The feasibility and trend of functional changes by using home-based exercise program delivered through telehealth platform for adolescents with spastic cerebral palsy: The impact of tele-coaching

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The feasibility and trend of functional changes by using home-based exercise program delivered through telehealth platform for adolescents with spastic cerebral palsy: The impact of tele-coaching

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Abstract

The most common type of cerebral palsy (CP) is spastic CP, representing around 82% of all CP types. Individuals with spastic CP usually receive intensive physical therapy during childhood years to improve gross motor function. They, however, often encounter complications during adolescence, including a decline in gross motor function, physical inactivity, impaired balance and walking, and poor quality of life. In recent years, telehealth systems in home exercise program have been widely used in patients with various neurological diseases. However, past studies showed mixed results about the effectiveness of telehealth home exercise program (HEP) for adolescents with CP, where most past studies lacked the individualization in training modules to target the individual patient's specific goals.

Furthermore, past studies utilized asynchronous telehealth technologies (videos, photos) with very limited interaction between therapist and participants. An individualized HEP along with the use of real-time tele-coaching (i.e., synchronous telehealth) may result in better outcomes of the HEP than traditional HEP. The tele-coaching can provide the continued monitoring and instant feedback on the exercise performance. Benefits of tele-coaching have been established in HEP for adolescents and adults with various disabilities, including improved adherence to HEP and better functional performance. Past studies have not examined the impact of tele-coaching in HEP among individuals with CP. Thus, this dissertation project evaluated the feasibility and trend of functional outcomes after a telehealth HEP, with or without online tele-coaching, for adolescents with spastic CP.

In chapter one, we described the definition, classification, primary and secondary complications of the condition of CP, focusing on the decline in motor function and physical activity. We further summarized health-related issues in individuals with CP during adolescence age. We then introduced the current evidence on the adherence of adolescents to

therapeutic interventions and the barriers that impact adherence and compliance. We reviewed home exercise programs (HEP) for adolescents with CP in general, and specifically the HEP that utilized telerehabilitation technologies. Finally, we explained the significance of this dissertation project and listed specific aims and hypotheses. This study is a pilot randomized controlled trial and participants were randomized into either tele-coaching experimental group or without tele-coaching control group. The specific aims of the study are listed in the following.

Aim 1: To examine the feasibility of an 8-week telehealth HEP for adolescents with spastic CP, with or without tele-coaching.

Aim 2: To evaluate the trend of change after the 8-week telehealth HEP to achieve individualized goals by adolescents with spastic CP, with or without tele-coaching.

Aim 3: To evaluate the trend of change after 8-week telehealth HEP in physical activity level, physical activity enjoyment, and quality of life in adolescents with spastic CP, with or without tele-coaching.

Exploratory aim: To explore the effectiveness of the prescribed telehealth HEP in adolescents with spastic cerebral, with or without tele-coaching, in the improvement of the performance of the prescribed exercise.

In chapter two, we reported results of our pilot randomized clinical trial on the feasibility including adherence rate of an 8-week HEP using telerehabilitation technology to deliver an individualized HEP with or without tele-coaching in adolescents with Spastic CP. In this pilot trial, twenty participants with Gross Motor Function Classification System (GMFCS) I-III spastic CP were recruited and randomly allocated to an experimental group or a control group. The experimental group received 8 weeks of individualized HEP with

30-60 minutes per exercise session, three sessions each week. The last exercise session within each week was a tele-coaching exercise session directed by a physical therapist. The control group received the same 8 weeks of individualized HEP without tele-coaching. The experimental group showed significantly higher adherence rates of completed sessions, completed exercises, and completed repetitions compared to the control group. The experimental group also showed a significantly higher acceptance rate for the exercise program and use of Physitrack compared to the control group. Our results suggest the use of telerehabilitation to prescribe HEP with an addition of tele-coaching for adolescents with spastic CP could further improve adherence rates.

In chapter 3, we reported the results of our pilot trial about occupational performance and satisfaction measured by Canadian Occupational Performance Measure (COPM) and quality of exercise performance measured by Correctness of Exercise Performance (COEP). The experimental group showed significantly higher mean-differences in Performance score and Satisfaction score compared to the control group. Furthermore, the experimental group showed a significantly higher percentage of exercise completed correctly measured by COEP at the 4^{th} week and at the end of 8-week compared to the control group. Our findings suggest that the individualized home exercise program with tele-coaching could result in further improvement in reaching the individualized goals and in the quality of exercise performance in adolescents with spastic CP.

In chapter 4, we reported the results of our pilot trial in physical activity level, physical activity enjoyment, and quality of life. The experimental group showed significantly higher mean-differences in physical activity level measured by Physical Activity Questionnaire (PAQ-A), and in quality of life measured by CP-Quality of life

Questionnaire (CP-QOL) compared to the control group. Our findings suggest that an individualized goal-directed home exercise program with tele-coaching could result in better improvement in physical activity level and quality of life in adolescents with spastic CP.

In Chapter 5, we summarized our findings and provided our suggestions for future directions of research in the same area.

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Chapter 1: Introduction

1.1. An overview of Cerebral Palsy (CP)

Cerebral palsy (CP) is "a group of permanent disorders of the development of movement and posture, which are attributed to a nonprogressive lesion in the immature fetal or infant brain. The motor impairments of cerebral palsy are often accompanied by dysfunction of sensation, cognition, communication, and behavior." [1-3] The prevalence of CP is 2 to 4 per1000 live births/year. More than 1,000,000 children and adults in the US have been diagnosed with CP.[2] The national cost for rehabilitation and treatment of CP is about $1.175 billion in the United States. Each family with a CP survivor is expected to spend $94,000 per person for the cost of rehabilitation, medications, and equipment.[4]

There are various features of CP, depending on the part and size of the brain lesion that can determine the classification and level of disability. The severity of disability ranges from mild unilateral body involvement with minimal functional impairment to total body involvement and maximal functional impairment.[3] CP has different classifications based on the pathogenesis process (spastic, dyskinetic, ataxic) or based on topographic or anatomical representation (unilateral or bilateral). The spastic type of CP is the most common and represents around 82% of all CP types and can be either unilateral (33%) or bilateral (49%).[1,3] An understanding of classification is necessary to select participants and interpret the results of studies targeting the CP population.

Impairment in the CP population can be measured using tools to categorize gross motor impairment for children with CP. The Gross Motor Function Classification System (GMFCS) is a five-level classification system for determining the level of current abilities and limitations in a person's gross motor function with CP. The classification system has been expanded to children and adolescents aged 12-18 years and revised according to activities that the children and adolescents usually perform in the familiar environments of home, school, and community (GMFCS- E&R). Adolescents classified within Level I move freely in almost all situations. Those classified in Level II can walk, run, and climb in most settings but may need held mobility equipment for safety and wheeled mobility for traveling long distances. Adolescents classified in Level III can walk using assistance and can self-propel manual or powered wheelchairs. Adolescents within Level IV can walk short distances with assistance but use wheeled mobility in most settings and need physical assistance for transfers. Adolescents classified in Level V require extensive support in all situations.[5,6]

1.1.1. Impacts of cerebral palsy on body function and structure

Although the primary deficit in CP is due to an injury to the brain, the limitations in movement imposed by the brain lesion can have a marked secondary effect on musculoskeletal and other systems.[7,8] Around 25–80% of Individuals with CP, depending on the type, will have secondary impairments, while patients with quadriplegic spastic CP having the highest chance of co-morbidities and secondary impairments.[9,10] Studies showed that 69 % of CP children at GMFCS levels I-III have gross motor function impairment, while 31% of gross motor impairments appear in CP children at GMFCS levels IV-V. [10,11]

1.1.2. Secondary complications at adolescence with CP

In the last few decades, CP has been predominantly a pediatric disorder. Recently, investigators have considered CP as a life-long disorder.[12,13] Many physiological and psycho-social changes occur during adolescence either due to the growth process or as a result of CP, which may impact adolescents' ability to participate in everyday social life.[14]

Secondary complications of CP that appear in adolescence are related to musculoskeletal deficits, including pain and fatigue.[15,16] Many adolescents experience a decline in gross motor function, as measured by gross motor function measure (GMFM-66 or 88) starting at age 10-11 years old, as a result of pain and fatigue and also due to problems with balance and muscle weakness.[15-17] The persistence of secondary impairments into adulthood could lead to the loss of walking ability before the age of 35 despite acquired ambulation during adolescence (GMFCS I-III).[15,16,18] Furthermore, a large number of adolescents with CP, regardless of the GMFCS level, who enter into their early adulthood, will experience a loss of independence much sooner than their age-matched peers. Furthermore, deterioration in GMFCS levels is most obvious in the late 20s and early 30s, and not enough rehabilitation and poor physical activity influence adults with CP.[19] It has been reported that gross function deteriorates more in adulthood for those adolescents who are not physically active or who not receiving enough rehabilitation. Furthermore, adolescents who are at GMFCS I-III may decline to IV-V with age, which adds more burden for their family members and caregivers and increases their need for assistive device use.[20,21]

1.2. Impact of CP on exercise performance in adolescents

The combination of primary and secondary impairments of CP limits adolescents' ability to participate in physical activity (PA) and regular exercise and increases the chance of a sedentary lifestyle, consequently increased the risk of developing other secondary health conditions in adulthood.[22,23] Many studies have shown that children with CP will have further complications as they transition into adolescence and adulthood, including a decline in gross motor function, walking deterioration, increased fatigue and pain, decreased motivation and participation in activities, and reduced adherence to rehabilitation programs.[24,25] Other expected secondary health conditions include increased spasticity, reduced muscular strength and endurance, reduced aerobic fitness, and depression.[22]

The secondary complications experienced by individuals with CP throughout life are furtherly complicated by the aging process as they grow up. The decline in walking ability and mobility limitations in adolescence can result in fewer chances to participate in the exercise, and consequently, an increased risk of developing lifestyle-related diseases in adulthood such as diabetes mellitus, cardiovascular disease, obesity, and chronic pain.[22,26] Furthermore, secondary complications of CP are highly related to the presence of risky behaviors that can persist in adulthood, such as a sedentary lifestyle, leading to further compromised health and quality of life of individuals with CP.[22,27,28]

Many secondary complications of CP are reversible. The management of motor impairments in CP should focus not only on the treatment of symptoms but also on proactive approaches of promoting physical activity and an active lifestyle, which may minimize the impact of complications as CP individuals aging.[28] Physical activity and exercise are quickly becoming recognized interventions for children with CP to improve muscle strength, aerobic capacity, and muscle function.[12,13] Due to the existing impairments that many adolescent teens living with CP have, activities such as walking independently, negotiating stairs, running, and even navigating uneven terrain prove to be difficult.[13] Thus, the primary therapeutic goal for care for children with CP is to improve their ability to perform meaningful, functional tasks in everyday life (i.e. walking, stair climbing, etc.) and thereby changing the level of the disability.

