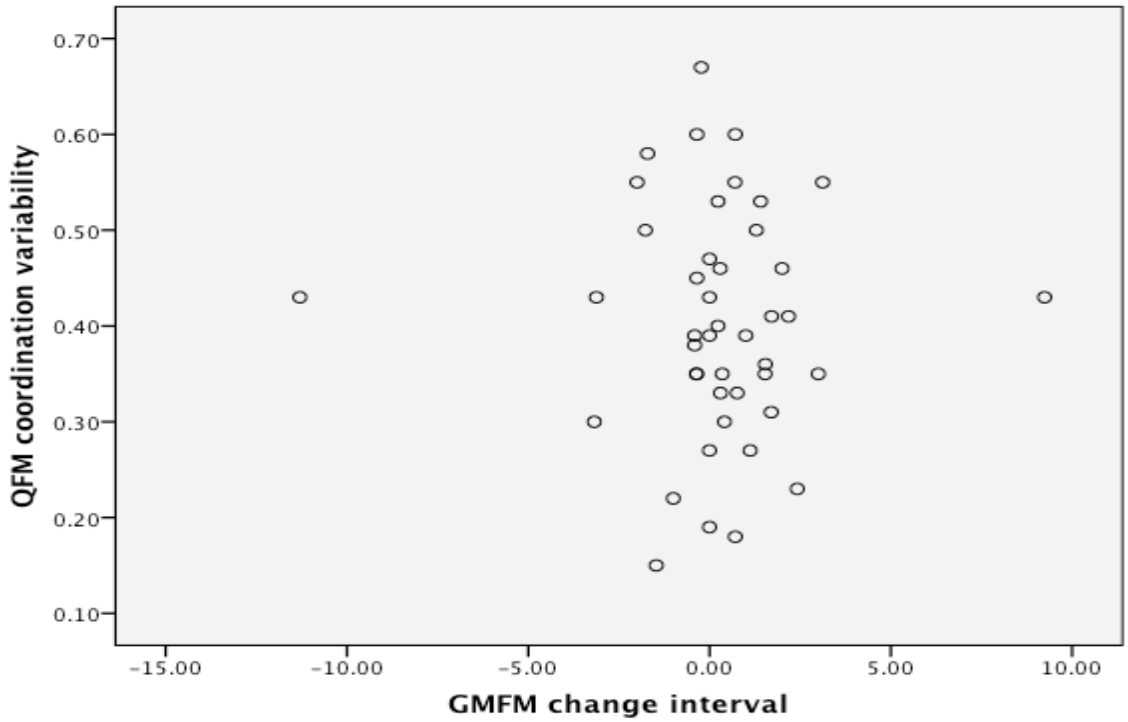


Figure 4.4 QFM Stability Variability Scores with GMFM Interval Change Scores

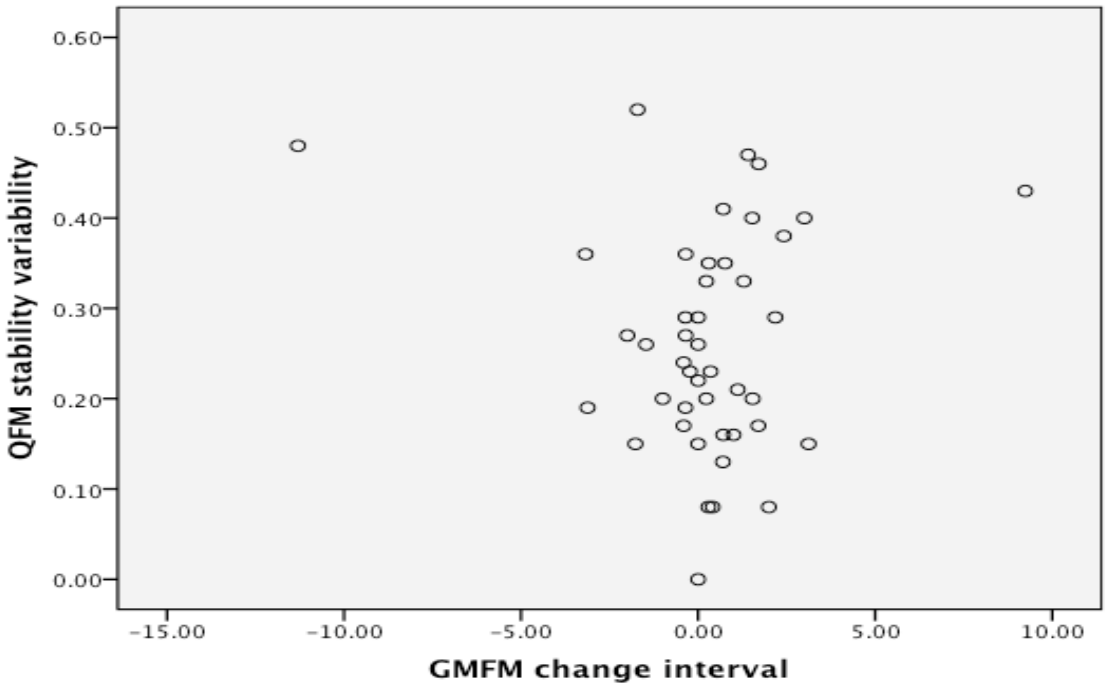
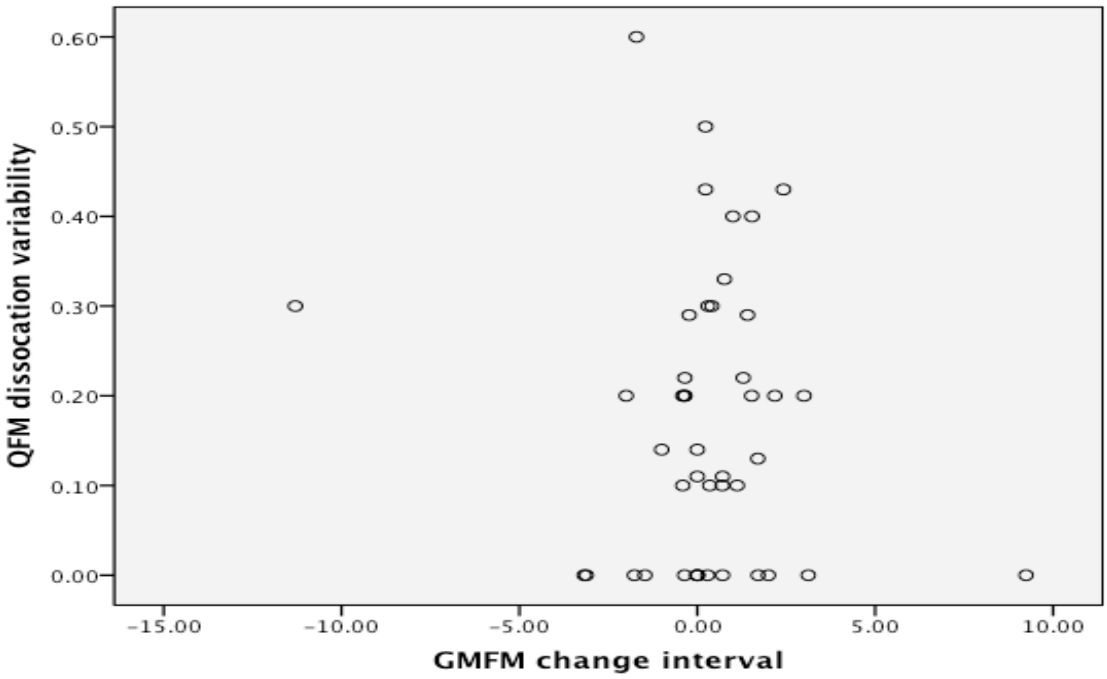


Figure 4.5 QFM Dissociation Variability Scores with GMFM Interval Change Scores



As can be seen in the above figures, no trends or associations were observed on visual inspection between GMFM interval change scores with any of the GMFM variability or QFM

variability scores for all children combined. Most GMFM interval change scores were small, ranging within + or – 3.0 points; however, there were a few outliers. Child 1 and Child 2 demonstrated larger changes on two occasions; Child 1 improved 8.2 points on the GMFM during the first time interval, while Child 2 changed by -11.3 points during the eighth interval and by +9.2 during the ninth interval.

The mean GMFM variability scores for all children combined ranged from 0.19 to 0.63; most of these scores were below 0.40 (**Figure 4.1**). In **Figure 4.2**, it is clear that most mean QFM weight shift variability scores fell under 0.60 with one score above this at 0.73 (Child 3). The lowest mean QFM weight shift variability score was 0.08 (also from Child 3). **Figure 4.3** shows the range of mean QFM coordination variability scores, from 0.15 to 0.67. The mean QFM stability variability scores tended to be a little lower, ranging from 0 to 0.52 (**Figure 4.4**), as where the mean QFM dissociation scores with all scores below 0.50, except one at 0.60 (**Figure 4.5**). Several of the mean QFM dissociation scores were at 0.

To visually inspect trends in the variability data further, the variability score for each item of the GMFM and QFM were ordered according to item difficulty (as per Rasch analysis of the GMFM-66). This allowed the observation of any trends in variability with item difficulty, in case greater variability scores were noted on harder items at the limits of the child's gross motor potential. No trends were observed in these data for the QFM or GMFM.

4.4 Associations Between DMQ and Child Engagement Scores with GMFM Change Scores

For the second study aim, the overall GMFM change scores, the total DMQ and GMP scores, and the scores for each section of the Child Engagement in Daily Life Measure were calculated.

4.4.1 Overall GMFM Change Scores

The Minimal Clinically Important Difference at the 95% confidence interval ($MCID_{95}$) was calculated for each child using the mean standard error of measurement for each child from the GMAE Software. Child 1 demonstrated the greatest change in GMFM from visit 1 to 10 with an overall GMFM change score of 8.9 ($MCID_{95}$ = 3.9). She had the lowest initial score for all the children in GMFCS level I (**Table 4.2**). Based on her age and GMFCS level, one would expect her to improve in motor abilities as measured by the GMFM over the study period as she is still over a year away from the level I age-90 (Rosenbaum et al., 2002). Child 2 showed an overall GMFM change of 5.6; note however, that the $MCID_{95}$ was 5.8. Child 3, who was past the age-90 (three years, 8 months) for GMFCS level III, had a small overall change score of 2.3 ($MCID_{95}$ = 3.3). Finally, Child 4 and Child 5 showed no true change from visit 1 to visit 10 with overall GMFM change scores of 1.0 ($MCID_{95}$ = 4.0) and 0.4 ($MCID_{95}$ = 4.1) respectively.

4.4.2 DMQ and Child Engagement Scores with Overall GMFM Change Scores

Correlation analyses for the overall GMFM change scores with DMQ and Child Engagement in Daily Life Scores (all children combined) (**Table 4.4**) revealed one statistically significant relationship: the overall GMFM change score was inversely correlated with the total DMQ score (r_s=-0.90; p=0.04). Thus, a lower total DMQ score was associated with a higher overall GMFM change score. No other correlations were statistically significant. The magnitude of the correlation coefficients between DMQ and GMP scores with overall GMFM change scores ranged from 0.70 to 0.90 indicating good to excellent associations (Portney & Watkins, 2000). The direction of these correlation coefficients were all negative (i.e., inverse).

For the data from the Child Engagement in Daily Life Measure, the correlation coefficient for Enjoyment scores and overall GMFM change scores was -0.78 (r_s) which would indicate moderate to good inverse associations (Portney & Watkins, 2000); however, this did not

reach statistical significance (p=0.12). The magnitudes of the coefficients for Participation, Self-Care and Ease of Care-giving with overall GMFM change scores were all 0.43 or less indicating fair to no relationships (Portney & Watkins, 2000). The Self-Care coefficient was the only one showing a positive direction, although not statistically significant.

Table 4.4 Spearman Rank Correlation Coefficients for DMQ and Child Engagement Scores with Overall GMFM Change Scores for All Five Participants Combined

	GMFM Overall Change Scores (n=5)
DMQ (n=5)	-0.90 (p=0.04)*
GMP (n=5)	-0.70 (p=0.19)
Participation (n=5)	-0.20 (p=0.75)
Enjoyment (n=5)	-0.78 (p=0.12)
Self-Care (n=5)	0.30 (p=0.62)
Ease of Care-giving (n=5)	-0.30 (p=0.62)

*Correlation is significant at the 0.05 level (2-tailed)

4.6 Field Note Data

Finally for the third study aim, no trends were noted when comparing the comments and observations documented in the field notes with the GMFM interval change scores.

4.6.1 Variability or Pending Change

The majority of the comments and observations representing variability or pending change were documented for Child 1 and Child 3, with some aspect of this category highlighted at most home visits. Only a few notes in this category were highlighted for the other three children. 'Variability or pending change' notes included parents' observations that the child "is walking on tip-toes more lately", "tripping more", "doesn't stand still lately", "seems less stable on her feet", or has been attempting new tasks lately. Also included in this category were reports of a new program starting (i.e., starting a new play group), acquisition of a new piece of equipment or orthotics, or changes in therapy routines. One child reported that he was "wobbly" lately (Child 5). The observations of variability or pending change included such things as noting when a child appeared close to acquiring a new ability:

- " She is so close to being able to jump 2 feet together; just her left big toe still in contact with floor. Child fell a couple of times while practicing jumping 2 feet together." (Observation of Child 1, Visit 9)
- "Child is so so close to standing up independently from midfloor; today she started to stand up (both hands were off floor) but then she fell back on two attempts. She seems so close to getting this." (Observation of Child 3, Visit 7)

Both children were able to achieve those tasks on subsequent visits and improve their GMFM scores for those items.

4.6.2 Stability

Fewer comments and observations were noted representing stability. The field notes for children 2, 4 and 5 contained more comments in this area than for children 1 and 3. Parental reports captured for stability included a few comments indicating the child "seems more stable", or the foster mother of Child 2 reporting "I think he is done learning new skills, now just improving the skills he has" (Visit 10). A note was documented when a child appeared to be gaining greater control with a task or when no changes were observed or reported.

5. DISCUSSION

5.1 Summary and Discussion of Results

Despite few significant results, this study contributes to the pediatric rehabilitation literature in several ways. According to available published literature, this study is the first to explore associations between motor acquisition (using the GMFM) and variability in motor abilities (GMFM) or motor performance (QFM), or the associations in child factors using the DMQ and Child Engagement in Daily Life Measure with GMFM change scores. In essence, this study attempted to identify variability in motor performance clinically with readily used clinical outcome measures. Although this issue is discussed widely in current literature, it remains an unsolved challenge.

With respect to the first study aim, no relationships were found between variability in a) motor function (variability in GMFM scores) and b) motor performance (variability in QFM scores) in young children with CP with subsequent motor ability acquisition, as measured by GMFM interval change scores. No statistically significant associations were identified in the data for the five children combined. Conversely for the second study aim, one statistically significant result was found while exploring associations between child factors, such as mastery motivation and engagement in daily activities, and the acquisition of motor ability in young children with CP. Specifically, a high inverse correlation between total DMQ and the overall GMFM change score (r_s=-0.90; p=0.04) was found. This finding is difficult to reconcile. No associations were found between any domains of the Child Engagement in Daily Life Measure with overall GMFM change. Finally, to address the third study aim, very exploratory field note data were reviewed. No trends were noted between environmental factors and the acquisition of motor ability in young children with CP.

This study features several strengths. In an attempt to capture variability in motor performance and change in abilities over time, biweekly repeated assessments were conducted over a four to four-and-a-half month time period. Furthermore, the outcome measures used for these assessments are valid and reliable tools commonly used in clinic and research with this population. Harbourne and Stergiou (2009) indicated that a time series is required to capture variability; specifically, repeated assessments using developmental measures are thought to be the best way to identify transition and change in this population over time (Case-Smith, 1996). An experienced pediatric physiotherapist completed all assessments with the children, following training and achievement of good agreement on criterion testing, documenting observations during each assessment and comments related to parental observations of any potential change. Darrah and Bartlett (1995) outlined that pediatric therapists have specific observational tools and skills needed to identify change or transition, while Law and colleagues (1998) noted that parents are able to identify when their child is changing or demonstrating aspects of readiness to acquire a new motor ability.

The inclusion criteria for this study targeted a sample of children with CP showing potential for change in motor abilities according to the motor growth curves (Rosenbaum et al., 2002). Thus, the children in this sample were expected to demonstrate change in GMFM scores over the study duration. Harbourne and Stergiou (2009) highlighted the need to evaluate abilities that show potential for change when examining variability in motor behaviour using nonlinear tools. It was anticipated that this principle would apply in this work using linear tools as well. Additionally, the sample was recruited from four treatment centres throughout Vancouver and the Lower Mainland with the expectation of greater diversity in participating children.

Notably, it is challenging to relate the overall GMFM change scores to clinical importance; a clinically significant change remains undefined for the GMFM-66. Whereas for the GMFM-88, a change of 4.6 points indicates a small positive change which parents perceive as clinically important (Russell et al., 1993). Russell et al. (2002) suggested that children in GMFCS level I aged four to six years should change 2.77 points on the GMFM-66 over six months. Only two of the children in this sample achieved this level of change.

As indicated previously, the concept of variability in motor behaviour is currently a popular topic in the rehabilitation literature. The challenge facing researchers and clinicians is the complicated nature of variability and it's measurement. This complicated nature likely contributed to the lack of associations (or 'negative results') found in this study.

Variability is thought to emerge at various points of time in the acquisition and mastery of motor abilities (Harbourne & Stergiou, 2009); variability is high while one is exploring different strategies to complete a task, then as the performance of that task becomes repeatedly successful the variability decreases (Harbourne & Stergiou, 2009). Finally, variability increases again as the task is mastered and there is flexibility in performance of that task under various constraints (Harbourne & Stergiou, 2009). Harbourne & Stergiou (2009) questioned: "how do we determine whether the variability we see is good variability or bad variability?" (p. 269).

This question became relevant during data collection for this study. On several occasions, all children in the sample demonstrated variability in their performance of tasks on which they had previously mastered. It appeared that if the task was easy enough for the child under the current task constraints, he or she used varying strategies to complete the task. At times, this approach led to successful completion of the task across all three trials (i.e., a score of 3 on the GMFM), but with varying motor performance scores (i.e., QFM). On other occasions the strategy resulted in variable GMFM scores across all three trials. Therefore, despite being

capable of successfully completing the task, the child's score would not always reflect this ability. The influence of the child's behaviour, effort, or desire to complete the task on the data collected is unclear. Thus, the impact of these factors on the results of this study requires further study.

Conversely, minimal or no variability was captured in scores on the GMFM or QFM despite subtle indications of exploratory motor behaviour when a child appeared to be close to acquiring a new task (i.e., improving his or her score on an item on the GMFM). These subtle cues seemed to appear as slight changes in weight-shift or varying use of upper extremities. Then suddenly, something would shift and the child would complete the task. Over the subsequent assessments, the child's attempt of that same task was not consistently successful. This was particularly evident for Child 1 as she began to jump two-feet together for the first time (i.e., GMFM item 80) and for Child 3 as she attained standing through half-kneeling (i.e., GMFM items 60 and 61). Unfortunately, the subtleties of changes in the child's initial attempts and this trend observed during assessments were not captured with the outcome measures and analyses used in this study.

This lack of sensitivity is not unique to this study. While comparing two different intervention strategies to improve sitting in infants at risk for CP, Harbourne et al. (2010) found that both groups showed similar gains in the GMFM Sitting Dimension; however, differences in the variability measures post-intervention which captured the subtle changes in postural control between the two groups were found. The ability of the variability tools to measure these subtleties provides valuable information about the adaptability of the infants' motor behaviour. As noted in our study, perhaps the GMFM is not sensitive to small, subtle changes in motor behaviour (Ustad, Sorsdahl & Ljunggren, 2009). Harbourne and colleagues (2010) recommended using linear and nonlinear tools in combination to comprehensively measure and

understand variability. Jointly, these tools may "quantify the somewhat qualitative observations that we suspect as we view the infants' attempts to move and stability in real time" (Harbourne et al., 2010, p. 1886).

When assessing postural control, linear tools used to measure the amount of variability in research settings include centre of pressure (COP) data (standard deviations and velocities) (Harbourne et al., 2010). However, as we have experienced, there are limitations to using linear tools (Harbourne & Stergiou, 2009). Harbourne and colleagues (2010) argued that there is more to know about variability than simply the amount; rather, the 'structure' of variability provides critical information regarding movement adaptability and the change in variability during the emergence of abilities over time. Nonlinear tools (i.e., the calculation of approximate entropy; see Harbourne & Stergiou, 2009, p.274 for more detail) measure the complexity of variability which indicates the flexibility of the child's motor behaviour or how many motor options the child has available to accomplish the task (Harbourne et al., 2010). Consequently, "the nonlinear tools best capture variation in how a motor behaviour emerges in time" (Harbourne & Stergiou, 2009, p. 270).

Thus, perhaps contributing to the lack of associations found in our current study, the tools used were likely unable to provide a comprehensive measurement of variability in motor abilities and performance. The challenge is that nonlinear approaches are not available clinically (Harbourne & Stergiou, 2009). Even the linear measures used in research involve force plate measurements rather than developmental observational tools; this equipment is not readily available to clinicians. Dusing and Harbourne (2010) are encouraged that "research is ongoing on the relationship between complexity in postural control and clinically feasible measures of behavior and developmental assessments" (p. 1845). They recommended that "clinicians should observe infants during their spontaneous movements, keeping variability in mind" (p. 1845).

The complicated nature of the population under investigation in our study may have further contributed to the lack of associations. Children with CP belong to a heterogeneous population; in addition to the characteristic challenges with movement and posture, impairments may be present in various body structures and functions ranging from communication, cognition, behaviour, sensation and perception, among others (Rosenbaum et al., 2007). Researchers have proposed that children with CP may demonstrate a limited ability to vary and adapt motor responses as a result of the associated motor and sensory impairments (Hadders-Algra, 2010; Harbourne et al., 2010). Currently insufficient information is available in the literature to understand the trends in variability and complexity in this heterogeneous population throughout motor ability acquisition.