1.2.1. Importance of exercise in adolescents with CP

Adolescents with CP are usually 4.5-times more physically inactive compared to normal peers.[29,30] Furthermore, adolescents with physical disabilities generally show more sedentary behaviors overall per school day than those without disabilities.[31-33] Moreover, adolescents with CP participate in 13% to 53% less exercise than normally developed peers.[30]

It is imperative to promote and facilitate exercising during adolescence, which may help establish long-term motor function maintenance into adulthood and reduce the risk of secondary health complications and increase life expectancy with high quality of life.[34-36] The adolescence stage is a critical time in personality development, such as developing self-perception, attitudes, and behaviors that carry forward into adulthood.[37,38] Patterns of healthy behaviors during adolescence, such as physical activity, usually persist into adulthood.[23,39]

1.2.2. Benefits of exercises for adolescents with CP

Adolescents with CP can experience many physiological benefits from exercises, including increase in bone density, lean muscle tissue, muscular strength, endurance, aerobic capacity, and a lowered risk of high blood pressure and obesity.[40-42] Literature shows that exercise substantially increases adolescents' life expectancy with disabilities and reduces the severity of secondary health conditions.[14,43] Exercise programs are safe and an effective way to improve muscular strength, walking ability, cardiopulmonary endurance in individuals with physical disabilities such as CP.[41,44]

The psychological and social benefits of exercises have been studied extensively. Studies showed that exercises protect against depression and reduce anxiety in adolescents and also promote positive effects on self-perceptions such as self-concept.[45-47] Providing adolescents, particularly those with CP, with opportunities to enhance their self-perception through exercise could create a life-long effect that can be maintained into adulthood.[48-50] Furthermore, exercises allow adolescents with CP to develop a strong physical identity, which has been associated with a better quality of life among adolescents with CP and has a positive influence on life satisfaction.[51-53] Among adolescents with disabilities, exercises are associated with improved self-esteem and social competence.[26,51,54,55]

Despite the benefits of exercise, adolescents with CP are less physically active than their typically developing peers.[53] A systematic review by Shields et al. (2012) highlighted the personal, social, and environmental barriers that influence the regular physical activity and integration of exercise programs among adolescents with CP.[23,56] Personal factors include the individuals' characteristics and can include psychological factors, and body functions and structures. The most prominent personal factors that often act as barriers to exercise include a lack of physical and social skills, preference for a sedentary lifestyle, fear, and a lack of knowledge about exercise's benefits, equipment, duration, frequency, and repetitions.[26,41] Regarding social barriers to exercise participation, caregivers usually have concerns about safety during exercise, and experience a perceived lack of support and feedback about exercise performance.[23,55,56]

Inadequate and inaccessible facilities and a lack of available transportation have been identified as the two major environmental barriers adolescents with CP face. Other barriers include limited financial resources and limited insurance coverage for exercise programs.[55,56]

1.3. Home-based exercises program (HEP) for adolescents with CP

Home-based exercise programs have emerged as alternatives that have been found encouraging and feasible for patients with neurological disorders.[57-60] Given the barriers to participating in exercise programs in a clinical or sport setting, home-based programs with self-supervision can be considered suitable for the lifelong commitment required for maintaining exercise benefits among adolescents with CP.[42,61,62] HEP can complement supervised direct intervention and help adolescents to achieve the necessary intensity of exercise, especially those who do not receive enough rehabilitation at school, or do not participate in physical activities at school or community.[59,62] HEP accounts for 50%–80% of the total therapy received, while supervised, direct intervention accounts for the remainder, 20%-50%.[59,63]

The effective use of HEP among adolescents with CP faces several challenges identified in the literature. The most recognized challenge was poor adherence to HEP. The factors that could cause low adherence include fear of harmful effects, difficulties incorporating the exercises into daily routines, boredom, and lack of motivation.[62,64-66] A study of 50 adolescents with CP receiving HEP showed that exercise logbooks were only completed on 68% of total prescribed exercise days. The full program completion was seen on only 58% of recorded exercise days. This study showed that adherence and its accurate measurement and reporting are significant challenges of HEP for both therapists and families of adolescents with CP with CP.[67]

Few studies investigated the measurement of adherence in adolescents with CP to HEP. The studies had small numbers of participants or were insufficiently detailed in the reporting of adherence measures.[68,69] Furthermore, these studies did not compare the effect of different exercise delivery strategies on adherence.[69] Past studies have recommended some strategies to improve adherence to HEP among CP adolescents, such as developing individualized HEP, engaging adolescents and caregivers in goals setting, respecting family preferences and needs, providing feedback to the patient, using a collaborative decision-making process, prescribing a small number of exercises in each session, and educating caregivers in providing emotional and physical support.[59,61,69,70]

Another common challenge identified in HEP for adolescents with CP is the lack of or limited control over the exercise performance in HEP due to the cessation of face-to-face supervision and corrective feedback.[71] Adolescents may attempt the instructed exercises, but there are concerns about whether they perform the exercises correctly. Previous studies investigated the Correctness of Exercise Performance (COEP) in adults, concluded that following face-to-face exercise instructions together with brochures were enough to achieve the desired performance. At the same time, the addition of audiotapes or videotapes did not provide further benefit in terms of COEP scores.[72,73] However, COEP has not been investigated in children or adolescents with CP when carrying out an exercise program at home.

A potential gap has been noticed among studies utilizing exercise programs for adolescents with CP, that most studies focused more on clinical outcomes related to body structures and functions, with less attention paid toward activity level and participation.[74]

A systematic review by Adair et al. (2015) showed only 3 out of 7 studies utilized participation outcomes as primary outcomes among adolescents with disabilities. Furthermore, the systematic review concluded that traditional HEP had minimal impact on participation outcomes, while individualized programs incorporating coaching, mentoring, and education achieved favorable results in improvement of activity and participation.[74]

1.4. Telehealth in rehabilitation

1.4.1. Telehealth definitions, terms, and types

Based on the definition provided by American Telehealth Association (ATA), "Telehealth uses electronic communications to provide information and health care services to patients and clients. These services are delivered in real-time by using audio and video or are distributed with store-and-forward technology.”

Telehealth can be used to overcome barriers of access to services caused by distance, unavailability of specialists and/or subspecialists, and impaired mobility. Telehealth offers the potential to extend physical therapy services to remote, rural, underserved, and culturally and linguistically diverse populations.[75] Telehealth has many synonyms include the terms "telemedicine," "virtual care," "eCare," "mHealth," "remote care," and "telepractice".

The following 3 distinct technologies fall under the umbrella of telehealth:

- Real-time (synchronous or instantaneous). These may include videoconferencing and the use of peripheral devices to enable live communication.
- Store-and-forward. Data are captured locally, then stored or cached for forwarding and later use. Requires use of a secure Web server, encrypted e-mail, appropriate store-and-forward software, or an electronic health record (EHR) system.
- Remote patient monitoring. Devices remotely collect, store, and communicate patient or client biometric health information to be given to practitioners.[75]

1.4.2. Benefits of telehealth in rehabilitation exercise programs

Using telehealth technology to deliver rehabilitation services has many benefits for the patients and clinicians. Telehealth services include therapeutic interventions, remote monitoring of progress, education, consultation, training, and a means of networking for people with disabilities.[76]. Telehealth enables the patients/guardians to be active partners rather than passive participants in rehabilitation care. It enables patients/clients 'reach' by overcoming the common barriers to face-to-face intervention or unsupervised home programs, especially those in remote areas or who have mobility issues associated with physical impairment. Simultaneously, telehealth could decrease the clinic's delivery costs or home visits related to travel expenses and time spent traveling for both the healthcare provider and the patient.[76,77]

Telehealth enables clinicians to remotely deliver patient care services and engage them away from the clinic, thus canceling distance and transportation barriers.[78]

Using telehealth in exercise programs improves self-efficacy, confidence, and adherence to interventions.[79] Current evidence confirms that including self-efficacy beliefs in the design of exercise programs for children or adults helps guide the participant towards adopting new behaviors, especially those complying with telehealth or mobile apps to practice exercise programs.[80] Potentially, the progress and feedback for rehabilitation can be tracked, monitored, and discussed with patients via telehealth apps.[81] This will ensure that patients see their progress and ultimately improve their self-efficacy beliefs by completing tasks. Furthermore, Telehealth apps can increase intrinsic and extrinsic motivation toward adherence and compliance to HEP. Encouragement can come from the physiotherapist to patients by text messages between the application or through e-mail. Reminders from the application may also prove helpful.[82]

Telehealth applications that allow constant communication and interaction between the therapist and patient can confirm that the task or exercise is attainable but not too simplistic for the patient to perform.[83] Telehealth apps allow therapists to monitor patients' progress and to analyze and understand the patient's growth over time.[82] Previous studies showed that adding real-time coaching or training could lead to better results than using online resources only.

Furthermore, studies indicated the importance of using multimodal telerehabilitation technologies (e.g., videoconferencing and email or text), which might accommodate the variant caregivers' goals and preferences.[84]

The exercise intensity and duration in telerehabilitation may consider a balance between the structured program and its flexibility to accommodate the needs of patients and families. Previous studies showed that the duration and frequency of telerehabilitation programs are variable according to participants' needs and impairments.[85] Studies suggested that the intervention's intensity should be sufficient to achieve improvement in engagement, satisfaction, and outcomes using telerehabilitation, such as 1-3 times per week for nine weeks recommended by some investigators.[85] Past studies also indicated that it is important to have pre-scheduled sessions that help families to determine their goals and abilities to participate in an exercise program; the telerehabilitation provider should be flexible to adjust intervention schedule according to family's/participant's needs.[85-87]

It is important to highlight that exercise non-compliance is highly attributed to higher treatment costs in the clinic or high home visit costs.[88] Telehealth applications can be cost-effective for the clinician and patients to increase motivation, reduce cancellations, and improve intervention compliance.[89]

1.4.3. Telehealth in HEP for CP

The efficacy of using telehealth to improve HEP adherence and performance has been established in adults with neurological disorders, showing its benefits to motivate adults to participate in the exercise. However, it has not been well documented in adolescents with neurological disorders such as CP. Furthermore, the factors influencing the adherence to telehealth HEP in adults may not be directly generalized to adolescents.[90] Cramer et al. (2019) reported that activity-based training produced substantial gains in arm motor function regardless of whether it was provided via home-based telerehabilitation or traditional in-clinic rehabilitation in individuals with stroke. This study's findings suggest that telerehabilitation can substantially increase access to rehabilitation therapy on a large scale.[91] Brown et al. 2010 reported that the internet-based Upper Limb Training and Assessment (ULTrA) home program benefited hand function among adults with CP and is safe and convenient to use.[92]

Only a few studies have investigated telehealth interventions among adolescents with CP, and they have their own limitations.[93-96] Most of those studies did not focus on adherence to exercise prescription and reporting. Furthermore, most of those studies did not compare the effect of different exercise delivery methods on adherence and performance. Blide et al. (2011) showed that it is feasible to deliver exercise training to children with CP at home through the internet and thereby ensured more intensive and longer-lasting training than what is usually offered to this group.[97] The training dosage was adjusted during the intervention to meet participants' progression. The study also showed that interaction with adolescents by skype or email helped to increase their exercise adherence. However, this study involved only nine young kids with CP (9-13 years old).

Some past studies reported the limitations of current telerehabilitation delivered HEP and suggested the need of tele-coaching to further improve the outcomes. In a study that examined the efficacy of individualized HEP delivered through the internet to 43 children with CP (aged 9–16; mean age 10.9 ± 2.4 years), the interactive home training enabled some functional motor improvements and increased activity perform daily activities.[97] However, this study reported that the adherence to the training program was lower than expected. Baque et al. (2017) showed that internet-based individualized training improved functional strength in adolescents with brain injury but no improvement in other motor outcomes.[86] It was suggested that the low adherence to exercise program might impact the outcomes and more supervision and feedback might help their participant for better engagement and performance. Similar findings have been reported by other researchers.[93,98] A recent study by Johnson et al. (2020) showed that using telehealth applications to deliver videos of exercises did not significantly improve adherence or performance outcomes in adolescents with CP.[95] Authors recommended the add-on of supervision, feedback, and interaction between therapist and participants.

So far, internet-based HEPs for patients with CP have utilized mostly text, graphics, or video-mediated with less interaction, largely ignoring remote supervision, instant feedback, correction of performance, and coaching. The addition of instant feedback and real-time coaching could be more viable by using synchronous telehealth systems. No past studies have compared the difference between different modes of exercise delivery. Furthermore, most of these studies did not report the adherence and adolescents' perception toward exercises using telehealth systems. The exercise modules were not individualized based on adolescents'/caregivers' goals and progression of improvement. Thus, there is a need to investigate the different telehealth HEP delivery modes in enhancing adherence and performance among adolescents with CP. In the proposed study, we utilized the telehealth system/app (Physitrack), which offers all features above-mentioned.

1.5. Rationale and Significance

Promoting exercise adherence and performance among adolescents with spastic CP is very important for reducing short and long-term complications of CP. For a long time, CP has been considered a pediatric condition while much less attention has been paid to adolescents with the condition [46,99] The shortage of rehabilitation and physical exercise and the dominance of sedentary behaviors are commonly presented in the adolescence stage of CP. However, the current research in rehabilitation for CP has rarely focused on adolescents.[46,100] Poor health and well-being and decreased functional performance are associated with a low level of physical activity in adolescents with CP.[25,100] Furthermore; it has been found in this population that the adherence and compliance to HEP are poor due to many barriers.[62,101] Telehealth service delivery is an emerging technology and holds promise as an accessible and cost-effective means of delivering exercise intervention to CP.[75-77,91,102] However, further research is needed to address several important issues related to telehealth delivery, including individualization of training modules, assigning the most effective intensity and duration, comparing modes of delivery, and additional components to the intervention such as including caregivers in the design of the intervention.