5.2 Limitations

Several limitations of this study must be noted. In describing the sample, it is unclear how the children in this current sample compare to other children with CP with regards to DMQ or Child Engagement in Daily Life scores; there are no normative data reported for these measures with children with CP in the literature. Furthermore, it is unclear how these scores can be classified or interpreted clinically. These data are unavailable.

The results of this study cannot be generalized to the larger population of children with CP. This exploratory study consisted of only five young children with CP, most of which (four of the five) were classified in GMFCS level I. Perhaps a larger sample representing various GMFCS levels and CP sub-types (i.e., hemiplegia, diplegia, quadriplegia) may have demonstrated greater variability in motor behaviours. In their small randomized, controlled trial, Harbourne and colleagues (2010) calculated vastly different variability and complexity values for an infant with spastic quadriplegic CP versus an infant with athetoid CP. The first infant had limited variability

paired with higher complexity indicating rigidity or a clinical picture of being 'stuck' in a sitting position with limited movement options. Conversely, the infant with athetoid CP demonstrated excessive variability and limited complexity indicating an unstable pattern, also resulting in decreased motor options for independent sitting.

Another limitation is the pooling of data within and across children in the sample. As this study was a case series, the data for each child were analyzed separately initially; however, the data for the five children were combined to achieve a larger set of data points for the exploration of associations for the first and second study aims. There was a lack of associations found with both approaches.

5.3 Recommendations for Future Research

The identification and measurement of variability during motor acquisition in children, both those developing typically and those with CP, is an important area of research. To further investigate the factors associated with motor acquisition in young children with CP, using a larger, more diverse sample is recommended with children with varying sub-types of CP, classified in a broader range of GMFCS levels and encompassing a broader age range (while remaining within the age limits for potential change according to the motor growth curves). Stratifying the sample by GMFCS level and age would also be important factors to study. Indeed, younger children may demonstrate greater amounts of variability as abilities are emerging, whereas children slightly older may demonstrate greater complexity or adaptability of their motor options as they have mastered those abilities and demonstrate less change on developmental tools. Furthermore, children in GFMCS levels IV and V may show lower complexity scores on nonlinear measures indicating fewer movement options than children classified in levels I to III. In future studies, the use of a combination of linear and nonlinear

tools is required to measure and understand variability and the resulting clinical implications. Perhaps using these tools to measure a limited selection of emerging motor abilities in the sample would be more feasible than assessing the whole range of GMFM items. Harbourne and Stergiou (2009) outlined guidelines for using nonlinear tools in the investigation of motor abilities. Furthermore, Harbourne suggested that clinical measures of variability in motor behaviour need to assess children performing tasks in multiple ways to capture the flexibility of their motor behaviour (personal communication, December 10, 2010). As noted in our current study, it would be interesting to explore the influence of behavioural factors on the observed variability in movement as well.

5.4 Recommendations for Clinicians

Although this study did not yield the anticipated results, there remain considerations for clinicians and clinical practice. First, clinicians are encouraged to consider the factors within the child, task and environment which may influence the child's motor behaviour. Although a finding difficult to reconcile, this study found an inverse relationship between scores of mastery motivation with motor ability acquisition (i.e., GMFM change score). These results conflict with previous findings that show that aspects of a child's motivation correlated with improved physical function (Majnemer et al., 2007). Based on the stronger findings by Majnemer and colleagues (2007), clinicians should consider motivation an important child factor during clinical decision-making. The results on this current study highlight the challenges of measuring transition periods and variability clinically. When considering this concept in practice, clinicians should reflect on how the features and types of variability impact the child's movement and motor behaviour. These factors may have implications for assessment and intervention approaches and may provide direction as to when services should be provided. Finally,

clinicians should choose outcome measures carefully, considering what clinical information they may or may not be designed to capture.

5.5 Conclusion

Although this small, exploratory study failed to identify associations between the factors explored, the results were likely impacted by the inability of the measurement tools used to capture subtle changes in motor behaviour and the small sample used. Further investigation is warranted using a larger, more diverse sample of children with cerebral palsy and nonlinear tools designed to measure variability in movement. Greater understanding of the implications of variability on the emergence of motor abilities in this population could offer critical insight into how children with cerebral palsy acquire motor abilities and select optimal motor strategies under varying task constraints.

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APPENDICES

Appendix A: Therapist Information Form

THERAPIST INFORMATION SHEET

Project Name:	Exploring Factors Associated with Readiness to Change During the Acquisition of Motor Abilities in Young Children with Cerebral Palsy
Principal Investigator:	Dr. Liisa Holsti, PhD (C), OTR Division of Neonatology and Assistant Professor, Department of Occupational Science and Occupational Therapy, The University of British Columbia. (604) 875-2000, local 5200
Co Investigators	Karen Sauve, PT, MSc (Candidate) Registered Physiotherapist, Sunny Hill Health Centre for Children Dr. Doreen Bartlett, PhD, PT Associate Professor, School of Physical Therapy, University of Western Ontario Lori Roxborough, MSc. Director of Therapy, Sunny Hill Health Centre for Children
Study Coordinator:	Karen Sauve: (604) 453-8300 ext. 8422

What is this study about?
This study will explore several factors that are thought to influence how and when a child with cerebral palsy (CP) learns new motor abilities. We hope to identify factors that therapists can measure clinically, to know when a child is most ready to benefit from physiotherapy intervention.

Who is conducting this study?
Dr. Liisa Holsti is supervising this study. Karen Sauve will be conducting the study as a requirement for the completion of her Masters of Science thesis for the University of British Columbia. None of the investigators of this study will receive payment for enrolment of participants or from the results of this study.

Why is this study being done?
The findings from this study may improve our understanding of gross motor development in children with CP. We may gain greater understanding of factors that physiotherapists can target and potentially modify to facilitate improved motor acquisition. Furthermore, the findings may give us information about how to identify when a child is most ready for physiotherapy intervention to optimize functional motor outcomes of treatment.

Who can participate?
Children with a diagnosis of CP classified in GMFCS levels I, II, or III are invited to participate. If a child does not yet have a confirmed diagnosis of CP, but their physiotherapist has observed a delay in gross motor development with impairments in: muscle tone, active range of motion during movement, righting and equilibrium reactions, and/or anticipatory postural movements, they may qualify for participation. Additionally, the child must be three or four years old, understand English instructions well enough to play "Simon says", and be able to engage in 45 minutes of gross motor play to be eligible for participation. The child's parent(s) must understand and speak English well enough to participate in two 30-minute interviews and have adequate space in their home (10ftx12ft) for the assessment of their child's motor abilities using standardized tests.

Who should not participate?
Children should not participate in this study if they have undergone orthopedic surgery 6 months before the study or have planned orthopedic surgery during the study duration. Children who have intrathecal baclofen, or hearing or visual impairments which would interfere with their ability to undergo standardized motor assessments should not participate. Finally, children who will be receiving botox injections for the first time during the study duration should not participate. Children who may be receiving routine botox injection during the study are still eligible for participation in the study.

What will participants be asked to do?
The children and parents who participate in this study will be asked to schedule ten home visits with Karen Sauve, at the family's convenience. The first and last home visit will last 75 minutes; 30 minutes for a parent interview and 45 minutes for the motor assessment of the child. The remaining home visits will last for 45 minutes and occur every two weeks over a four-month period. The parents will be asked to complete two interviews (first and last home visit) to answer questions related to their child's motivation, current services and goals of services, regular activities and enjoyment in those activities. The children will be asked to participate in gross motor assessments at each home visit. These standardized assessments require the child to be videotaped for scoring purposes. The parents will be asked to videotape the motor assessments following specific videotaping guidelines, if willing. Karen will train the parents on use of the video camera and guidelines to be followed. If the parent prefers not to help with the videotaping, a tripod will be used. If the parent does not want their child to be videotaped during the assessments they can choose not to participate in the study.

What are the possible risks?
There are minimal risks to participants in this study. Very rarely, a child may become upset about being assessed or meeting a new person in their home. The parent will be present for all assessments, helping to reduce any anxiety experienced by the child. Additionally, the home

visits will be scheduled at the family's convenience and may be rescheduled as needed. The parents can withdraw from the study at any time. Karen Sauve is experienced in administering the standardized tests to be used in this study. She will closely guard each child during all motor assessments to minimize the risk of injury during testing.

What are the possible benefits?
Children who participate in this study will undergo a thorough assessment of their gross motor skills and change in those skills over four months by an experienced pediatric physiotherapist. Parents will be given a copy of the initial and final assessment score sheets and video clips. Each child will receive a one-piece sun suit to wear during all study-related assessments and to keep after the study is completed.

What will my involvement be as the treating therapist?
As the child's treating therapist, you will be asked to identify potential participants for this study. You are asked to inform eligible families of the study by providing them with a consent form to review. You are asked to gain consent from those families to release their contact information to Karen Sauve. Karen will then contact the family to discuss the study details and answer any questions. Karen will wait 48 hours after talking with the family to allow them time to consider the information. After 48 hours, Karen will re-phone families to gain informed consent.

What will the study cost the family?
There is no cost to participating families. Karen Sauve will travel to each family's home to conduct the home visits.

How will the information of the child and family be kept confidential?
Each child will be assigned a code number; all data will be labeled with the code number instead of their name (including videotapes). All videos will be saved on two password-protected external hard drives. All data (paper and video) will be kept in a locked file cabinet in a locked office at Children's & Women's Hospital. After five years, all paper data will be shredded and videos will be destroyed using demagnetization at Children's & Women's Hospital.

Where can I get further information?
For more information about the study or eligibility for participation, please phone Dr. Liisa Holsti at (604) 875-2000, local 5200.

Appendix B: Consent Form

CONSENT FORM

Exploring Factors Associated with Readiness to Change During the Acquisition of Motor Abilities in Young Children with Cerebral Palsy

Principal Investigator: Dr. Liisa Holsti, PhD (C), OTR
Division of Neonatology and Assistant Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia. (604) 875-2000, local 5200

Co-Investigator Karen Sauve, PT, MSc (Candidate) Rehabilitation Science
Registered Physiotherapist, Sunny Hill Health Centre for Children

Dr. Doreen Bartlett, PhD, PT
Associate Professor, School of Physical Therapy, University of Western Ontario

Lori Roxborough, MSc.
Director of Therapy, Sunny Hill Health Centre for Children

Sponsor: Funding for this project is provided by graduate awards from the Canadian Institutes of Health Research (CIHR) and the University of British Columbia.

You and your child are being invited to participate in a study because your child has a diagnosis of cerebral palsy (CP).

What is this study about?
This study will explore several factors that are thought to influence how and when a child with CP learns new motor abilities. We hope to identify factors that therapists can measure clinically, to know when a child is most ready to benefit from physiotherapy intervention.

Who is conducting this study?
Dr. Liisa Holsti is supervising this study. Karen Sauve will be conducting the study as a requirement for the completion of her Master of Science thesis for the University of British Columbia. Findings from this study will be submitted for publication in a peer-reviewed journal. None of the investigators of this study will receive payment for enrolment of participants or from the results of this study.

Why is this study being done?
The findings from this study may improve our understanding of gross motor development in children with CP. We may better understand what factors a physiotherapist can work on with children with CP to improve their motor skills. Furthermore, the findings may give us information about how to identify when a child is most ready for physiotherapy intervention to ensure the best possible outcomes of treatment.

Who can participate?
Your child is eligible to participate if he or she is 3 or 4 years old, has a diagnosis of CP and is able to walk with or without a walker or holding onto your hands. If you are not sure if your child qualifies, please ask your child's physiotherapist about these criteria. Additionally, if your child can follow the rules of games such as "Simon says" in English and can participate in gross motor activities for 45 minutes, he or she qualifies for this study. As a parent, you will be asked to participate in two 30-minute interviews for this study. If you can speak and understand English fluently, you are eligible for this study. Finally, if you have adequate room in your home (a space of 10 ft x 12 ft) for the assessment of your child's motor skills, you and your child are eligible to participate.

Who should not participate?
Your child should not participate in this study if they have had surgery on his or her bones or muscles in the past 6 months, or if he or she is scheduled to have surgery during the course of this study. Your child should not participate if he or she has intrathecal baclofen to control his or her muscle tone, or if he or she will be receiving botox injections to any muscles for the first time during the duration of this study. If your child has hearing or visual difficulties which would make him or her unable to participate in a standardized gross motor test, he or she should not participate in this study.

What will participants be asked to do?
If you agree to participate in this study, you and your child will be asked to schedule 10 visits at your home with Karen Sauve (Physiotherapist). These visits will be scheduled at your convenience, every two weeks for 4 months. The first and last home visit is expected to last 75 minutes; 30 minutes for a parent interview and 45 minutes for assessment of your child. Home visits 2-9 are expected to last 45 minutes. During the first and last visit, you will be interviewed to complete questionnaires about what therapy services your child receives, the goals of those services, your child's motivation, what activities your child does and how much you think your child enjoys these activities (e.g., Crafts, gymnastics, puzzles, watching movies, etc). Additionally, your child's gross motor skills will be assessed using standardized tests at each home visit. These standardized tests require that your child be videotaped; if you do not want your child to be videotaped you can choose not to participate in the study. You will be asked to help Karen video tape each standardized assessment of your child. You do not need a video camera; Karen will bring one to each home visit. If you agree to videotape, Karen will teach you how to use the camera and what parts of the assessment to tape. If you choose not to perform the videotaping, a tripod will be used. Your child will be recognizable from the videos, including his or her face, as facial expressions and reactions to the test items are important for scoring the tests. If you have other children or family members in your home, they will not be videotaped. The study team will have access to the videotapes for scoring purposes. The videos will be used for scoring of the standardized measures only; video clips will not be used for presentation or

publication purposes. However, the data and results of this study will be submitted for publication and presentations. The videos will be saved on two password protected external hard-drives and stored in a locked file-cabinet, in a locked office at Children's & Women's Hospital. These video files will be stored for five years and then destroyed using demagnetization procedures.

What are the possible risks?
There are minimal risks to you or your child if participating in this study. There is a rare chance that your child may become upset about being assessed or meeting a new person in their home. You will be present for all assessments, helping to reduce any anxiety experienced by your child. Each home visit will be scheduled when it is most convenient for you and your child. Home visits can be rescheduled as needed and you may withdraw from the study at any time and without providing any reasons for your decision. Karen Sauve is experienced in administering the standardized tests to be used in this study. She will closely guard your child during all motor assessments to minimize the risk of injury during testing. Signing this consent form in no way limits your legal rights against the sponsor, investigators, or anyone else.

What are the possible benefits?
If you agree to participate, your child will receive a thorough assessment of his or her gross motor skills and change in those skills over 4 months by an experienced pediatric physiotherapist. You will be given a copy of the initial and final assessment score sheets and video clips. Your child will receive a one-piece sun suit to wear during all study-related assessments and to keep after the study is completed.

Why are you being asked to participate?
Your child's physiotherapist at the Centre for Ability, the Centre for Child Development, Reach Child and Youth Development Society or the North Shore Paediatric Resource Team was asked to tell you about this study because your child meets the eligibility criteria to participate.

How will this affect your child's current therapy services?
This study does not interfere with your child's current physiotherapy services at the Centre for Ability, the Centre for Child Development, Reach Child and Youth Development Society or the North Shore Paediatric Resource Team. This study is not related to those services, rather provides your child additional gross motor assessment over the 4 months of the study.

What will the study cost your family?
There is not cost for participating in this study. Karen Sauve will travel to your home for each home visit. No remuneration will be offered to participating families.

How will the information about you and your child be kept confidential?
Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent to the disclosure. However, research records and medical records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Research Ethics Boards for the purpose of monitoring the research. However, no records which identify you by name or initials will be allowed to leave the Investigators' offices. Your child and all children participating in this study will be assigned a non-identifying code number; all data will be labeled with the code number instead of their name (including video tapes). As mentioned above, all videos will be saved on

two password-protected external hard drives. All paper and video data will be kept in a locked filing cabinet in a locked office at Children's & Women's Hospital for five years. After five years, all paper data will be shredded and videos will be destroyed using demagnetization at Children's & Women's Hospital.

Who can you contact if you have any questions or concerns about the study?
If you have any questions or desire further information with respect to this study, you may contact Dr. Liisa Holsti at (604) 875-2000, local 5200.

Who can you contact about the rights of research participants?
If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Consent
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your child's physiotherapy services.

Your signature indicates that you consent to participate in this study.

I consent/I do not consent (circle one) to my child's participation in this study.

Parent Signature, Parent Printed Name, Date

Appendix C: Focus of Therapy Services

Study ID	Primary Impairments	Secondary Impairments	Activity Limitations	Environment Factors	Participation Restrictions
1	3.00	4.67	3.67	4.50	2.50
2	1.00	1.33	1.33	1.50	2.00
3	3.67	2.67	4.33	4.50	4.00
4	3.33	3.67	1.67	1.50	3.00
5	3.67	3.33	4.00	2.00	4.00

***The highest mean score for each area is 5.00**

Appendix D: The Dimension of Mastery Questionnaire

The Dimensions of Mastery Questionnaire (DMQ): Appendix

Copies of the Six Parallel Versions of the DMQ and How to Score Them

George A. Morgan
Colorado State University

Nancy A. Busch-Rossnagel
Fordham University

Karen C. Barrett
Colorado State University

Jun Wang
Colorado State University

Scoring the DMQ

Agreement Memo (2pages)

English Motivation Questionnaire
- Infant (6-18 months)
- Preschool (1 ½ -5 years)
- Child (6-12 years, by adults)
- Child (self-ratings)
- Teen (self-ratings)
- Teen (by adults)

Spanish Motivation Questionnaire
- Infant (6-18 months)
- Preschool (1 ½ -5 years)
- Child (6-12 years, by adults)
- Child (self-ratings)
- Teen (self-ratings)
- Teen (by adults)

Chinese Motivation Questionnaire
- Infant (6-18 months)
- Preschool (1 ½ -5 years)
- Child (6-12 years, by adults)
- Child (self ratings)

Scoring the DMQ

The DMQ is easy to administer and score. No instructions other than those on the questionnaires (attached) are necessary. The ratings usually take about 10-15 minutes to complete.

To score the DMQ 17 (all age versions), use the formulas shown below for the seven scales. The items marked with an R need to be recoded or reversed; i.e., scores of 5 become 1, 4 become 2, 2 become 4, 1 become 5, and 3 stay 3.

To compute the scales, use the following formulas:

1. **Object-Oriented Persistence** = (item 1 + 7 + 9R + 14 + 17 + 23 + 24 + 29 + 31)/ 9
2. **Social Persistence with Adults** = (8 + 15 + 19 + 22 + 33R + 37)/ 6
3. **Social Persistence with Children** = (25 + 28 + 30 + 32 + 35 + 39R)/ 6
4. **Gross Motor Persistence** = (3R + 12 + 16 + 26 + 27 + 36 + 40 + 45)/ 8
5. **Mastery Pleasure** = (2 + 11R + 18 + 21 + 41 + 43)/ 6
6. **Negative Reaction to Failure** = (5 + 34 + 38 + 42 + 44)/ 5
7. **General Competence** = (4 + 6R + 10 + 13R + 20)/ 5

Note. For infants, negative reaction to failure is computed from items (38 + 42 + 44)/3, and for self ratings of elementary and high school students negative reaction to failure is (34 + 38 + 42 + 44)/4.

Copies of the DMQ

Attached are copies of the current Dimensions of Mastery Questionnaire (DMQ 17) for adults to rate infants (6-18 months), preschoolers (1½-5 years), elementary school-age children (6-12 years), and teens (13-19 years). There are also self-rating forms for children and teens. The forms are identified on the back. If the assessed child has significant developmental delays, it may be best to use an age version that corresponds to the child's developmental age.

Motivation Questionnaire

Child's age_____ Circle one: Boy Girl Today's Date_____
Years Months
Rater's relationship to child: Mother _____ Father _____ Other (please specify) _____

This child is developing normally/typically ____ or has special needs (please specify) _____

CIRCLE the number that best indicates how typical each statement is of this child. Think of a rating of 3 as an average child of approximately this child's age. Children vary; most are motivated to do some things but not others. Please try to answer all questions even if you are not sure.

		NOT AT ALL TYPICAL				VERY TYPICAL
1.	Repeats a new skill until he or she can do it well.	1	2	3	4	5
2.	Smiles broadly after finishing something.	1	2	3	4	5
3.	Gives up if he or she cannot do physical skills well.	1	2	3	4	5
4.	Solves problems quickly.	1	2	3	4	5
5.	Gives up easily if cannot do something.	1	2	3	4	5
6.	Is a little slow understanding things.	1	2	3	4	5
7.	Likes to try hard problems instead of easy ones.	1	2	3	4	5
8.	Enjoys talking with adults, and tries to keep them interested.	1	2	3	4	5
9.	If a toy or task is hard to do, stops trying after a short time.	1	2	3	4	5
10.	Is very good at doing things.	1	2	3	4	5
11.	Does not smile when he or she makes something happen.	1	2	3	4	5
12.	Tries to do well in physical activities even when they are hard.	1	2	3	4	5
13.	Has some difficulty doing things as well as other children his or her age.	1	2	3	4	5
14.	Tries to complete things, even if it takes a long time to finish.	1	2	3	4	5
15.	Tries hard to interest adults in playing with him or her.	1	2	3	4	5
16.	Likes physical games and tries to do them very well.	1	2	3	4	5
17.	Explores all parts of an object or toy with many parts before doing something else.	1	2	3	4	5
18.	Gets excited when he or she figures something out.	1	2	3	4	5
19.	Likes to play actively with me or other adults.	1	2	3	4	5
20.	Does things that are hard for children for his or her age.	1	2	3	4	5
21.	Is pleased when solves a hard problem.	1	2	3	4	5
22.	Tries hard to get adults to understand.	1	2	3	4	5