The patient-therapist interaction is a strong predictor of patient compliance throughout exercise intervention.[103] Physiotherapy exercises prescribed through telehealth systems can facilitate this interaction by engaging patients with individualized programs.[77,102] Furthermore, instant feedback and correction of performance can promote compliance to HEP and improve exercise performance. Therefore, we anticipate that this study will clarify the difference between asynchronous and synchronous roles in performance and adherence to HEP and the additional benefits of instant coaching. A significant limitation of many past studies is the lack of individualization of HEP based on adolescents' & caregivers' goals, their perception of physical activity and exercise at home, and their progression in the improvement of exercise performance.

Our study will work with adolescents with CP and their caregivers to identify the goals, benefits, attitudes, and perceived barriers of physical activity participation in telehealth HEP. Moreover, we will use a valid outcome measure, the Canadian Occupational Performance Measure (COPM), to set up intervention goals. Our study will use the “Physitrack” website & app to provide exercise programs, coaching sessions, and supplementary materials. Physitrack can offer a low-cost, sustainable, and more convenient resource for training adolescents with CP. Additionally, the results of this study may ultimately contribute to optimally integrated physiotherapy services for the target population to facilitate individualized management of this disabling condition.

The dissertation work is highly significant for many reasons. Firstly, this work involved both Adolescents/guardians in the goals settings of the home exercise programs. In HEP, the therapist, the patient, and the caregivers must collaborate in setting and achieving goals of exercise programs, the goals that are specific, measurable, achievable, realistic, and have a time-frame (S.M.A.R.T).[83] To ensure practical goal setting, the telehealth app we used allowed us and the patient/guardian to receive and send feedback to each other. This guaranteed that both sides could understand the progress of the exercise program.

We used sensitive and valid outcome measures to examine goal achievement and the HEP program's efficacy.[104] Previous studies have also reported the relationship between goal-related outcome measures (COPM) and standardized gross motor function measures.[105,106] Therefore, therapy focusing on family-selected goals integrated into a home exercise program can improve the performance of everyday activities and gross motor capacity, such as walking and balance.[106] The COPM is widely adopted in the literature for assessing goal achievement. It works well within the family-centered exercise programs because it encourages the family to lead the goal setting and facilitate individualization, which is important for a heterogeneous condition such as CP.[64,104,107]

Video conferencing allow researchers to supervise the exercise's performance, provide instant feedback, and provide verbal and visual instructions.[108] Furthermore, videoconferencing will enable therapists to train caregivers to deliver specific exercises or utilize outcome measures that need a hands-on assessment. Also, video conferencing can facilitate compliance by improving HEP engagement when they feel that they receive therapists' support.[109] Tele-coaching is widely used in delivering mental, speech, and behavioral intervention for adolescents/caregivers with disabilities, but our study is the first to utilize videoconferencing for tele-coaching in-home exercise in adolescents with CP.[110] To broaden telehealth use in HEP, therapists need to be trained to deliver video conferencing coaching via telehealth to teach adolescents and involve caregivers in HEP.

We used an interactive telehealth app, Physitrack, to ensure an accurate exercise prescription. Physitrack offers options to count/report sets, repetitions, and duration and the feature of pop-motivational notifications.[111] Physitrack also offers the features to collect pain and difficulty feedback from patients to help modify exercise prescriptions and provide statistical analysis about adherence, satisfaction, and progress. All these features may increase subjects' motivation and compliance to HEP.[82] Moreover, Physitrack offers the option to provide adolescents/caregivers with additional resources relevant to adolescents' condition, further engaging the adolescents/caregivers to HEP and building a greater understanding and partnership with the therapist.

1.6. Specific Aims and Statement of Hypotheses

Adolescents with spastic CP often encounter complications, including a decline in gross motor function, physical inactivity, impaired balance and walking, and poor life quality. Previous studies have shown that HEP is a feasible alternative to supervised exercise programs for children with CP, but there is only a limited number of published studies on HEP for adolescents with CP. Furthermore, previous studies reported that motivation and adherence to home exercise decreased after cessation of professional supervision in CP patients due to the lack of support or feedback. Recently, telehealth systems in healthcare delivery have been successfully used in patients with various neurological diseases. Telehealth allows the healthcare team to interact with patients and their families in a home environment. Previous studies showed that using telehealth systems is feasible in delivering HEP for children with a physical disability. However, most previous studies lacked the individualization in training modules to target the individual patient's specific goals and his or her caregivers. An individualized HEP targeting limited activities or tasks may result in better outcomes than a general exercise program. Furthermore, previous studies have not examined the importance of feedback for HEP in CP patients. Benefits of continued monitoring and instant feedback that has been established in HEP for adolescents and adults with other disabilities and have shown improved adherence to HEP and better performance of prescribed exercises.

Therefore, the proposed study evaluated the feasibility and trend of functional outcomes after a telehealth HEP, with or without tele-coaching, for adolescents with spastic CP. The participants will be randomized into either tele-coaching group or without tele-coaching group.

Aim 1: To examine the feasibility of an 8-week telehealth HEP for adolescents with

spastic CP, with or without tele-coaching. Feasibility of protocol will be assessed by Recruitment rate (percentage of recruited participants from the individuals who were contacted and assessed for eligibility), Adherence rate (# of completed exercises, sessions, and reps), completion rate (# participants who completed the exercise program), and acceptance of using telehealth (Telehealth Usability Questionnaire will be used) will be examined in the proposed project.

Aim 2: To evaluate the trend of change after the 8-week telehealth HEP to achieve individualized goals by adolescents with spastic CP, with or without tele-coaching. We hypothesize that the tele-coaching group will show greater achievement of individualized goals (by Canadian Occupational Performance Measure (COPM)) (H2.1) compared to the without coaching group.

Aim 3: To evaluate the trend of change after 8-week telehealth HEP in of physical activity level, physical activity enjoyment, and quality of life. in adolescents with spastic CP, with or without tele-coaching. We hypothesize that the tele-coaching group will show more significant improvement in physical activity level (by The Physical Activity Questionnaire for Adolescents (PAQ-A-A)) (H3.1), physical activity enjoyment (by Physical Activity Enjoyment Scale (PACE)) (H3.2), quality of life (by CP- Quality of Life Questionnaire (CP-QOL (H3.3), compared to self-monitored (without coaching) group.

Aim 4: Exploratory aim: To explore the effectiveness of the prescribed telehealth HEP in adolescents with spastic cerebral, with or without tele-coaching, in the improvement of the performance of the prescribed exercise. Performance of prescribed exercise will be measured (by Correctness of Exercise Performance (COEP).

In summary, the presented work in this dissertation has or will lead to the submission of 3 unique manuscripts: 1) Telerehabilitation with coaching may improve adherence to home exercise in adolescents with spastic cerebral palsy: a pilot feasibility study (to be submitted to the Telemedicine Journal and E-health), 2) Tele-coaching may improve performance and satisfaction after 8-week home-exercise delivered through telerehabilitation in adolescents with spastic cerebral palsy (To be submitted to the Journal of Telemedicine and Telecare.), 3) Tele-coaching may improve physical activity and quality of life after 8-week home-exercise delivered through telerehabilitation in adolescents with spastic cerebral palsy (to be submitted to the Journal of Telemedicine and Telecare).

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Chapter 2: Telerehabilitation with coaching may improve adherence to home exercise in adolescents with spastic CP: a pilot study

Abstract

Background: low adherence to home exercise programs (HEP) in adolescents with cerebral palsy (CP) is a major concern in rehabilitation. Telerehabilitation has emerged as an effective way to prescribe HEP and provide real-time coaching in adults with neurological disorders. However, the feasibility of telerehabilitation to prescribe and improve adherence to HEP in adolescents with CP has not been examined. In this pilot study, we evaluated the feasibility of a telerehabilitation application in delivering HEP and provide real-time coaching for adolescents with spastic CP. **Methods:** Twenty one participants with Gross Motor Function Classification System (GMFCS) I-III spastic CP were recruited and randomly allocated to an experimental group receiving 8 weeks of individualized HEP with tele-coaching (30-60 minutes/session, 3 sessions/week), or a control group receiving the same 8 weeks of individualized HEP without tele-coaching. We measured the rates of recruitment, completion, and adherence, and acceptance score. **Results:** Twenty participants completed the intervention and post-intervention assessment. The experimental group showed a significantly higher rate than the control group of completed sessions (95% vs 85%, Mann-Whitney U=1.5, $p<0.05$), completed exercises (88% vs 81%, Mann-Whitney U=18, $p<0.05$) and completed repetitions (87% vs 83%, Mann-Whitney U=18, $p<0.05$). The reported acceptance for the exercise program and telerehabilitation platform was also significantly higher ($p<0.05$) in the experimental group (M= 6.6, SD=0.33) compared to the control group (M= 5.28, SD=0.77). **Conclusions:** Our pilot study suggests that the use of telerehabilitation to prescribe HEP and provide real-time coaching for adolescents with Spastic CP was feasible and could potentially improve adherence to HEP.

2.1. Introduction

Rehabilitation interventions among children with CP occur mainly in early childhood and decrease in frequency during school-age and adolescent years, despite new challenges arising during those transition periods.[1,2] Furthermore, conventional rehabilitation for school-aged children focuses mostly on body functions and structure, which does not always correspond to adolescents' specific needs, such as participating in activities and increasing independence in school.[3-5] Home exercise programs (HEP) are widely prescribed by physical therapists working with children with CP as a mean to complement supervised intervention and help children to achieve the optimal intensity of exercise, especially for those who do not receive enough rehabilitation at school or do not participate in physical activities at school or community.[6-8] HEP accounts for 50%–80% of the total therapy received among children with CP.[9,10] The of HEP focuses on therapeutic activities or exercises that children perform with parental assistance in the home environment to achieve health outcomes desired by the children and families.[11-13] However, current HEP for children with CP faces the challenge of poor adherence.[8,14,15] A study of 50 children receiving HEP showed only 68% completion of the total prescribed exercise days.[16] Past studies showed adherence rates to HEP without supervision varying between 11% and 37% in adolescents with disabilities.[17]

Telerehabilitation technologies may offer a novel way to enhance adherence and compliance to HEP in children.[18] Telerehabilitation can be classified as either "synchronous" where rehabilitation provider and patients are connected during therapy session disregarding their physical locations, or "asynchronous" where the rehabilitation provider and patients are not connected at real time but using 'store and forward' data transmission including video clips, digital photos, or virtual technologies.[19-22] Past studies have indicated that using asynchronous telerehabilitation to share information or exercise videos among children with CP did not improve home exercise adherence compared to traditional HEP.[23-25] For example, Johnson et al. (2020) recently showed that using an online tool to provide exercise videos did not show any superiority to a traditional paper-based delivery method for improving adherence to HEP in children with CP or other neurological disorders.[23] Furthermore, past studies have indicated the ability of the therapist to interact with children and caregivers to provide ongoing follow-up and supervision as key contributors to adherence to HEP among children with CP.[26-28] Therefore, it is important to highlight the need to offer some real-time supervision sessions in HEP to avoid 'set and forget approach' in adolescents with CP. The utilization of synchronous telerehabilitation to provide real-time treatment, supervision, and feedback has been developed in people with neurological disorders and has shown promising results for promoting adherence to HEP.[29-33] For instance, a randomized clinical trial in 2018 showed a higher adherence rate of 99.2% in an internet-based home exercise program with tele-coaching sessions, compared to the rate of 35.9% in the same HEP without tele-coaching in patients with Parkinson's disease.[32] In the pediatric patient population, synchronous telerehabilitation has been utilized to provide real-time treatment and supervision in psychology and speech-language therapy.[34] However, there is a lack of research on the role of synchronous telerehabilitation in promoting adherence and acceptance of HEP in adolescents with CP, despite its great potential.

Therefore, we conducted this pilot RCT of individualized HEP in adolescents with spastic CP using the telerehabilitation approach. Specifically, the aims of this pilot study were to (1) evaluate the feasibility of an exercise program using telerehabilitation technology to deliver an individualized HEP for adolescents with Spastic CP; and (2) to examine adherence rates to the individualized HEP with or without tele-coaching sessions.