OVER PLEASE

		NOT AT ALL TYPICAL				VERY TYPICAL
23.	Works for a long time trying to do something hard.	1	2	3	4	5
24.	Tries to do hard cause and effect toys such as a jack-in-the-box.	1	2	3	4	5
25.	Gets very involved in pretend play with friends.	1	2	3	4	5
26.	Repeats skills like jumping or running until he or she can do them well.	1	2	3	4	5
27.	Tries hard to throw balls so he or she can do it well.	1	2	3	4	5
28.	Tries hard to make friends with other kids.	1	2	3	4	5
29.	Will work for a long time trying to put something together.	1	2	3	4	5
30.	Likes to "talk" with other children.	1	2	3	4	5
31.	Tries to complete toys like puzzles even if they are hard.	1	2	3	4	5
32.	Tries to get included when other children are playing.	1	2	3	4	5
33.	Gives up quickly when playing with adults.	1	2	3	4	5
34.	Looks down or away when he or she tries but cannot do something.	1	2	3	4	5
35.	Tries to keep play going for a long time when around other kids.	1	2	3	4	5
36.	Repeats motor skills, such as climbing, to do them well.	1	2	3	4	5
37.	Enjoys playing make-believe with adults.	1	2	3	4	5
38.	Lowers head or slumps over when he or she does not do well at something.	1	2	3	4	5
39.	Avoids getting involved with other children.	1	2	3	4	5
40.	Tries to do well at athletic activities like exercising or "dancing."	1	2	3	4	5
41.	Smiles when he or she makes something happen.	1	2	3	4	5
42.	Avoids looking at others after failing at something he or she tried hard to do.	1	2	3	4	5
43.	Shows excitement when he or she is successful.	1	2	3	4	5
44.	Gets upset if he or she cannot do something after trying hard.	1	2	3	4	5
45.	Tries hard to get better at catching or retrieving things.	1	2	3	4	5

DMQ 17 preschool. January 27, 1997

Appendix E: The Child Engagement in Daily Life Measure

Child Engagement in Daily Life Measure

Attribute measured: Engagement in Play & Self-Care

Why this is important: Engagement in play and self-care is one of the primary outcomes of interest in the study. Engagement in play and self-care reflects the participation dimension of the International Classification of Function (World Health Organization, 2001). In this classification, participation is defined as individual involvement in life situations. For young children, involvement in life situations can be viewed as the degree to which children are able to participate in their daily activities such as interactions with others, play, and self-care. Engagement in play and self-care is intended to capture the degree to which the child uses their developmental abilities during day-to-day family and community activities.

Description of Measure:

The Child Engagement in Daily Life Measure, is a 30-item questionnaire developed by the research team. The questionnaire consists of four parts: A) Interaction with Others and Play: Participation in Family and Community Life, B) Interaction with Others and Play: Participation in Leisure and Recreational Activities, C) Self-Care: Activities of Daily Living, and D) Self-Care: Ease of Care Giving.

Interaction with others and play measures the participation of the child in family / community life and leisure / recreational activities. Two dimensions are scored on a 5- point Likert scale: how often a child participates (very often to never) and the degree of enjoyment (a great deal to not at all).

Self-care: Activities of Daily Living measures the degree that the child is able to participate in their daily self-care activities (feeding, dressing, bathing, and toileting). The ratings for daily self-care activities (yes, does the activity consistently to no, unable) distinguish the need for physical help of an adult and, for children who do not require adult help, whether the child is able to consistently do the activity.

Self-Care: Ease of Care-Giving measures the parent or caregiver perception of how difficult it is for them to safely help their child to perform activities of daily living (no help needed to very difficult). The Ease of Care-Giving dimension will not be included as an indicator of the child's engagement in self care but will be utilized to answer auxiliary questions related to family outcomes for young children with cerebral palsy. This information is being collected within this questionnaire for ease of family's response to these items.

The sections on participation of the child in family and community life, activities of daily living, and ease of care giving have been adapted from the Pediatric Physical Therapy Outcomes Management System (PPT-OMS) (Palisano et al. 1999).

 "The authors acknowledge the contribution of Stephen M. Haley for his work as an author, in collaboration with Robert J. Palisano and Sally Westcott McCoy, on the Pediatric Physical Therapy Outcomes Management System (PPT-OMS). The Child Engagement in Daily Life Measure had its genesis in the Self-care and Participation items on the Early Movement Outcomes Program of the PPT-OMS."

Overview of Administration Guidelines:

- This is a caregiver completed, self-report measure.

The caregiver may have completed the measure prior to your visit or alternately will complete the measure during your visit.

At the end of your visit review the measure to insure that all items are completed. If an item is left blank please ask the caregiver if they have elected not to answer that item or if it was accidentally missed. In the later case please have the caregiver answer the item.

Familiarize yourself with the items, scaling responses, and tips indicated below so that you are knowledgeable in answering any question the caregiver may have regarding the measure.

Equipment required to administer: Only the questionnaire.

Overview of items and response options:

Part A: Interaction with Others and Play: Participation in family and community life: Family activities at home, family outings in the community, indoor play with adults, indoor play with children, outdoor play with adults, outdoor play with children.

Part B: Interaction with Others and Play: Participation in leisure / recreational activities: Quiet recreation; organized lessons, adapted sports, & arranged play groups; active physical recreation; entertainment outings; social activities.

Response Options: Caregiver will rate how often their child participates in the various activities and their perception of how much the child enjoys each activity.

How often:

Very Often - Your child always participates in the activity (at every opportunity)

Often - Your child frequently participates in the activity

Once in a while - Your child sometimes participates in the activity

Almost never - Your child rarely participates in the activity

Never - Your child never participates in the activity

How much your child enjoys the activity:

A great deal – Your child loves the activity

Very much – Your child really likes the activity

Somewhat – Your child likes the activity

Very little – Your child is okay with the activity

Not at all – Your child dislikes the activity

Part C: Self-Care: Activities of Daily Living: Feed self finger foods, feed self with spoon or fork, drink from a bottle or cup, dress upper body, dress lower body, bathe / groom, use of potty / toilet.

Response Options: Items are scored using a five-point rating scale. The ratings distinguish the need for **physical help** of an adult and, for children who do not require adult help, whether the child is able to **consistently** do the self-care activity. Children may use special equipment, walking devices, or wear an orthosis to do an activity in daily living. Adult supervision for safety is also permitted. The five responses options are:

Yes, does the activity consistently – The child consistently does the activity during daily routines without adult help

Yes, does the activity inconsistently – The child is able to do the activity without adult help but is not successful or motivated to do it all of the time

Yes, with help for part of the activity – The child completes part of the activity without help but requires help of an adult to complete the activity

Yes, with constant help – The child cooperates but is unable to do any part of the activity without the help of an adult

No, unable – The child is unable to do the activity

Part D: Self-Care: Ease of Care-Giving: Items measure the parent perception of how difficult it is for them to safely help the child do activities of daily living such as moving, positioning, dressing, bathing, toileting, eating, drinking, and getting in and out of a vehicle.

Response Options: Items are scored using a five-point rating scale. The five response options are:

No help is needed - The child does the activity of daily living without the help of an adult

No difficulty – The parent or caregiver helps the child and reports that they have no difficulty providing help

A Little - The parent or caregiver helps the child and reports that they have only a little difficulty providing help

Somewhat – The parent or caregiver helps the child and reports that providing help is somewhat difficult

Very - The parent or caregiver helps the child and reports that providing help is very difficult

The distinction among **Very**, **Somewhat**, and **A Little** is made based on the following considerations: safety, physical demands, confidence of person providing the help, and time needed to complete the activity.

Tips and Considerations:

The questionnaire is designed to measure **what the child currently does during daily routines**, not what the child can do under optimal circumstances or standardized test conditions.

Because of the young age of the children in this study, regardless of their level of disability, it is not expected that children this young are participating or able to do all of these activities.

The scale does not provide information on the reason(s) for a child's limited participation. Parents may want to discuss, provide explanations, or put comments on the form. Lack of participation in some activities may reflect a child or family's interests and lifestyle. Please acknowledge that there is no right or wrong answer but that we are interested in learning about what children do.

The activities in Parts A and B are broad categories. Examples listed are not exclusive.

References:

Palisano RJ, Haley SM, Westcott SL, Hess A. Pediatric Physical Therapy Outcomes Management System. *Pediatric Physical Therapy*. 1999;11, 220.

World Health Organization. *International Classification of Functioning, Disability, and Health*. Geneva: author; 2001.

Case id _____

Child Engagement in Daily Life

We are interested in HOW MUCH AND HOW OFTEN your child is able to PARTICIPATE IN DAILY ACTIVITIES such as interactions with others, play, and self-care.

Part A- Interaction with Others and Play: Participation in Family and Community Life

The next 3 pages ask questions about your child's participation in family and community life. There are 2 parts to each question- how often your child participates and how much your child enjoys it.
The responses and definitions below are guidelines to help you choose the best response for your child.

1) HOW OFTEN YOUR CHILD PARTICIPATES IN THE ACTIVITY

Very Often	- Your child always participates in the activity (at every opportunity)
Often	- Your child frequently participates in the activity
Once in a while	- Your child sometimes participates in the activity
Almost never	- Your child rarely participates in the activity
Never	- Your child never participates in the activity

2) HOW MUCH YOU THINK YOUR CHILD ENJOYS THE ACTIVITY

A great deal	- Your child loves the activity
Very much	- Your child really likes the activity
Somewhat	- Your child likes the activity
Very little	- Your child is okay with the activity
Not at all	- Your child dislikes the activity

PUT A CHECK MARK IN THE BOX BESIDE THE BEST ANSWER FOR YOUR CHILD- REMEMBER TO USE THE INFORMATION ON PAGE 1, IF YOU NEED HELP TO DECIDE WHICH ANSWER IS BEST.(There will be boxes put in)

ENG 1

(a) How often does your child participate in family activities at home such as chores, mealtime, watching TV?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

ENG 2

(a) How often does your child participate in family outings in the community (for example- shopping, going to religious services or the library, visiting family and friends)?

Very often often once in a while almost never never

(b) How much do you think your child enjoys this activity?

A great deal very much somewhat very little not at all

ENG 3

(a) How often does your child participate in indoor play with adults?

Very often often once in a while almost never never

(b) How much do you think your child enjoys this activity?

A great deal very much somewhat very little not at all

ENG 4

(a) How often does your child participate in indoor play with children?

Very often often once in a while almost never never

(b) How much do you think your child enjoys this activity?

A great deal very much somewhat very little not at all

ENG 5

(a) How often does your child participate in outdoor play with adults?

Very often often once in a while almost never never

(b) How much do you think your child enjoys this activity?

A great deal very much somewhat very little not at all

ENG 6

(a) How often does your child participate in outdoor play with children?

Very often often once in a while almost never never

(b) How much do you think your child enjoys this activity?

A great deal very much somewhat very little not at all

Part B- Interaction with Others and Play: Participation in Leisure and Recreational Activities

The next questions are about your child's participation in Leisure and Recreational Activities. Again -there are 2 parts to each question- how often your child participates and how much your child enjoys it.
PUT A CHECK MARK IN THE BOX BESIDE THE BEST ANSWER FOR YOUR CHILD- REMEMBER TO USE THE INFORMATION ON PAGE 1, IF YOU NEED HELP TO DECIDE WHICH ANSWER IS BEST.