2.2. Materials and methods

2.2.1. Study design and participants

This pilot study used a randomized clinical trial (RCT) design. Participants in this study were children with spastic CP living in the USA who met our inclusion criteria: with Gross Motor Functional Classification System (GMFCS) I-III, We selected only ambulatory GMFCS I-III, because most cases are falling under those levels and for the safety of participants and caregivers we cannot include those who are at GMFCS V and IV where they need more assistance and using of assistive devices,[35] aged 11 to 18 years old, having a stable health status for six weeks before screening, having the cognitive ability to follow an exercise instruction in either written or electronic format, with or without assistance from family members, with approval from caregivers/guardians for participating in this study, having access to the internet at home and access to the exercise's website/app via PC or mobile app, being able to understand and follow verbal commands in English. We excluded individuals who had unstable medical condition during the past 6 weeks, had other neurological disorders that may cause further decline in balance and walking abilities (head injury, vestibular dysfunction, or Spinal cord injury), or any musculoskeletal condition that would interfere with safe performance of the exercise intervention or testing protocol, and who had been scheduled surgical operations or castings during the study period. Participants were recruited through physical therapists working in school districts, hospitals, and private clinics, flyers, Facebook posting, and Frontiers/Pioneers Research Participant Registries using the Healthcare Enterprise Repository for Ontological Narration (HERON) database at the University of Kansas Medical Center. Prior to their participation in this study, they received detailed information about the study and signed an informed consent approved by the KUMC institutional review board (IRB).

2.2.2. Randomization

After the informed consent, the participants were randomly assigned to an experimental group (with tele-coaching) or a control group (without tele-coaching) at a 1:1 ratio. We first used the age of participants to stratify them into (10-12), (13-15), and (16-18) years-old categories.[36,37] We then randomly assigned participants into one of the two groups using computer-generated random sequence numbers.

2.2.3. Telerehabilitation platform used in our interventions

Physitrak™ is a HIPAA compliant commercial exercise programming website (https://www.physitrack.com) or app (android/IOS). It provides exercise therapists access to more than 3500 exercise videos with an option to upload new and customize existing exercise videos. Those videos include spoken audio instruction and subtitles. Physitrack™ allows therapists to set exercises on a weekly calendar and assign each exercise session daily or on specific days of the week. Therapists can also customize the number of repetitions, frequency, and duration of each exercise session. Physitrack™ also provides an encrypted video-conferencing feature.

2.2.4. The 8-week HEP with tele-coaching vs without tele-coaching

Prior to starting the intervention, the researchers scheduled 2 virtual meetings with the participant and caregivers/guardians. In the first meeting, the researchers collected data of demographics and medical history, explained how to use the telehealth platform, and made any troubleshooting as needed. In the second meeting, the researchers worked with the participant/caregivers to configure 3 to 5 desired specific goals of the exercise program that were used to guide the selection of exercises for HEP. After the 2 virtual meetings, the researchers reviewed the goals and constructed the home programs exercises, sets, repetitions, and duration. The exercise program had various components for gross motor function, functional tasks, lower limb strength, balance, upper limb function, stretching, leisure or sport-based, game-based exercises, and ADL tasks. All exercise components were selected to achieve the individualized goals of the participant.

The participants in both groups received an individualized HEP delivered via Physitrack™ for 8 weeks with three sessions per week, with each session lasting for 30-60 minutes. The repetitions, sets, and duration of exercises were adjusted weekly by the study therapist based on participants' performance, pain, and discomfort report. In general, the exercise program was individualized to meet the desire of each participant/family and exercise parameters (repetitions, sets, and duration) varied week-by-week depending on the progress and perception of the participant. We selected the session duration 30-60 minutes based on recommendations from past studies that utilized the individualized programs for children with CP, in order to accommodate individual differences in gross motor levels and to avoid causing fatigue, especially for those with a high level of disability.[38,39] Most of the exercise sessions lasted about 45 minutes.

For participants in the control group (without tele-coaching), all three weekly exercise sessions were self-monitored without any interaction with the study therapist. They received exercise videos via Physitrack™ and were asked to follow an actor in the videos as he/she was performing the prescribed exercises.

For the experimental group (with tele-coaching), the first 2 exercise sessions in a week were self-monitored the same as in the control group. The third session was a tele-coaching session (30- 60 minutes of real-time coaching) using the videoconferencing feature in Physitrack™ app, in which the participant was asked to perform the prescribed exercise while the study therapist observed the performance and provided (a) positive feedback for the correct performance, (b) corrective feedback for incorrect performance, and (c) assurance of understanding of corrective feedback by asking questions or asking the participant to repeat the corrective feedback. The study therapist would also train the caregivers on specific exercises to be delivered to the child. During the tele-coaching session, the study therapist followed a particular guideline (see the supplementary materials) that we developed by adapting APTA and ATA guidelines to fit with our design and population. Specifically, the study PT used the following steps to assure consistency in all tele-coaching sessions: a greeting; to state the timeline of the sessions; a brief description of the targeted exercise/activity and a demonstration or video; the participant to demonstrate the exercise and use both planned and spontaneous actions to improve performance; to make positive comments on performance and indicate the areas of correct performance; to interrupt the participant if he/she made an error and ask what he/she did wrong; to allow the participant to do self-correction; to demonstrate the correct response if he/she fails to correct the error; to interact and motivate the participant and involve caregivers; to encourage the participant to ask questions; to ask the participant to reflect on his/her progress before ending the coaching session, and to end the session by summarizing the performance improvement. The feedback included but not restricted to the correctness of alignment, posture, the substitution of movement, rhythm, and coordination of movement, and any other aspect related to dosage of exercises or task completion.

The study therapist might modify the prescribed exercises and exercise parameters (repetition, frequency, and duration) during the tele-coaching session based on patient progress and report of pain and discomfort.

2.2.5. Measurements

Feasibility was evaluated through a set of operational variables, i.e., recruitment rates, withdrawal rates before and during the intervention, completion rate, adherence to the HEP and the tele-coaching sessions, technical issues, and acceptance evaluation. The recruitment rate was calculated as the percentage of recruited participants from the individuals who were contacted and assessed for eligibility.[40] The withdrawal rate before the intervention was the percentage of participants who were consented but withdrew before the start of the intervention. The withdrawal rate during the intervention was the percentage of participants who completed at least one telerehabilitation exercise session and withdrew before the end of the intervention. The completion rate is the number of participants who completed the whole intervention as well as post-intervention assessments.[41] Adherence was monitored in both groups using Telerehabilitation (Physitrack™) adherence analysis tool. It gives the number of sessions and exercises completed each week, and the number of repetitions, and the total adherence proportion of 8-weeks. In our study, we used 3 measures to refer to adherence rates: completed sessions in 8 weeks, completed exercises in 8 weeks and completed repetitions.[32] Technical issues that disrupted or delayed the telerehabilitation meetings were documented. Acceptance of intervention and telerehabilitation platform was measured by using Telehealth Usability Questionnaire (TUQ), which has 21 questions with a score ranging from 1 to 7 for each question. At the end of intervention, caregivers were asked to fill out the TUQ.[42,43]

2.3. Statistical Analysis

Descriptive statistics were used to calculate participant demographic, social, and clinical characteristics of participants in the intervention and control groups. Mann-Whitney U test and independent t-test were used to compare both groups. Due to the small sample size of this pilot study, the significance level was set at $\alpha = 0.10$.

2.4. Results

2.4.1. Participants' characteristics

A total of 145 individuals were contacted during recruitment, and 21 (9 males, 12 females) participants were recruited and randomly assigned into either tele-coaching (n=11) or no tele-coaching (n=10) group (Figure 2.1). Twenty participants completed the baseline assessment, the intervention, and post-intervention assessment. Baseline demographic, social, and clinical characteristics were similar between the two groups (Table 2.1).

2.4.2. Feasibility results

The recruitment rate was 21(recruited subjects) out of 82 (assessed for eligibility) which corresponds to (26%). There was no withdrawal before the start of the intervention, but one withdrawal from the tele-coaching group after 2 telerehabilitation sessions (1/21, 4.8%). The completion rate of the HEP was 20/21 (95.2%).

Table 2.2 summarizes differences in adherence rates between the two groups. The experimental group showed significantly higher rate of completed sessions (Mann-Whitney $U=1.5$, $n1=n2=10$, $p<0.001$), completed exercises (Mann-Whitney $U=10$, $n1=n2=10$, $p= 0.002$) and of completed repetitions (Mann-Whitney $U=18$, $n1=n2=10$, $p=0.015$).

Regarding tele-coaching group compliance to tele-coaching sessions, there were only 5 missing sessions out of a total of 80 tele-coaching sessions (6.25%) and needed to be rescheduled in less than 24h notice. Various technical issues occurred in 10 (12.5%) out of the 80 tele-coaching sessions. No major technical issue necessitating a cancellation of a session. No harm or unintended adverse effects were recorded.

The experimental group showed a significantly higher acceptance for the exercise program and usability of Physitrack™ ($M= 6.6$, $SD=0.33$) compared to the control group (M=

5.28, SD=0.77) ($p<0.05$).

2.5. Discussion

This pilot study examined the feasibility of an individualized HEP, delivered through a telerehabilitation application (Physitrack™) in adolescents with spastic CP. The study was focused on participants' adherence to the same HEP through a comparison between an experimental group with tele-coaching and a control group without tele-coaching. The results of this study demonstrated that the combination of tele-coaching and individualized HEP delivered through telerehabilitation approach was feasible in adolescence with spastic CP and may further improve exercise adherence compared with HEP without tele-coaching.

Our results showed that the use of a telerehabilitation platform accompanied by tele-coaching might further improve adherence to HEP among adolescents with CP. Participants in the tele-coaching group showed a significantly higher adherence rate (95% completed exercise sessions) compared to participants without tele-coaching (85% completed exercise sessions). This study is the first study to utilize tele-coaching in HEP among adolescents with CP. There has been no direct comparison of the current finding in the literature. However, there have been many indirect evidences supporting the benefit of tele-coaching in exercise adherence from studies in people with other health conditions. For instance, Lai et al. (2018) has reported that the coaching-assisted group showed a higher adherence rate (99.2%) to internet-based home exercises program compared to the self-managed group in Parkinson's population.[32] Similar findings were observed in studies of tele-exercise of Tai Chi in elderly people [44], telehealth intervention in children with Autism [45], adults with spinal cord injury [31], or stroke survivors [46,47], and HEP with coaching for youths with arthrogryposis multiplex congenita.[48]. Future large-scale clinical trials are needed to further confirm the enhanced exercise adherence by tele-coaching in adolescents with CP.

The higher adherence rate in the tele-coaching group may be attributed to multiple factors. Weekly interaction between the study therapist and participants in the tele-coaching group might help the participants to receive ongoing support for their engagement in the exercise program.[32,49,50] Furthermore, participants who received the tele-coaching could enhance their self-efficacy or self-confidence in completion of the prescribed exercise program through positive feedback as well as resultant behavioral change toward exercises. Previous studies have shown that self-efficacy has a central influence on direct or indirect behavioral changes among people with neurological disability.[51,52]

The recruitment rate in our study was relatively low (26%), since most recruitment activities occurred during the school shutdown due to the COVID-19 pandemic. We had difficulty in reaching out to potential participants from school districts and physical therapy departments in hospitals after governmental lockdown due. It took us extra time to finish recruitment because therapists at schools and clinics took a longer time to figure out their caseloads during COVID-19 lockdown. Furthermore, the recruitment was affected by the change in parents' work schedule. The parents who have been working from home reported that they did not have the time to be committed to our study beside their work duties and their kids' online schooling. Although the efficiency of different recruitment methods was not directly examined, we noticed that it was easier to recruit participants through their usual therapists instead of phone calls. Some participants at 17-18 years of age were recruited through Facebook's groups targeting adolescents, adults with CP, or caregivers of CP children. Our results showed that participants in both groups were committed to HEP, with only one withdrawal due to the lack of time of the caregiver.

The support from families was important for most of the participants, specifically for the younger participants and those more severely affected by CP (GMFCS III). In almost 99% of the tele-coaching sessions, the caregiver was present to help position the camera, position or assist the participant or deliver specific exercise and help in session set-up. In the current study the caregivers were actively involved in design of the exercise program and implementation of the home exercise program; provide emotional support and facilitate the interaction with the therapist. Furthermore, caregivers played an important role in maintaining a high adherence and compliance to the HEP. Furthermore, caregivers played an important role in provision of adherence and compliance for their children and communicated about it with our research team.