ENG 7

(a) How often does your child participate in quiet recreational activities such as coloring, card games, reading books?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

ENG 8

(a) How often does your child participate in organized lessons, adapted sports, and arranged play groups such as swimming, dance / creative movement, parent & me classes?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

ENG 9

(a) How often does your child participate in active physical recreation such as climbing on playground equipment, riding a tricycle, swimming, running outside?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

ENG 10

(a) How often does your child participate in entertainment outings such as going to the zoo, a children's museum, the circus, or concerts?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

ENG 11

(a)How often does your child participate in social activities such as a play date, going to parties?

Very often often once in a while almost never never

(b) How much do you think your child enjoys these activities?

A great deal very much somewhat very little not at all

Part C- Self Care:
Activities of Daily Living

This section asks you to rate how your child does some activities of daily living- activities like getting dressed, feeding, drinking and using the toilet. We want to know how well your child is able to do these activities.

The 5 answers below describe different ways that children do activities of daily life. We don't expect that young children will be able to do all these activities without help. We realize that sometimes adult help is necessary for safety. Also, we know that some children may need to use special equipment, walking devices, or wear an orthosis / brace to do these activities.

When you read the descriptions below, you will see there are 2 main ideas to think about when answering the questions:

Does your child need the help of an adult to do the activity?

Does your child do the activity consistently - that is to say - is your child always able to do it?

THESE ARE THE 5 CHOICES FOR ANSWERS:

1. **YES, DOES THE ACTIVITY CONSISTENTLY -**
   The child consistently does the activity during daily routines without adult help.

2. **YES, DOES THE ACTIVITY INCONSISTENTLY -**
   The child is able to do the activity without adult help but is not successful or motivated to do it all of the time.

3. **YES, WITH HELP FOR PART OF THE ACTIVITY -**
   The child completes part of the activity without help but requires the help of an adult to complete the activity.

4. **YES, WITH CONSTANT HELP -**
   The child cooperates but is unable to do any part of the activity without the help of an adult.

5. **NO, UNABLE -**
   The child is unable to do or does not do the activity.

ANSWERS

1. Yes, does the activity consistently
2. Yes, does the activity inconsistently
3. Yes, with help for part of the activity
4. Yes, with constant help
5. No, unable

CIRCLE THE ANSWER THAT DESCRIBES YOUR CHILD.

ENG 12 Does your child feed him/herself finger foods?

1 2 3 4 5

ENG 13 Does your child feed him/herself with spoon or fork?

1 2 3 4 5

ENG 14 Does your child drink from a bottle or cup?

1 2 3 4 5

ENG 15 Does your child dress his or her upper body?

1 2 3 4 5

ENG 16 Does your child dress his or her lower body?

1 2 3 4 5

ENG 17 Does your child bathe / clean and tidy him/herself?

1 2 3 4 5

ENG 18 Does your child use the potty or toilet?

1 2 3 4 5

Part D Self Care: Ease of Care-Giving

Please think about HOW DIFFICULT it is for YOU to SAFELY HELP YOUR CHILD to do activities of daily living.

When thinking about how difficult it is for you, please consider the following things:

- safety
- physical demands on you
- your confidence about providing the help
- the time needed to complete the activity

You have 5 choices for answering the questions on the next page:

1. **No help is needed** -

   Your child does the activity of daily living without the help of an adult.

2. **No difficulty** -

   You help your child and you have no difficulty providing help.

3. **A Little difficulty**-

   You help your child and you have only a little difficulty providing help.

4. **Somewhat difficult**-

   You help your child and providing help is somewhat difficult.

5. **Very difficult**-

   You help your child and providing help is very difficult.

ANSWERS	
1.	no help needed
2.	no difficulty
3.	a little difficulty
4.	somewhat difficult
5.	very difficult

CIRCLE THE ANSWER THAT DESCRIBES YOUR CHILD.

HOW DIFFICULT IS IT FOR YOU TO SAFELY HELP YOUR CHILD.....

ENG 19 to move at home and in the community?

1 2 3 4 5

ENG 20 to position for sleeping?

1 2 3 4 5

ENG 21 to position for feeding?

1 2 3 4 5

ENG 22 to position for bathing?

1 2 3 4 5

ENG 23 to position for playing?

1 2 3 4 5

ENG 24 to put on / take off clothing?

1 2 3 4 5

ENG 25 to put on / take off an orthosis or brace (if applicable) ?

1 2 3 4 5 not applicable

ANSWERS
1. no help needed
2. no difficulty
3. a little difficulty
4. somewhat difficult
5. very difficult

CIRCLE THE ANSWER THAT DESCRIBES YOUR CHILD.

HOW DIFFICULT IS IT FOR YOU TO SAFELY HELP YOUR CHILD.....

ENG 26 to bathe / clean and tidy?

1 2 3 4 5

ENG 27 to use the potty or toilet, or for you to change his/her diapers?

1 2 3 4 5

ENG 28 to eat?

1 2 3 4 5

ENG 29 to drink?

1 2 3 4 5

ENG 30 to get in and out of a car / van / bus?

1 2 3 4 5

Appendix F: Services Questionnaire

Appendix Q: Service Questionnaire

Part A: Types and Intensity of Programs and Services Your Child Receives

Please check the programs / services that your child currently receives **(Check all that apply)**

Does your child participate in any of the following community recreational programs?

___ Horseback riding	Is a therapist involved in the program? __ Yes __ No
___ Aquatics	Is a therapist involved in the program? __ Yes __ No
___ Gym programs	Is a therapist involved in the program? __ Yes __ No
___ Dance / movement programs	Is a therapist involved in the program? __ Yes __ No
___ Sports program	Is a therapist involved in the program? __ Yes __ No
___ Other: _____	Is a therapist involved in the program? __ Yes __ No

What type of school does your child currently attend?

___ Does not attend any school or program

___ Participates in an early intervention program
___ Home-based ___ Typical child care center ___ Special center program

___ Preschool Please specify: ___ Typical preschool ___ Special Preschool

___ School Please specify: ___ Neighborhood school ___ Special School
Please specify: ___ Typical classroom ___ Special Classroom

Does you child receive any services from the following providers?

_____ ***early childhood education specialist / special education teacher***

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

If child attends a preschool program:

How often (# of times per week): _____

How long (# of hours per day): _____

_____ ***occupational therapy***

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

_____ ***physical therapy***

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

_____ ***speech therapy***

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

Where: _____ How often (# of times per month): _____

If less than 1 time per month, how often: _____

Average # of minutes per visit: _____

_____ ***nutrition consultation***

How many times per year: _____

_____ ***home health care*** (like home nursing, home health aid to help with bathing or dressing)

How often (# of times per month): _____

If less than 1 time per month, how often: _____

Part E: Focus of Therapy Services

1. Think of your child's therapy sessions during the past year. Please rate the extent to which your therapist provided these interventions. Circle your response for each statement.

	All the time	To a large extent	To a fair extent	To a small extent	Not at all
Relaxation of muscles (gently moving, rocking, massaging, etc)	5	4	3	2	1
Balance activities (practice with your child holding different positions, responding to a bump or tilt, or reaching and regaining balance, etc)	5	4	3	2	1
Physically guiding your child's way of moving during any motor activities (therapist's hands on your child to guide movements)	5	4	3	2	1
Stretching exercises (moving or positioning your child's limbs to stretch tight muscles)	5	4	3	2	1
Strengthening exercises (muscle activity against a resistance such as lifting heavy toys, riding a tricycle with weights, use of ankle or wrist weights, etc.)	5	4	3	2	1
Endurance exercises (activities which require movement for a sustained period of time such as long walks, bike rides, active games)	5	4	3	2	1
Transfer training (moving from one position to another, transferring from one surface to another)	5	4	3	2	1
Mobility training (movement through the environment via crawling, walking, use of crutches / walker, use of a wheelchair, etc)	5	4	3	2	1

	All the time	To a large extent	To a fair extent	To a small extent	Not at all
Practice of specific tasks (such as opening a door, putting toys away, doing some motor activity of your or your child's choice, etc.)	5	4	3	2	1
Assistive devices and/or equipment training (measuring, fitting, adjusting, and use of braces, switch activation of toys, special chairs, standers, bathroom devices, etc.)	5	4	3	2	1
Adaptations / modifications for the home, classroom, or child care setting (size and location of furniture, ramps, use of visual and auditory cues, etc.)	5	4	3	2	1
Self-care routines (dressing, bathing, feeding, hygiene)	5	4	3	2	1
Structured play activities (focus on play and interaction with toys & people)	5	4	3	2	1

2. Please share with us other types of specific interventions that your child participates in or the therapist does that we have not listed:

Appendix G: Gross Motor Function Measure Basal and Ceiling Version

GROSS MOTOR FUNCTION MEASURE (GMFM)
SCORE SHEET (GMFM-66)
MacKeith Press, 2002
(Abbreviated version adapted for the Move & Play study)

ID # _____

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring.

SCORING KEY
0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
NT = not tested

It is important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) because we will use the Gross Motor Ability Estimator software.

MINIMUM REQUIRED SCORING
3 consecutive "3s" as basal; 3 consecutive "0s" as ceiling
(except for potential floor and ceiling effects for children in levels V and I)
Scoring of all items between basal and ceiling
Minimum of 15 items total

USE THE SUGGESTED STARTING POINTS AS A GUIDE ONLY

A **LYING AND ROLLING**
B **SITTING**
C **CRAWLING AND KNEELING**
D **STANDING**
E **WALKING, RUNNING, & JUMPING**

A	B	C	D	E		0	1	2	3	NT	
	22.				SIT ON MAT, SUPPORTED AT THORAX: lifts head midline, maintains 10 seconds						IV & V all ages
	21.				SIT ON MAT, SUPPORTED AT THORAX: lifts head upright, maintains 3 seconds						
10.					PR: lifts head upright						
2.					SUP: brings hands to midline, fingers one with the other						
6.					SUP: reaches out with R arm, hand crosses midline						
	18.				SUP,HANDS GRASPED BY EXAMINER: pulls self to sitting with head control						
7.					SUP: reaches out with L arm, hand crosses midline						
	23.				SIT ON MAT, ARM(S) PROPPING: maintains 5 seconds						III @ 2
	24.				SIT ON MAT: maintain, arms free 3 seconds						
	25.				SIT ON MAT WITH SMALL TOY IN FRONT: leans forward, touches toy, re-erects without arm propping						
	34.				SIT ON BENCH: maintains, arms and feet free, 10 seconds						
	27.				SIT ON MAT: touches toy placed 45° behind child's L side, returns to start						
	26.				SIT ON MAT: touches toy placed 45° behind child's R side, returns to start						
	30.				SIT ON MAT: lowers to PR with control						III @ 3 II @ 2
		39.			4 POINT: maintains, weight on hands and knees, 10 seconds						
		41.			PR: attains 4 point, weight on hands and knees						
			53.		STD: maintains, arms free, 3 seconds						
				67.	STD, 2 HANDS HELD: walks forward 10 steps						
		36.			ON THE FLOOR: attains sit on small bench						
			52.		ON THE FLOOR: pulls to STD at large bench						
		48.			SIT ON MAT: attains high KN using arms, maintains, arms free, 10 seconds						
		40.			4 POINT: attains sit arms free						
		44.			4 POINT: crawls or hitches forward 1.8 m (6')						
		43.			4 POINT: reaches forward with L arm, hand above shoulder level						III @ 4 II @ 3 I @ 2
		42.			4 POINT: reaches forward with R arm, hand above shoulder level						
	31.				SIT ON MAT WITH FEET IN FRONT: attains 4 point over R side						
	37.				ON THE FLOOR: attains sit on large bench						
				65.	STD, 2 HANDS ON LARGE BENCH: cruises 5 steps to R						II @ 4
	32.				SIT ON MAT WITH FEET IN FRONT: attains 4 point over L side						
				66.	STD, 2 HANDS ON LARGE BENCH: cruises 5 steps to L						
			54.		STD: holding on to large bench with one hand, lifts R foot, 3 seconds						
			59.		SIT ON SMALL BENCH: attains STD without using arms						
		45.			4 POINT: crawls reciprocally forward 1.8 m (6')						

A LYING AND ROLLING
B SITTING
C CRAWLING AND KNEELING
D STANDING
E WALKING, RUNNING, & JUMPING

A	B	C	D	E		0	1	2	3	NT
			55.		STD: holding on to large bench with one hand, lifts L foot, 3 seconds					
	35.				STD: attains sit on small bench					
		46.			4 POINT: crawls up 4 steps on hands and knees/feet					
				68.	STD, 1 HAND HELD: walks forward 10 steps					
		51.			HIGH KN: KN walks forward 10 steps, arms free					
			62.		STD: lowers to sit on floor with control, arms free					
			56.		STD: maintains, arms free, 20 seconds					
			63.		STD: attains squat, arms free					
			64.		STD: picks up object from floor, arms free, returns to stand					
			61.		HIGH KN: attains STD through half KN of L knee, without arms					
			60.		HIGH KN: attains STD through half KN of R knee, without arms					
				69.	STD: walks forward 10 steps					
				70.	STD: walks forward 10 steps, stops, turns 180º, returns					
				72.	STD: walks forward 10 steps, carrying a large object with 2 hands					
				84.	STD, HOLDING 1 RAIL: walks up 4 steps, holding 1 rail, alternating feet					
				85.	STD, HOLDING 1 RAIL: walks down 4 steps, holding 1 rail, alternating feet					
				78.	STD: kicks ball with R foot					
			57.		STD: lifts L foot, arms free, 10 seconds					
				79.	STD: kicks ball with L foot					
				71.	STD: walks backward 10 steps					
			58.		STD: lifts R foot, arms free, 10 seconds					
				73.	STD: walks forward 10 consecutive steps between parallel lines 20 cm (8") apart					
				77.	STD: runs 4.5 m (15'), stops & returns					
				75.	STD: steps over stick at knee level, R foot leading					
				76.	STD: steps over stick at knee level, L foot leading					
				80.	STD: jumps 30 cm (12") high, both feet simultaneously					
				74.	STD: walks forward 10 consecutive steps on a straight line 2 cm (3/4") wide					
				81.	STD: jumps forward 30 cm (12"), both feet simultaneously					
				88.	STD ON 15 cm (6") STEP: jumps of, both feet simultaneously					
				86.	STD: walks up 4 steps, alternating feet					
				87.	STD: walks down 4 steps, alternating feet					
				82.	STD ON R FOOT: hops on R foot 10 times within a 60 cm (24") circle					
				83.	STD ON L FOOT: hops on L foot 10 times within a 60 cm (24") circle					

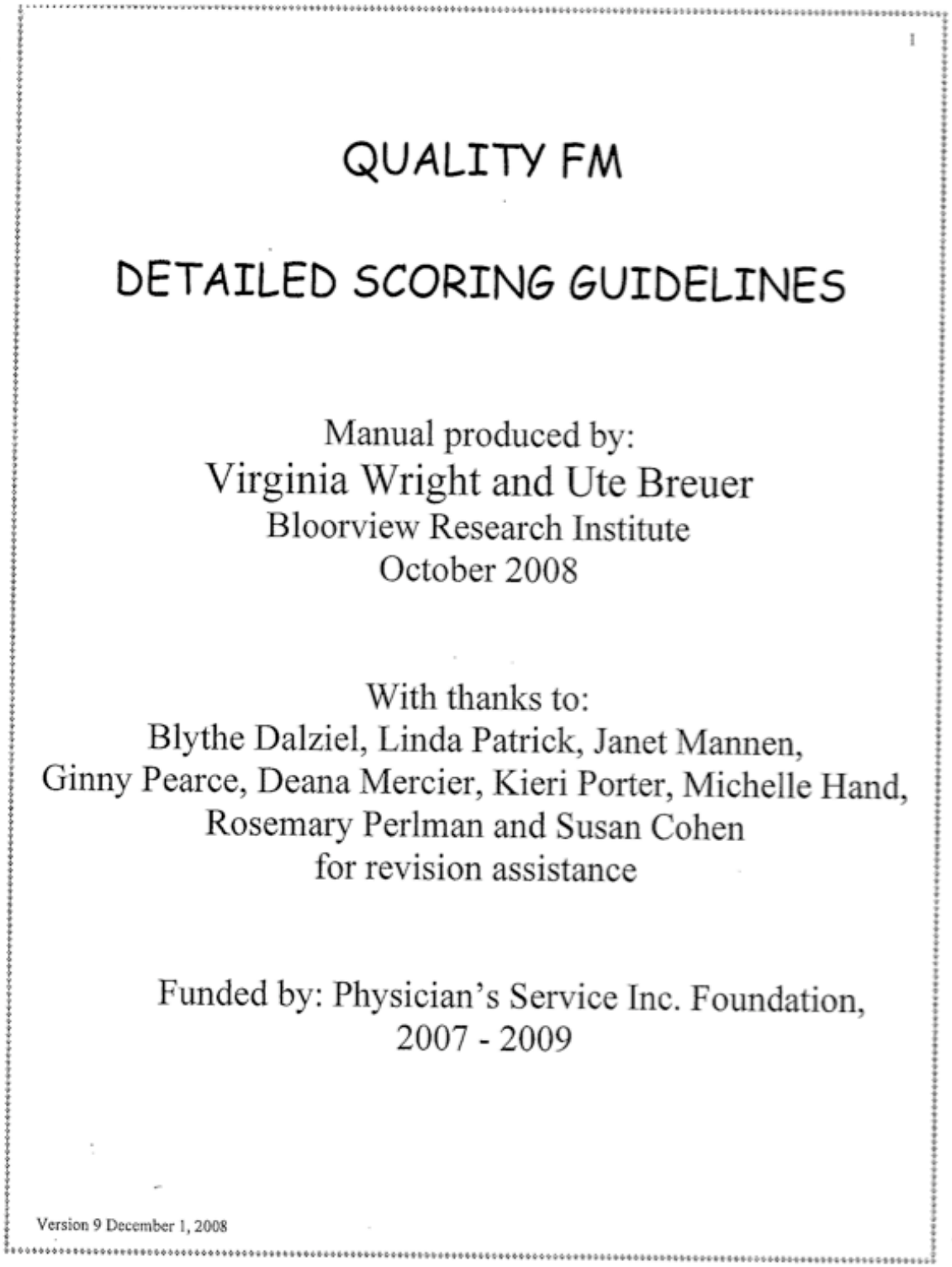
I @ 3

I @ 4

Appendix H: Quality FM

Bloorview
RESEARCH INSTITUTE

Quality FM used with permission from Bloorview Research Institute, Toronto, Canada



QUALITY FM

DETAILED SCORING GUIDELINES

Manual produced by:
Virginia Wright and Ute Breuer
Bloorview Research Institute
October 2008

With thanks to:
Blythe Dalziel, Linda Patrick, Janet Mannen,
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QUALITY FM SCORE FORM DETAILED GUIDELINES

GMFM

0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
NT = not tested

QUALITY FM – refer to code sheet for detailed guidelines for each attribute

0 = a lot of difficulty
1 = some difficulty
2 = a little difficulty
3 = no difficulty (i.e., looks fine!)

GMFM 52 **Pulls to standing at large bench**

_____

Coordination:

1st Trial	2nd Trial	3rd Trial

Transition between **main parts of task**:
1. pulling up from floor (likely through kneel or side-sit)
2. rising up into standing
3. achieving a balanced standing position facing bed

Dissociated Movement:

1st Trial	2nd Trial	3rd Trial

Think of dissociation between hips/legs while pulling up. and within legs when straightening into standing
Child can score a '0' or '1' on dissociation even if '2' or '3' on GMFM since it is possible to keep legs together and stiff for most or all of task (GMFCS III).
If has evidence of one component of dissociation in the task, e.g., takes a step(s) forward/sideways to achieve good position at bed after pulling up with legs together, can score as '1'

Weightshift:

1st Trial	2nd Trial	3rd Trial

Three part process:
1) weight shift forward to pull up
2) elongation of body upwards in rise to stand
3) shift/step to well-balanced standing position facing bed
If child does task using a sideways weight shift approach and ends oblique to bed, score as '1'. Should not be leaning on hands at finish position.
Children with good weight shift often choose to let go once in final stand position

Version 9 December 1, 2008

GMFM 53 **Maintains, arms free, 3 seconds**

_____ **Upper Body Alignment**:
Any malpositioning, even if due to tone, or habit or to maintain balance, needs to be rated as malalignment
Note: If shoulders and/or elbows are flexed > 40 degrees (either for stability or due to spasticity), score no more than '1'.

1st Trial	2nd Trial	3rd Trial

LE Alignment:
Any malpositioning, due to ROM, tone or to maintain balance, is rated as malalignment

1st Trial	2nd Trial	3rd Trial

Stability:
Should seem that the child can hold the position indefinitely. **If scores < '3' on GMFM trial, automatically score '0' for stability.**

1st Trial	2nd Trial	3rd Trial

GMFM 54 **Holding onto a large bench with one hand, lifts right foot 3 seconds**

_____ **LE Alignment:**
Focus on alignment of left hip, knee, ankle
Any malpositioning, due to ROM, tone or to maintain balance, needs to be rated as malalignment
Do not rate position of lifted R hip/knee here

1st Trial	2nd Trial	3rd Trial

Stability:
If unstable, will lean on support hand/forearm, may rotate and side flex through trunk.
If score is < '3' on GMFM trial, score '0' for stability i.e., does not hold for 3 sec or uses 2 hands on bed
If leans onto bed with one hand but holds very still, score as '2'
If leans onto bed with one hand and shifts a lot, score as '1'

1st Trial	2nd Trial	3rd Trial

Weightshift:
Two part process:
1) lateral weight shift over L leg
2) leveling of the pelvis.
Failure to weight shift in correct directions may result in not being able to hold R foot off ground without a lot of trunk compensation (low foot clearance) or extra hiking of lifted R leg, rotating trunk, leaning onto supporting hand/arm or use of non-support arm to pull weight over supporting leg
If no evidence of trying to level pelvis and reduce weight on the support hand, score no more than '1'.