This study had some limitations. First, small sample size and individuals with only spastic CP may limit the results to be generalized to a large population with CP. Second, neither study participants nor study examiner in this pilot study was blinded to the intervention's allocation. Third, we did not include the behavior changes and self-efficacy assessments in the study, which might help in better explain differences among groups and the role of coaching. Fourth, we did not collect data about the change in medications during the intervention, as well as changes in exercises provided by participants' OTs or PTs at school or home. Fifth, we did not systematically document the assistance needed from caregivers to help in implementation of specific exercises or assistance, which could influence the participants' performance and progress. Sixth, we did not statistically analyze the factors that influenced our recruitment procedure and adherence rates, especially those related to caregivers working from home, school settings change during shutdown due to COVID-19. Finally, our study used a specific telehealth platform (Physitrack™) to deliver HEP. It is unclear whether different telehealth platforms could be equally effective in providing HEP. We speculate that the results may apply to other telehealth platforms with similar design features (such as videos, reminder text messages).

2.6. Conclusion

No past studies utilized telerehabilitation to provide real-time coaching in children with CP. Results of our pilot study suggest that it is feasible to use telerehabilitation to prescribe HEP and to provide real-time coaching for children with Spastic CP. Such an approach can increase adherence to HEP. Lessons can be learned from the challenges and positive aspects of the current pilot study, leading to future large-scale clinical trials. Further research is necessary to develop and test methods that maximize adherence to larger home exercise programs in children with CP.

Table 2.1: Demographics and clinical features of study participants in the experimental group and control group using independent sample t-test and Chi-square

	Experimental Group (n=10)	**Control Group (n=10)**	***p*-value**
Age, Mean (SD)	14.80 (2.3)	14.30 (2.06)	0.615
Female, n (%)	6 (60%)	5 (50%)	0.653
Topographical classification			
Hemiplegia, n (%)	5 (50%)	5 (50%)	0.158
Diplegia, n (%)	5 (50%)	5 (50%)	
GMFCS level			
I	7	6	0.871
II	2	3	
III	1	1	

Table 2.2: Outcomes of adherence measurements in experimental and control groups. Mann-Whitney test.

	Experimental Group (n=10)	**Control Group (n=10)**	**U-value**	**p-value**
Sessions Completed %	95.8%	85%	1.5	**<0.001**
Exercises completed %	87.9%	81%	18	**0.002**
Repetitions completed %	87%	83%	18	**0.015**

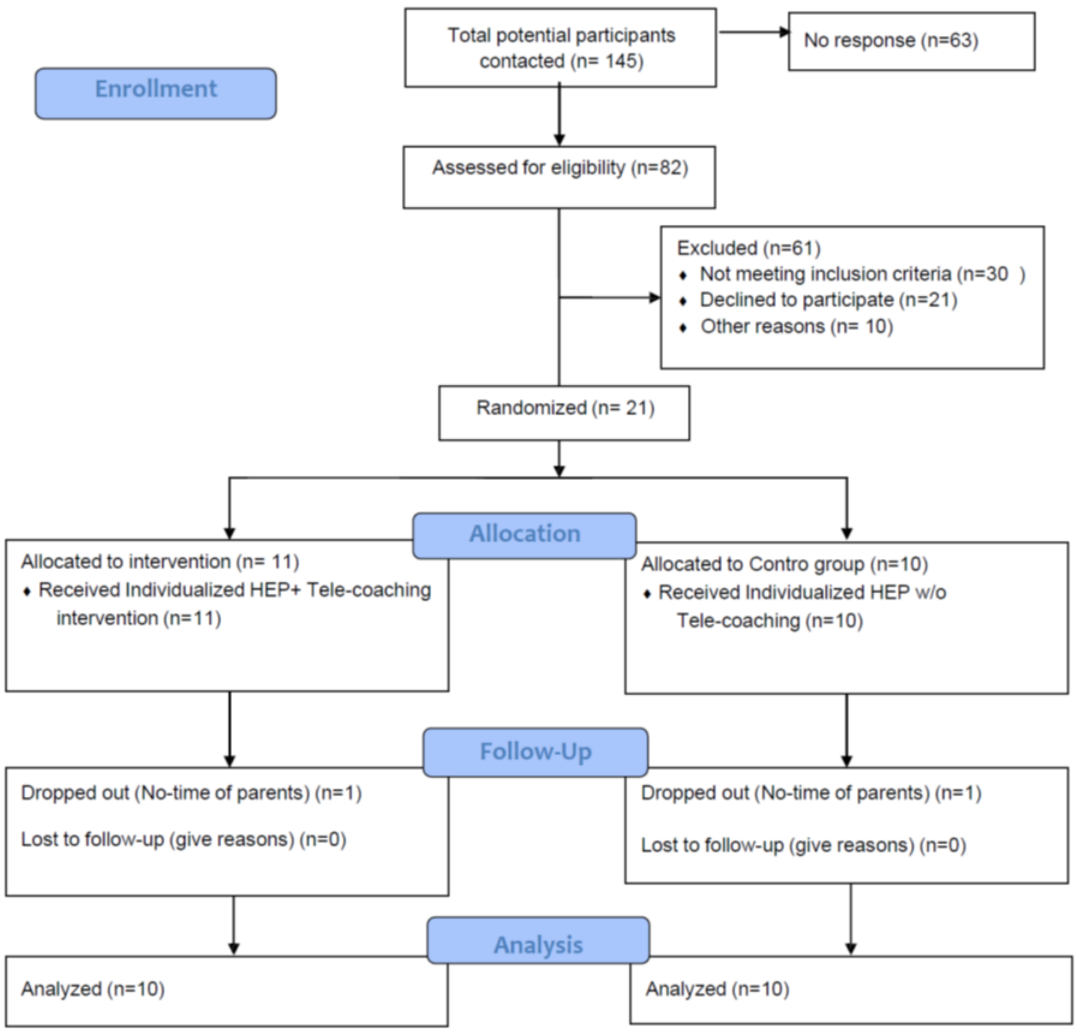

Figure 2.1. Participant recruitment process flowchart

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Chapter 3: Tele-coaching may improve performance and satisfaction after 8-week home-exercise delivered through telerehabilitation in adolescents with spastic cerebral palsy

Abstract

Background: Adolescents with spastic cerebral palsy (CP) often experience a decline in motor function and activities in daily living, partially due to insufficient or inaccessible face-to-face rehabilitation services or due to non-efficient home exercise programs. Utilization of telerehabilitation to prescribe goal-directed home exercise programs (HEP) could provide appropriate exercise dosage, needed feedback, and real-time training to improve functional performance and skills of activities of daily living. In this pilot study, we evaluated the outcomes of individualized HEP implemented through Telerehabilitation with or without tele-coaching for adolescents with spastic Cerebral Palsy.

Methods: Twenty-one participants with Gross Motor Function Classification System (GMFCS) I-III spastic CP were recruited and randomly allocated to receive either eight weeks of individualized HEP with tele-coaching (experimental group) or individualized HEP without tele-coaching (control group). Canadian Occupational Performance Measure (COPM) was used to evaluate the achievement in goal performance and satisfaction. The correctness of exercise performance (COEP) scale was used to examine the quality of exercise performance. The baseline and postintervention COPM scores were collected. COEP was measured at the 1^{st}, 4^{th}, and 8^{th} weeks.

Results: Twenty participants were assessed for post-intervention assessment. Significant changes from baseline were observed in performance scores of the experimental group (1.98± .24, $p<0.001$) and control group (1.16± .34, $p<0.001$), and in the satisfaction scores of the experimental group (1.86± .14, $p<0.001$) and control group (1.10± .34, $p<0.001$). The

experimental group showed significantly higher mean-differences in performance score (0.82, $p<0.001$) and satisfaction score (0.76, $p<0.001$) compared to the control group. Four participants in the experimental group showed a clinically meaningful change in COPM scores, while only one subject showed it in the control group. The experimental group showed a significantly higher percentage of exercise scored “1” on COEP at 4th week ($p<0.05$) and at the end of 8-week intervention ($p<0.001$) compared to the control group.

Conclusions: Our pilot RCT suggests that an individualized home exercise program with tele-coaching could result in better achievement of individualized goals and improvement in the quality of exercise performance among adolescents with spastic CP.

3.1. Introduction

The most common type of cerebral palsy (CP) is spastic CP which represents around 82% of all patients with CP. Spastic CP can be either unilateral (33%) or bilateral (49%).[1,2] The goal of therapeutic interventions for individuals with CP varies according to the changes in individual's needs throughout the lifespan.[3,4] The goal of early intervention during childhood is usually to reach motor milestones and maximize functional gains.[5] Later in life, especially during adolescents, the goal of interventions is often focusing on maintaining gains and maximizing function to promote participation in school activities and employment activities.[6,7]

Secondary complications and declines in function have been reported in adolescents and adults with spastic CP due to muscle spasticity and weakness, orthopedic contractures, poor aerobic fitness, and chronic pain and fatigue.[8,9] The functional declines can result in a sedentary lifestyle that contributes to cardiopulmonary disorders, depression, poor quality of life, and decreased lifespan.[10,11] These consequences may be prevented with adequate exercise during adolescence. Exercise has been shown to increase muscle strength, decrease pain and fatigue, improve motor function, activities of daily living and quality of life among adolescents with cerebral palsy.[12,13]

Despite the benefits of exercise, adolescents with CP are less physically active than their typically developing peers.[14,15] A systematic review by Shields et al. (2012) highlighted the personal, social, environmental, and program-related barriers that influence the participation in exercise programs among adolescents with CP.[4,12,16] The most prominent personal factors include a lack of physical and social skills, preference for a sedentary lifestyle, fear of pain, and a lack of knowledge about exercise's benefits, equipment, duration, frequency, and repetitions.[10,16]

Caregivers often concern about children's safety, lack of support, and lack of feedback about exercise performance. Inadequate and inaccessible facilities and a lack of available transportation are two major environmental barriers faced by adolescents with CP.[12,16] Other barriers include limited financial resources and limited insurance coverage for exercise programs. In addition, HEP adjunct to clinical therapeutics faces also challenges including poor adherence due to the lack of supervision and interaction between therapist and patients.[16-19]

The goal-directed intervention delivered through telerehabilitation technologies may offer a solution to address some barriers that prevent adolescents with CP from participating in exercises and result in better functional performance. Telerehabilitation can be classified as either "synchronous" or "asynchronous". The former would allow real-time interaction between therapists and the patients regardless of their physical locations and the later could not provide real-time interaction but use 'store and forward' data transmissions such as video clips, digital photos, or virtual technologies.[20-22] The asynchronous telerehabilitation has shown its feasibility and benefits in children with neurological disabilities.[23-26] The synchronous telerehabilitation can provide therapist-client interaction for real-time coaching.[27] For example, Gagnon et al. (2020) reported that synchronous telerehabilitation was feasible and effective in remote delivery of 12-week HEP with coaching for youths with arthrogryposis multiplex congenita.[28] Lai et al. (2018) reported that therapist-assisted telerehabilitation HEP is more feasible and efficient than self-directed telerehabilitation HEP among adults with Parkinson's.[29] Wu et al. 2010 reported that the tele-practice of Tai chi is more effective than home-based videos among elderly people.[30] We speculate that combining a synchronous tele-coaching with an asynchronous telerehabilitation may add the needed therapist-patient interaction while without a significant increase in the cost.

However, no studies have examined the effect of a combined telerehabilitation in adolescents with CP.

The objective of this pilot study was to evaluate the trend of change after the 8-week telehealth HEP in goals achievement by adolescents with spastic CP, with or without tele-coaching. We hypothesis that study participants would show significantly better outcomes after the 8-week integrated telerehabilitation exercise with tele-coaching compared to the same 8-week asynchronous telerehabilitation exercise program without tele-coaching. The outcome measurements in this pilot study focused on the performance and satisfaction evaluated by both therapists and patients/caregivers.

3.2. Materials and methods

3.2.1. Study design and participants

This pilot study used a randomized clinical trial (RCT) design. Participants in this study were children with spastic CP living in the USA who met our inclusion criteria: with Gross Motor Functional Classification System (GMFCS) I-III,[31] aged 11 to 18 years old, having a stable health status for 6 weeks before the screening, having the cognitive ability to follow an exercise instruction in either written or electronic format, with or without assistance from family members, with approval from caregivers/guardians for participating in this study, having access to the internet at home and access to the exercise's website/app via PC or mobile app, being able to understand and follow verbal commands in English. We excluded individuals who had reported unstable medical condition during the past 6 weeks, had other neurological disorders that may cause further decline in balance and walking abilities (head injury, vestibular dysfunction, or Spinal cord injury), or any musculoskeletal condition that would interfere with the safe performance of the exercise intervention or testing protocol, and who had been scheduled surgical operations or castings during the study period. We selected the Spastic type to avoid high heterogeneity of the sample and because it represents around 82% of all CP types.[1] We selected this age range based on adolescence definition based on WHO and American Academy of Pediatrics.[32]

Participants were recruited through physical therapists working in school districts, hospitals, and private clinics, flyers, Facebook posting, and Frontiers/Pioneers Research Participant Registries using the Healthcare Enterprise Repository for Ontological Narration (HERON) database at the University of Kansas Medical Center (KUMC). Prior to their participation in this study, each of them received detailed information about the study and signed an informed consent approved by the KUMC institutional review board (IRB).

3.2.2. Randomization

After the informed consent, the participants were randomly assigned to an experimental group (with tele-coaching) or a control group (without tele-coaching) at a 1:1 ratio. When randomly assigning participants into one of the two groups, we first used the age of participants to stratify them into (10-12), (13-15), and (16-18) years-old categories.[33,34] Then, we randomized participants to either with tele-coaching or without tele-coaching groups using computer-generated random lists. The reason that we chose age as a stratifying factor is that the motor function as measured by functional GMFCS is correlated with age. Specifically, the proportion of children walking independently on uneven surfaces was incrementally higher in each age group up to 18 years.[35]

3.2.3. Assessment timeline and outcome measures

Before the interventional HEP, a study physical therapist (PT) had two baseline video conference meetings via the Physitrack platform with each participant and caregivers/guardians. In the first baseline meeting, the study PT collected data of demographics and medical history of the participant, explained the procedures of using the telehealth platform, and conducted any troubleshooting needed.

The second baseline meeting was a semi-structured videoconference interview with participants/caregivers to determine up to 5 goals/problems of importance to be focused in our exercise intervention. We used the adapted version of the Canadian occupational performance measure (COPM) during this meeting to determine the important goals and to scale its performance and satisfaction scores. The adapted version of COPM includes 3 occupational performance areas; (1) Self-care: occupations aimed at getting ready for the day and getting around. We measured 3 aspects of the self-care area: personal care, functional mobility, and community management; and (2) Productivity: occupations aimed at maintaining home and family, providing service to others, and/or developing one's capabilities. We measured the only school and play aspect of the productivity area; and (3) Leisure: occupations performed by an individual when freed from the obligation to be productive. We measured 3 aspects of leisure area: quiet recreation, active recreation, and socialization.[36]

The goal determination scoring was done by: (1) identifying problems in each area and aspect, where the problem could be defined as the occupation/task that the person wanted to do, needed to do or was expected to do, but couldn't do it, did not do it, or was not satisfied with way he or she did it; (2) asking caregivers/participants to rate each one in terms of its importance in his or her life on a ten point scale, where 1 equal to not important at all and 10 equals to extremely important; (3) asking participants/caregivers to choose up to five problems that seems most pressing or important, using rating done in pervious step; (4) asking participants/caregivers to rate the performance of the participant in doing the activity, using a ten point scale where 1 stands for not able to do it at all and 10 stands for able to do it exceptionally well, and to rate the satisfaction of the participant with the way he/she in doing the activity, on a ten point scale where 1 stands for not satisfied at all and 10 stands for extremely satisfied; and (5) computing the average scores of 5 problems on performance and satisfaction. Those goals/problems yielded from the COPM interview were used later to guide the researchers in selecting HEP exercise for the participants.

At the end of the 8-week intervention, the study PT scheduled the participants/caregivers for a videoconference meeting to reassess performance and satisfaction scores of problems selected at baseline. Differences in performance and satisfaction scores were calculated.

Our secondary outcome was the Correctness of Exercise Performance (COEP) scale.[37,38] COEP was used to grade the quality of exercise performance on an ordinal scale (1) the performance has been carried out so well that the goal of the exercise is reached; (2) the exercise was not performed correctly, and the goal was not reached, although no negative effect is to be expected; and (3) the exercise was carried out incorrectly, the goal was not reached and there were reasons to assume that the exercise causes harm.

Caregivers of participants were asked to videotape their adolescents while they were performing the prescribed exercises at home. Videos were recorded at the beginning, halfway (4 weeks), and end of the 8-week intervention period. We selected a list of exercises based on commonly selected individual goals of participants and embedded those exercises in participants' programs. Those exercises were used to examine the change in the quality of exercise performance. The participants were evaluated for the performance of the same list of exercises at 1st session, 4th week, and 8th week. Recordings were used to scale the correctness of performance on the ordinal scale mentioned earlier, and to see how the proportion of correctly completed exercise improved over 8 weeks.

3.2.4. Telerehabilitation platform used in our interventions

Physitrak is a commercial exercise website (https://www.physitrack.com) or app (android/IOS) with HIPAA compliance. It provides exercise therapists access to 3500 videos of the exercise library with an option to upload self-made videos and customize existing videos. Those videos include audio instruction and subtitles. Physitrack allows therapists to set exercises on a weekly calendar and assign each exercise session daily or on specific days of the week. Therapists can also customize the number of repetitions, frequency, and duration of each exercise component. Physitrack also provides an encrypted video-conferencing feature, so that the therapists can coach patients/caregivers either by the demonstration of specific exercise component or instruction of the correct performance sequence. Also, the option of recording and saving the exercise sessions onto the therapist's computer allows therapists to revisit the sessions recorded and rate the performance. Patients can log in to Physitrack via computer, tablet, or smartphone. The system will enable patients to print the exercise program and review their performance in the exercise program. Patients can interact with therapists via an encrypted messaging feature. Patients can also rate their pain or discomfort after each exercise.

3.2.5. The 8-week HEP

The individualized goals and other relevant information obtained from the second initial meeting were used by the researchers to develop an exercise package of the 8-week HEP for the participant. Our exercise program includes various exercise components for gross motor function, functional tasks, lower limb strength, balance, upper limb function, stretching, leisure or sport-based, game-based exercises, and ADL tasks. The primary principle in selecting exercise components included in the package is whether they can help to achieve the individualized goals of the participant. The selection targeted at exercise components that help either to improve performance in activities identified by the individualized goals (i.e. ball kicking, ball throwing, etc.…) or improve motor, cognitive, or visual perceptual functions that constitute a basis for developing skills related to their individual goals. For example, if an individualized goal is to achieve bicycle riding, we would select exercises targeting at muscle strength and joint range of motion of lower limbs, balance control, as well as reaction time. Personal and environmental needed to accomplish the exercise goal also influence the selection of exercises. For example, it was not possible to practice bicycle riding at home during a coaching session. In such a case, the selected exercises would focus on the individual's body structures and functions (i.e., knee ROM and muscle strength) to develop the riding capability. The International Classification of Functioning, Disability and Health (ICF) model suggested that health condition improvement can result from improvement and interaction of body structure/function, activity level, or participation. Based on this model, targeting the goal-oriented activity directly, the task-specific training can improve not only the performance of the task but also basic motor skills, functions, and participation. On the other hand, targeting the body structure and function one can improve motor skills directly that may lead to improvement in the goal-oriented activity and participation indirectly.

3.2.5.1. Intervention for the control group (without tele-coaching)

The participants in both groups received an exercise package of HEP delivered via Physitrack for 8 weeks with 3 sessions a week for 30-60 minutes each session. For participants in the control group (without tele-coaching), all three weekly exercise sessions were self-monitored without any interaction with the therapist. Participants in the control group received exercise videos via Physitrack. They were asked to follow an actor in the videos as he/she performed the prescribed exercises. The exercise program was adjusted weekly as needed based on the participant's progress as measured by performance and feedback of pain and discomfort reported in Physitrack. The adjustment was mainly made for sets, repetitions, and duration of exercises. Furthermore, the position of the exercise, instruction, and sometimes the type of exercise was changed if participants reported severe pain or they reported that exercise was too strenuous.

3.2.5.2. Intervention for the experimental group (with tele-coaching)

For the experimental group, the first 2 sessions within a week were self-monitored and the third session was a tele-coaching session (30- 60 minutes real-time coaching) using the videoconferencing feature of Physitrack. The participants were asked to perform the prescribed exercise during the tele-coaching session while the study PT observed the participant's performance. The purpose of this session was to deliver performance feedback, including (a) positive feedback for the correct performance, (b) corrective feedback for incorrect performance, and (c) assurance of understanding of corrective feedback by asking questions or asking the participant to repeat the corrective feedback. Besides, the study PT trained caregivers/ guardians to help in delivering specific exercises to participants.

Our study PT followed the general guidelines published in "telehealth in practice section" on APTA website in 2019[39], "Core operational guidelines for telehealth services involving provider-patient interactions," and "operating procedures for pediatric telehealth" published by ATA 2014 and 2017, respectively.[40,41] These guidelines are made to assure the uniform quality of service to patients and promote reasonably and informed expectations in patients. The guidelines have provided all core operational procedures of telehealth application, including the provider-patient interaction, technology consideration, equipment, patient safety, parental presence, and clinical application. Our research team adopted and followed those procedures in three significant aspects. The first aspect is related to the administrative process. Before starting the tele-coaching session, the therapist informed and provided the participant in real-time of all pertinent information through discussions of the structure and timing of services, scheduling, privacy and security, potential risks, and any other information specific to the nature of videoconferencing. The therapist ensured that workspaces were secure, private, reasonably soundproof, and have a lockable door to prevent unexpected entry. Efforts were made to ensure privacy so speech cannot be overheard by others outside of the room where the service was provided. If other people were in either the participant's or therapist's room, both the professional and patient were aware of the other person and agreed to their presence. The participants and caregivers identified an appropriate space for the real-time conference meeting. Ideally, the room should be large enough to comfortably accommodate the patient, up to two parents or legal representatives, along with necessary exercise equipment. As in our research, the parents were required to be present all the time during the session to ensure the participants' safety and privacy. In addition to that, the therapist assured to minimize distraction, background noise, and other environmental conditions that may affect the quality of the participants' performance.

Second, the technical procedures; the therapist was keen on communication with participants about the device (laptop, iPad, etc..) used during tele-coaching session to ensure that both therapist and participants use high-quality cameras (video and/or still as clinically appropriate for the intended application), audio. At the same time, the therapist checked that participants' devices were not connected to social media that could interrupt the interaction between therapist and participants. The privacy of audio and video was guaranteed in our research by using Physitrack™, which offers encrypted video/audio videoconferencing.

Third, the clinical procedures; the therapist reviewed with the participants' and caregivers' expectations of the intervention between sessions. The therapist was keen to consistent in providing assessment, intervention, and feedback that could fit the study's population age and disability. It is recommended to build up the tele-coaching session to match the relevant guidance of in-person therapy. In our study, the therapist has had enough experience to deliver physical therapy sessions to children with CP and providing feedback for this population. The therapist, during tele-coaching session, focused on common elements in performance feedback protocols including (a) positive feedback for correct performance, (b) corrective feedback for non-correct performance, and (c) ensuring understanding of corrective feedback by asking questions or asking the participant to repeat corrective feedback. Specifically, the therapist provided the therapeutic instructions using the following steps to assure consistency in all tele-coaching sessions: a greeting; to state the timeline of the sessions; a brief description of the targeted exercise/activity and a demonstration or video; the participant to demonstrate the exercise and use both planned and spontaneous actions to improve performance; to make positive comments on performance and indicate the areas of correct performance; to interrupt the participant if he/she made an error and ask what he/she did wrong; to allow the participant to do self-correction, to demonstrate the correct response if he/she fails to correct the error; to interact and motivate the participant and involve caregivers; to encourage the participant to ask questions; to ask the participant to reflect on his/her progress before ending the coaching session and to end the session by summarizing the performance improvement. The feedback included but was not restricted to the correctness of alignment, posture, the substitution of movement, rhythm, and coordination of movement, and any other aspect related to dosage of exercises or task completion.