1st Trial	2nd Trial	3rd Trial

Version 9 December 1, 2008

GMFM 55 **Holding on to a large bench with one hand, lifts left foot 3 seconds**

_____

LE Alignment:
Focus on alignment of R hip, knee, ankle
Any malpositioning, due to ROM, tone or to maintain balance, needs to be rated as malalignment
Do not rate position of lifted L hip/knee here or trunk position

1st Trial	2nd Trial	3rd Trial

Stability:
If unstable, will lean on support hand/forearm, may rotate and side flex through trunk.
If score is < '3' on GMFM trial, score '0' for stability
i.e., does not hold for 3 sec or uses 2 hands on bed
If leans onto bed with one hand but holds very still, score as '2'
If leaning onto bed with one hand and shifts a lot, score as '1'

1st Trial	2nd Trial	3rd Trial

Weightshift:
Two part process:
1) lateral weight shift over R leg
2) leveling of the pelvis.
Failure to weight shift in correct directions may result in not being able to hold L foot off ground without a lot of trunk compensation (low clearance) or extra hiking of lifted L leg, rotating trunk, leaning onto supporting hand/arm or use of non-support arm to pull weight over supporting leg
If no evidence of trying to level pelvis and reduce weight on the support hand, score no more than '1'.

1st Trial	2nd Trial	3rd Trial

GMFM 56 **Maintains stand, arms free, 20 seconds**

_____

Upper Body Alignment:
Focus on alignment at head, neck, trunk
Any malpositioning, even if due to tone, or habit or to maintain balance, needs to be rated as malalignment.
Note: If shoulders and/or elbows are flexed > 40 degrees (either for stability or due to spasticity), score no more than '1'.

1st Trial	2nd Trial	3rd Trial

LE Alignment:
Focus on alignment of hips, knees, and ankles
Any malpositioning, due to ROM, tone or to maintain balance, needs to be rated as malalignment

1st Trial	2nd Trial	3rd Trial

Stability:
If stable, arms will not be used to aid balance.
Should seem that the child can hold the position indefinitely. **If holds < 5 sec, score '0' for stability.**
Do not penalize for occasional voluntary movements of arm or head (e.g., fidgets that often occur in younger children). **If the child takes a step (for whatever reason), do not score stability higher than '2'.**

1st Trial	2nd Trial	3rd Trial

Version 9 December 1, 2008

GMFM 69 **Walks forward 10 steps**

_____

LE Alignment:
Focus on alignment in weightbearing leg:
hips, knees, ankle, pelvis at peak midstance.
Score alignment based on most involved leg.

1st Trial	2nd Trial	3rd Trial

Co-ordination:
Look carefully step rhythm, accurate foot placement.
arm swing and arm sequencing with legs, and overall
ease of movement. Is the gait pattern smooth?
Very slow gait needs to be marked down to a '1'
even if well-targeted, i.e., more than 2 seconds between steps.

1st Trial	2nd Trial	3rd Trial

Dissociated movement:
Should see heel-toe pattern with each step,
and flexion/extension action at hip and knee
through stance and swing phases (segmental mov't)
Watch for compensatory trunk/pelvic rotation.

1st Trial	2nd Trial	3rd Trial

Stability:
Line of progression gives cues about stability.
Should be a straight line of steps!
Are the arms used for balance for any or all of the task?
If needs to be supported at end of 10 steps, score '1'.
If does not complete 10 steps before assisted, score '0'
Side steps/protective steps may indicate an issue

1st Trial	2nd Trial	3rd Trial

Weightshift:
Two directions of movement: forward/backward
and lateral onto the weight bearing leg.
Watch for: backward lean, inappropriate
lateral weightshift such as Trendelenberg.
Uneven stance time may reflect issues with weightshift.
Subtle weight shift issues during gait may present as vaulting
in which vertical excursion in increased, or there may be
lack of heel-toe pattern (i.e., insufficient weight transfer forward through foot).

1st Trial	2nd Trial	3rd Trial

Version 9 December 1, 2008

GMFM 70 **Walks forward 10 steps, stops, turns 180°, returns**

_____ **LE Alignment:**
Focus on alignment in weightbearing leg: hips, knees, ankle, pelvis at peak midstance. Score alignment based on most involved leg. May show more alignment issues than in #69 since focusing on the turn component of the task

1st Trial	2nd Trial	3rd Trial

Co-ordination:
Look carefully step rhythm, accurate foot placement, arm swing and arm sequencing with legs
Handling of the turn is a critical feature – does the child do a controlled stop and then a small turn?
If the child does not stop, the turn must appear fluid and efficiently executed in order to consider a '3' for co-ordination.

1st Trial	2nd Trial	3rd Trial

Stability:
Consider equally for the straight forward walking aspect and during the turn. Is the line of progression straight? If the child needs to do a large turn or does multiple wide-based steps on the, turn this indicates stability issues. **If the child does not stop, do not score higher than '2'. Score '0' if does not complete the turn or if does the turn and loses balance before returning to starting place.** Side steps/protective steps indicate an issue. Are the arms used for balance for any or all of the task?

1st Trial	2nd Trial	3rd Trial

GMFM 71 **Walks backward 10 steps**

_____ **Co-ordination:**
Look carefully step rhythm and pattern, accuracy of foot placement, arm and leg sequencing. Check for smoothness and economy of movement. Child should be able to do while looking straight ahead, and not hesitate at all. **Score as '1' if speed is very slow, even if accurate.**

1st Trial	2nd Trial	3rd Trial

Dissociated movement:
Should see toe-heel pattern with each step, and flexion/extension action at hip and knee. Stiff gait, short steps, uneven step length reflect dissociation. issues

1st Trial	2nd Trial	3rd Trial

Stability:
Expect a slight reciprocal arm swing. Are the arms used for balance for any or all of the task?
Is there erratic use of arms?
Is the line of progression straight? Small steps may indicate balance issues. Side steps/protective steps may indicate an issue.

1st Trial	2nd Trial	3rd Trial

GMFM 81 **Jumps forward 12", both feet simultaneously**

_____

Co-ordination:
Watch sequencing between legs and upper body. Consider smoothness and timing. If used, arms should move in a controlled manner to assist the jump forward. Excessive preparation and arm use (too much effort) indicates co-ordination issue.
If does not clear finish line with the back of both heels, score no more than '2'.

1st Trial	2nd Trial	3rd Trial

Stability:
The key component of this is the ability to stabilize self in the landing position without excess use of arms. How much balance adjustment is required?
If the child put hands down to stop forward fall, score stability as '0'. If small step(s) taken to stick the landing, score no higher than '2'.

1st Trial	2nd Trial	3rd Trial

Weightshift:
Three-parts task:
1) Shift weight forward and up to make the jump (may bend knees and use arms to get forward momentum). (more capable jumpers will do a two-footed jump with arm and knee use)
2) Land with flexed knees to absorb jump
3) Shift weight back and upwards to hold secure upright landing with suitable weight distribution
Need to see a soft flexible landing to score '3' (knee/ankle stiffness will prevent this).
If does not touch or cross finish line with both heels, score no more than '1'

1st Trial	2nd Trial	3rd Trial

GMFM 82 **Hops on right foot 10 times within a 24" circle**

_____

Co-ordination:
Is the hopping rhythm regular and smooth? Consider whether child hops evenly in same spot or hops erratically even with cues to hop in one place. Does child start and stop hopping with control? Excessive effort indicates co-ordination issue Are associated reactions evident in the arms?

1st Trial	2nd Trial	3rd Trial

Stability:
Does child look secure in their dynamic balance? Are the start and finish positions stable? Are the arms used for adjusting balance, and if so, how much and how often? Traveling in the circle indicates a stability issue.
Score as '0' if hops no more than 5 times
Score as '1' if only hops 6 to 9 times.

1st Trial	2nd Trial	3rd Trial

Weightshift:
Does child transfer weight effectively through supporting hip, knee and ankle when hopping, i.e., is there a good shock absorbing bounce or is the hopping stiff? Higher hops indicate better weight transfer. Turning may indicate weight shift issues.

1st Trial	2nd Trial	3rd Trial

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Appendix I: Associations for GMFM and QFM Variability Scores with GMFM Interval Change Scores for Each Child

Child 1: Spearman Rank Correlation Coefficients for GMFM and QFM Variability Scores with GMFM Interval Change Scores

	GMFM Interval Change Scores (n=9)
GMFM Variability (n=9)	-0.22 (p=0.57)
QFM Weight Shift Variability (n=8)	-0.37 (p=0.37)
QFM Coordination Variability (n=8)	-0.30 (p=0.47)
QFM Stability Variability (n=8)	0.22 (p=0.61)
QFM Dissociation Variability (n=8)	0.27 (p=0.52)

Child 2: Spearman Rank Correlation Coefficients for GMFM and QFM Variability Scores with GMFM Interval Change Scores

	GMFM Interval Change Scores (n=9)
GMFM Variability (n=9)	-0.17 (p=0.67)
QFM Weight Shift Variability (n=9)	-0.28 (p=0.47)
QFM Coordination Variability (n=9)	-0.61 (p=0.08)*
QFM Stability Variability (n=9)	0.02 (p=1.0)
QFM Dissociation Variability (n=9)	-0.60 (p=0.09)*

*** Correlation is significant at the 0.10 level**

Child 3: Spearman Rank Correlation Coefficients for GMFM and QFM Variability Scores with GMFM Interval Change Scores

	GMFM Interval Change Scores (n=9)
GMFM Variability (n=9)	-0.84* (p=0.01)
QFM Weight Shift Variability (n=9)	-0.35 (p=0.35)
QFM Coordination Variability (n=9)	-0.46 (p=0.22)
QFM Stability Variability (n=9)	-0.20 (p=0.61)
QFM Dissociation Variability (n=9)	0.09 (p=0.81)

*** Correlation is significant at the 0.01 level**

Child 4: Spearman Rank Correlation Coefficients for GMFM and QFM Variability Scores with GMFM Interval Change Scores

	GMFM Interval Change Scores (n=9)
GMFM Variability (n=9)	-0.42 (p=0.26)
QFM Weight Shift Variability (n=9)	0.15 (p=0.70)
QFM Coordination Variability (n=9)	0.52 (p=0.16)
QFM Stability Variability (n=9)	-0.47 (p=0.21)
QFM Dissociation Variability (n=9)	0.24 (p=0.54)

Child 5: Spearman Rank Correlation Coefficients for GMFM and QFM Variability Scores with GMFM Interval Change Scores

	GMFM Interval Change Scores (n=9)
GMFM Variability (n=9)	0.51 (p=0.16)
QFM Weight Shift Variability (n=9)	-0.47 (p=0.20)
QFM Coordination Variability (n=9)	-0.03 (p=0.91)
QFM Stability Variability (n=9)	0.07 (p=0.86)
QFM Dissociation Variability (n=9)	0.40 (p=0.28)