The study PT could modify the prescribed exercises and exercise parameters (repetition, frequency, and duration) during the tele-coaching session based on patient progress and report of pain and discomfort. For example, in a single-stance exercise, while eyes closed, one participant was asked to hold this position for 30 seconds and repeat the tasks three times in a set for a total of 3 sets in a session in the first week. She reported in the first 3 sessions a completion of 20 seconds of exercise, 2 repetitions per set, for 3 sets with an average pain level of 3. In the 4th session she could complete 30 seconds of exercise, 3 repetitions per set, for 3 sets without pain. She maintained the same performance in 5th and 6th session without pain. The therapist increased the number of repetitions to 5 and the number of sets to 4 after the 6th session. Furthermore, the therapist could provide emotional support and motivation adjustment as needed during coaching sessions to help the engagement and compliance of the participants to the exercise program. For example, prizes and rewards were offered by the therapist through parents in case of completion of exercise goals correctly and on time. The behavioral therapy components were incorporated as needed with collaboration with caregivers to help participants to be confident about their abilities to complete the exercise program. Also, the therapist was culturally competent to deliver the intervention to the participant with awareness of participants' geographical location, socioeconomic and cultural backgrounds, recent significant events, and cultural mores of the community, which helped in building up the trust between therapist and participants.

3.3. Data and Statistical Analysis

Data entry was performed using Microsoft Office Excel 16 for Windows 10, with ongoing data monitoring and organization. Windows SPSS Statistics 26, 2020 version was be used to perform all statistical analyses.[42] Considering that it is a pilot study and a relatively small sample size, the significance level was set at $\alpha = 0.10$, upon the suggestion by our statistician.[43]

Descriptive statistics were used to calculate participant demographic, social, and clinical characteristics of participants in the intervention and control groups. The COPM performance and satisfaction scores were calculated for each participant, and the difference between pre-and post-intervention scores within each group was analyzed using a paired t-test. Between-groups differences were measured as the mean change after the intervention, and the independent t-test was used to detect the significant difference between the two groups. The change of 2-points or more is clinically meaningful.[36,44] The proportion of participants in each group that show a 2-point change in COPM score was compared between the two groups using the Fisher-exact test. For COEP measurement, Wilcoxon signed-rank test was used to determine any changes from baseline to 4th week to post-intervention and the Mann-Whitney test to determine differences between groups at each time point. We used Pearson correlation analysis to examine the possible correlations between the adherence measure of exercise sessions completed, COEP, and COPM performance and satisfaction scores.

3.4. Results

3.4.1. Participants' characteristics

We recruited 21 (9 males, 12 females) children and randomly assigned them into an experimental group (n=11) or control group (n=10) (see details in Figure 2.1 in Chapter 2). No significant differences between two groups in baseline demographic, social, and clinical characteristics (Table 2.1 in Chapter 2).

3.4.2. Changes in COPM performance and satisfaction scores

Twenty subjects completed the 8-week intervention and post-assessments. Participants in the experimental group reported an adherence rate (%completed sessions) of 95%, while participants in the control group reported an 85% adherence rate over 8-week HEP (All details about feasibility outcomes and procedures are in the manuscript for Aim 1).

Goals reported by both groups varied and were related to lower-limb strength, daily activities (e.g. balance during bathing, control up and down-stairs, et.), walking endurance or speed, sports (e.g. soccer and basketball), keeping up with peers at school (e.g., going to the lunchroom and standing in the line). Some goals also were related to transitions (e.g., from the floor to standing without help), balance (e.g., standing or hopping on one foot). In addition, some children had goals related to dressing and to hand activities (e.g., carrying a large laundry basket, writing, zipping of a jacket, and ball throwing). The median number of goals established with the participants was 4 (range: 3 to 5). A total of 87 goals were selected by both groups, where the tele-coaching group had 44 goals while the control group had 43 goals.

Both groups were similar in COPM baseline scores of performance and satisfaction. Results have shown a significant change in post-intervention scores of performance and satisfaction of tele-coaching group (1.98, p<0.001) and (1.86 p<0.001); and of the control group (1.16, p<0.001) and (1.10, p<0.001). The tele-coaching group showed a significantly higher score on the COPM performance scale by 0.82 (p<0.001) and on the satisfaction scale by 0.76 (p<0.001). Table 3.1 summarizes within and between groups differences in COPM score. Four participants (40%) in the tele-coaching group showed a clinically meaningful change of 2 points or more on both performance and satisfaction scales. In contrast, only one participant in the control group showed a change of 2 points (10%). However, there was no significant difference between groups (p=0.3). Correlational analysis revealed strong significant correlations between adherence and change in performance (r=0.82, p<0.001) and satisfaction (r=0.78, p<0.001).

3.4.3. Changes in COEP scale

Our results have shown that (58%) of exercises were completed by participants in both groups, with ‘performance sufficiently correct to achieve the purpose of the exercise’ and scored for “1” on COEP. While 40% of videos were rated with ‘exercise performance that does not achieve the goal of the exercise’ and scored for “2” on COEP, and 2% were rated as ‘not achieving the goal and also may cause harm’ and scored for “3” on COEP. No statistically significant differences were found between groups at baseline (p=0.72). The tele-coaching group showed a significantly higher percentage of exercise scored “1” at 4^{th} week (p<0.05) and at the end of 8-week (p<0.001). Table 3.2 summarizes the results of COEP among both groups. Correlational analysis revealed a significant correlation between COEP at end of intervention, and each of adherence rate (r=0.54, p<0.05), COPM-performance (r=0.63, p<0.05), and COPM-satisfaction (r=0.61, p<0.05).

3.5. Discussion

This pilot RCT is the first study to utilize a telerehabilitation technology combining synchronous and asynchronous modules to deliver an individualized HEP for adolescents with spastic CP, as well as the first study to provide tele-coaching for HEP in this population. Both groups showed a significant improvement in COPM scores between baseline and end-intervention assessments. However, the participants allocated to the experimental group achieved significantly greater improvements in performance and satisfaction, indicating an excellent potential for the combined approach to improve the outcomes of HEP further.

We used a telehealth platform in delivering HEP to the participants and observed significant improvement in both groups before and after the intervention. Our control group showed a significant improvement from baseline in COPM performance by 1.16 points and satisfaction by 1.10 points. This result agrees with the results reported by James et al. (2015), in which they reported a COPM improvement by 1.29 points in children with CP after individualized internet-based HEP.[23] Similar improvements were also reported in studies by Lorentzen et al. (2015) and Baque et al. (2017).[24,45] However, Sakzweski et al. (2016) observed no significant differences in COPM scores compared to the usual care group in children with acquired brain injury who received a web-based intervention.[46] Nevertheless, most of the past studies confirmed our results.

Past studies have shown the additional benefit of adding tele-coaching in telerehabilitation programs in children or adults with various disabilities. Ingersoll et al. (2017) showed better outcomes in children with autism who went through a therapist-assisted telehealth intervention compared to a control group without therapist-patient interaction.[47] Similar results were reported by Ferre et al. (2017) in children with unilateral CP, by Gagnon et al. (2020) in adolescents with AMC.[28,48] Lai et al. (2018) observed greater improvement in walking capacity in adult patients with Parkinson's disease who exercised under tele-coaching supervision using the videoconferencing compared to self-managed exercise through online resources.[29] Similar findings have been reported by Wu et al. (2010) and Duruturk et al. (2019) studies.[30,49] This pilot results indicated for the first time that additional tele-coaching for HEP in adolescents with spastic CP might further improve outcomes in COPM performance and satisfaction scores. Furthermore, we observed a significant increase in adherence to HEP in the experimental group with tele-coaching and a significantly strong correlation between the increase in adherence and changes in COPM scores. The increased adherence to HEP may be a significant factor for the improvement in COPM outcomes. Further research with large sample size is required to confirm our findings in this pilot study.

Both groups showed improvement in performance and satisfaction after our goal-directed HEP. This improvement could be attributed to the collaborative partnership between the therapist and families, which allowed the participants and their families to set goals based on their performance and satisfaction levels.[50] Furthermore, a goal-directed program could help in incorporating activities or exercises into the daily routine of family and child. We especially utilized a small number of exercises in each session to help participants feeling confident in carrying out the exercise safely.[50-52] Furthermore, the provision of high-quality exercises videos with clear audio instructions and captions delivered through Physitrack; ability to report the completed exercises and pain level online; provision of adherence rates; and receiving reminders to practice could help our participants to be better engaged in the exercise program as compared to traditional HEP with paper-based handouts and logbook.[53] The further improvement in the tele-coaching group emphasizes the benefit of supervision in-home exercise programs. Tele-coaching offered weekly interaction between therapist and participants/families to provide positive or corrective feedback about exercise performance, to identify participants' progress, and to adjust the exercise program as needed. Furthermore, tele-coaching sessions could help to increase exercise engagement and self-confidence.[20,28,54,55]

The duration for each exercise session and the entire exercise program in our study was comparable to past studies. Past studies by Novak et al. (2009) and Reedman et al. (2019) showed detectable changes in COPM scores after 4-8 weeks of individualized goal-directed exercise programs in children with CP.[56,57] Sorsdahi et al. (2010) showed that 30-60 minutes/ sessions for 15 sessions resulted in the achievement of individualized goals of children with CP who are at GMFCS I-III.[58]

The increase in quality of exercise performance as measured by COEP highlights the importance of continuous review of how children perform prescribed exercises to improve the safety and effectiveness of HEP. Furthermore, we observed a significant correlation between COEP and COPM. The improvement in the quality of exercise performance may be a significant factor for the improvement in COPM outcomes. Further research with a large sample size warrants confirmation of our findings.

This pilot study has some limitations. The small sample size and targeting only spastic CP with GMFCS I-III may limit the generalization of the results. The small sample size may be partially the reason for the lack of significance between two groups in the number of individuals who reached the clinically meaningful change in COPM. No blinding was used in this study. It was impossible to blind our participants from knowing their group assignment due to the nature of the tele-coaching approach. Also, it was not possible to blind our research team to participants' allocation. Goal-directed intervention can improve gross motor function and other activities of daily living, as shown in high-quality research evidence in children with cerebral palsy.[56,59] In this pilot study, although some participants indicated their improvement in strength, balance, and other gross motor function, in this study with online intervention and assessment we did not include any gross motor measurements in the study protocol due to the limitation of online study. Furthermore, there was no data collection about changes in medications, physical therapy, or occupational therapy treatment received by the participants during the study.

3.6. Conclusion

Our pilot RCT study suggests that using Physitrack to prescribe individualized HEP and to provide coaching sessions for children with Spastic CP could result in better improvement of occupational performance, satisfaction, and exercise performance compared to self-monitored HEP. A larger multisite RCT is needed to confirm the effectiveness of the approach, to include more outcome measures related to gross motor, and to supervise caregiver-directed interventions or assessments for very young children.

Table 3.1: Canadian Occupational Performance Measure (COPM) individualized goal activity performance and satisfaction outcomes. The difference is calculated by post score minus pre score.

	Experimental group (n=10) Mean (SD)			**Control group (n=10) Mean (SD)**			**Between groups difference**	***p*-value**
COPM	**Pre**	**Post**	**Difference**	**Pre**	**Post**	**Difference**		
Performance	5 (.73)	6.98 (.80)	1.98 (.24) *	4.9 (.57)	6.06 (.64)	1.16 (.34) *	0.82	**p<0.001**
Satisfaction	4.8 (.54)	6.6 (.59)	1.86 (.14) *	4.78 (.34)	5.88 (.41)	1.10 (.34) *	0.76	**p<0.001**

**Significant within-group change from baseline measured by paired t-test.*

p-value represents between-group differences compared using independent t-test.

Table 3.2: Correctness of Exercise performance (COEP) at T1 (1st week), T2 (4th week), and T3 (8th week)

	Experimental group (n=10) Mean (SD)			**Control group (n=10) Mean (SD)**			**p-value**		
	T1	**T2**	**T3**	**T1**	**T2**	**T3**	**T1**	**T2**	**T3**
COEP %	54%	63% *	66%**	53%	54%	56%	p=.72	**p=0.036**	**p=0.001**

COEP%: represents exercises that were completed correctly on the scale of the correctness of exercise performance

**Significant within-group change from T1 measured by signed-rank test*

*** Significant within-group change from T2 measured by signed-rank test*

p-value represents between-group differences compared using Mann-Whitney U test:

T1: the difference between groups at 1st week

T2: the difference between groups at 4th week

T3: the difference between groups at 8th week

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Chapter 4: Tele-coaching may improve physical activity and quality of life after 8-week home-exercise delivered through telerehabilitation in adolescents with spastic cerebral palsy

Abstract

Background: Adolescents with spastic cerebral palsy (CP) are physically inactive and often present a poor quality of life. Telerehabilitation delivery of home exercise programs (HEP) may promote exercise and provide interactive tele-coaching to further improve exercise performance and quality of life. In this pilot study, we evaluated the changes in physical activity level and enjoyment, and quality of life after an 8-week goal-directed HEP implemented through Telerehabilitation with or without tele-coaching in adolescents with spastic CP. **Methods:** Twenty-one participants with Gross Motor Function Classification System (GMFCS) I-III spastic CP were recruited and randomly allocated to an experimental group (EG) receiving 8 weeks of individualized goal-directed HEP with tele-coaching, or control group (CG) with individualized goal-directed HEP without tele-coaching. All participants were evaluated at baseline and end-intervention using: the Physical Activity Questionnaire for Adolescents (PAQ-A) for physical activity level, the Physical Activity and Enjoyment Scale (PACES) for the enjoyment of physical activity, and the Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen) for quality of life. **Results:** Twenty participants completed the end-intervention evaluations. Both groups showed significant changes from baseline to end-intervention evaluations in PAQ-A scores (EG: 0.4, $p<0.001$; CG: 0.16, $p<0.05$), PACES scores (EG: 0.33, $p<0.001$; CG: 0.33, $p<0.05$), and QOL scores (EG: 3.8, $p<0.001$; CG: 1.7, $p<0.001$). The EG group showed significantly higher mean-differences in PAQ-A (0.24, $p<0.05$) and QOL score (2.1, $p<0.001$) compared to the CG group. **Conclusions:** The results of our pilot RCT indicated that an individualized goal-directed home exercise program with tele-coaching could result in better improvement in physical activity level and quality of life in adolescents with spastic CP.

4.1. Introduction

Cerebral palsy (CP) is a condition of permanent disorder of movement and posture control, causing activity limitations caused by non-progressive disturbances to the fetal or infant brain. The most common type of cerebral palsy (CP) is spastic CP which represents around 82% of all types of CP, and approximately 90% of CP children survive into adulthood. Adolescents and young adults with CP often experience musculoskeletal pain or other problems, loss of function, reduced level of everyday physical activity due to reduced level of gross motor function.[1-3] Adolescents are recommended to be physically active at least 60 minutes per day with diversified exercise and leisure activities.[4] However, studies have shown that adolescents with CP are less physically active participating in 13% to 53% fewer exercise programs compared to normally developed peers, and have a higher tendency for a sedentary lifestyle.[4-7] Adolescents with CP usually experience a poor quality of life because of poor motor function, musculoskeletal contractures, increased body weight, and sedentary lifestyle or physical inactivity.[8-12] Improving physical activity, participation, and quality of life is essential for adolescents with CP since most of the benefits and the improved behaviors during this transitional age will be translated and persist during adulthood.[3,13] Therefore, many interventional approaches have been developed including telerehabilitation for this population.

Telerehabilitation may improve the current home exercise program (HEP) in adolescents with CP, but more clinical research is needed. Past studies have reported that adolescents with CP encountered multiple barriers influencing their participation in exercise or physical activities, including personal, social, environmental, and program-related barriers.[14,15] The most important personal barriers are the lack of physical and social skills, lack of knowledge on benefits of exercise, and lack of instant feedback about exercise performance and closer supervision.[15] The two major environmental barriers are inadequate and inaccessible facilities and a lack of available transportation.[15] Telerehabilitation holds many advantages, including high accessibility regardless of physical location, accessibility 24 hours a day, interactivity, and ability to modify information easily that may help to address the aforementioned exercise barriers. Goal-directed home exercise delivered through telerehabilitation has shown the enhancement of function, activity, and participation.[16,17] There have been a few studies reported mixed results of telerehabilitation in adolescents with CP, but no study utilized interactive tele-coaching in the intervention.[18-21]Past studies have shown clearly that HEP in children with CP faces a challenge of poor adherence as a result of supervision cessation and lack of interaction between therapist and patients.[20,21] On the other hand, studies that utilized the interactive tele-coaching in people with other type of disabilities have shown significant improvements in physical activity and quality of life.[22-24] We expected that the addition of tele-coaching component to goal-directed HEP might provide the required interaction and supervision to HEP and improve outcomes in adolescents with CP while without a significant increase in the cost.

Here we report the trend of changes observed in this pilot study after the 8-week goal-directed HEP delivered through a telerehabilitation platform with or without tele-coaching in the physical activity level, physical enjoyment, and quality of life in adolescents with spastic CP.

4.2. Materials and methods

4.2.1. Study design and participants

This pilot study used a randomized clinical trial (RCT) design. Participants in this study were children with spastic CP living in the USA who were with Gross Motor Functional

Classification System (GMFCS) I-III,[25] aged 11 to 18 years old, having a stable health status for 6 weeks before the screening, with approval from caregivers/guardians for participating in this study, having access to the internet at home and access to the exercise's website/app via PC or mobile app, being able to understand and follow verbal commands in English. We excluded individuals who had reported unstable medical condition during the past 6 weeks, had other neurological disorders that may cause further decline in balance and walking abilities (e.g. head injury, vestibular dysfunction, or spinal cord injury), or any musculoskeletal condition that would interfere with the safe performance of the exercise intervention or testing protocol, and who had been scheduled surgical operations or castings during the study period. To reduce the heterogeneity of our sample, we limited our participants to children with spastic CP because it represents around 82% of all CP types.[26] The age range of our participants was based on the definition of adolescence by WHO and the American Academy of Pediatrics.[27]

Participants were recruited through physical therapists working in school districts, hospitals, and private clinics, flyers, Facebook posting, and Frontiers/ Pioneers Research Participant Registries using the Healthcare Enterprise Repository for Ontological Narration (HERON) database at the University of Kansas Medical Center (KUMC). Prior to their participation in this study, they received detailed information about the study and signed an informed consent approved by the KUMC institutional review board (IRB).

4.2.2. Randomization procedure

After the informed consent, the participants were randomly assigned to an experimental group (with tele-coaching) or a control group (without tele-coaching) at a 1:1 ratio. In the procedure of participant assignment, we first used the age of participants to stratify them into (10-

12), (13-15), and (16-18) years-old categories,[28,29] and then randomized participants to either with tele-coaching or without tele-coaching group using a computer-generated random list. The reason that we chose age as a stratifying factor is that the motor function as measured by functional GMFCS is correlated with age. Specifically, the proportion of children walking independently on uneven surfaces was incrementally higher in each age group up to 18 years.[30]

4.2.3. Assessment timeline and outcome measures

Before the interventional HEP, a study physical therapist (PT) had two baseline video conference meetings via the Physitrack platform with each participant and caregivers/guardians. In the first baseline meeting, the study PT collected data of demographics and medical history of the participant, explained the procedures of using the telehealth platform, and conducted any troubleshooting needed.

The second baseline meeting was a semi-structured videoconference interview with participants/caregivers to determine up to 5 goals/problems of importance to be focused on in our exercise intervention. We used the adapted version of the Canadian occupational performance measure (COPM) during this meeting to determine the important goals and to scale its performance and satisfaction scores.

Participants were also asked to complete the following questionnaires: (1) The Physical Activity Questionnaire for Adolescents (PAQ-A) version was used to evaluate physical activity level. The PAQ-A is a self-administered, 7-day recall instrument. It was developed to assess general levels of physical activity in school students between 8-19 years old. It has 8 items, and each item is ranked on a 5-point scale.[31] (2) The Physical Activity and Enjoyment Scale (PACES) utilized to evaluate the enjoyment in physical activity of the participants. This questionnaire consists of 16 statements that are scored on a five-point rating scale (1 = disagree a lot, 5 = agree a lot).[32] (3) Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen) was utilized to evaluate the quality of life. CP QOL-Teen has recently been developed for adolescents. It assesses different domains, including general well-being and participation, Communication and physical health, School well-being, Social well-being, and Feelings about Functioning.[33]

The same questionnaires were completed again by participants after the 8-week intervention period. The data collected at baseline and end-intervention allowed the researchers to examine changes in outcome measurements between two times points and between two groups.

4.2.4. Telerehabilitation platform used in our interventions

Physitrak is a commercial exercise website (https://www.physitrack.com) or app (android/IOS) with HIPAA compliance. It provides exercise therapists access to 3500 videos of the exercise library with an option to upload self-made videos and customize existing videos. Those videos include audio instruction and subtitles. Physitrack allows therapists to set exercises on a weekly calendar and assign each exercise session daily or on specific days of the week. Therapists can also customize the number of repetitions, frequency, and duration of each exercise component. Physitrack also provides an encrypted video-conferencing feature so that the therapists can coach patients/caregivers either by the demonstration of specific exercise components or instruction of the correct performance sequence. In addition, the option of recording and saving the exercise sessions onto the therapist's computer allows therapists to revisit the sessions recorded and rate the performance. Patients can log in to Physitrack via computer, tablet, or smartphone. The system will enable patients to print the exercise program and review their performance in the exercise program. Patients can interact with therapists via an encrypted messaging feature. Patients can also rate their pain or discomfort after each exercise.

4.2.5. The 8-week HEP

The individualized goals of the exercise program and other relevant information obtained from the second initial meeting were used by the researchers to develop an exercise package of the 8-week HEP for the participant. Our exercise program included various exercise components for gross motor function, functional tasks, lower limb strength, balance, upper limb function, stretching, leisure or sport-based, game-based exercises, and ADL tasks. All exercise components selected and included in the final package were to achieve the individualized goals of the participant. For example, for the goal of improving basketball play skills, the exercise would include bending down and jump up to shoot the basketball.

4.2.5.1. Intervention for the control group (without tele-coaching)

The participants in both groups received an exercise package of HEP delivered via Physitrack for 8 weeks with 3 sessions a week for 30-60 minutes each session. For participants in the control group (without tele-coaching), all three weekly exercise sessions were self-monitored without any interaction with the therapist. Participants in the control group received exercise videos via Physitrack. They were asked to follow an actor in the videos as he/she performed the prescribed exercises. The exercise program was adjusted weekly as needed based on the participant’s progress as measured by performance and feedback of pain and discomfort reported in Physitrack. The adjustment was mainly made for sets, repetitions, and duration of exercises. Furthermore, the position of the exercise, instruction, and sometimes the type of exercise was changed if participants reported severe pain or they reported that exercise was too hard.

4.2.5.2. Intervention for the experimental group (with tele-coaching)

For the experimental group, the first 2 sessions within a week were self-monitored and the third session was a tele-coaching session (30- 60 minutes real-time coaching) using the video conferencing feature of Physitrack. The participants were asked to perform the prescribed exercise during the tele-coaching session while the study PT observed the participant's performance. The purpose of this session was to deliver performance feedback, including (a) positive feedback for the correct performance, (b) corrective feedback for incorrect performance, and (c) assurance of understanding of corrective feedback by asking questions or asking the participant to repeat the corrective feedback. In addition, the study PT trained caregivers/guardians to help in delivering specific exercises to participants.

4.3. Data and Statistical Analysis

Data entry was performed using Microsoft Office Excel 16 for Windows 10, with ongoing data monitoring and organization. Windows SPSS Statistics 26, 2020 version was used to perform all statistical analyses.[34] Considering that it is a pilot study and a relatively small sample size, the significance level was set at $\alpha = 0.10$, upon the suggestion by our statistician.

Descriptive statistics were used to calculate participant demographic, social, and clinical characteristics of participants in the intervention and control groups. The differences between pre-test and post-test scores within each group were analyzed using a paired t-test. Groups were compared by independent t-test to detect the significant difference between groups. We used Pearson correlation analysis to examine the correlational relationship among the measured outcome variables of COPM, adherence rates, PAQ-A, PACES, and QOL.

4.4. Results

Twenty-one (9 males, 12 females) participants were recruited and randomized to an experimental (n=11) or control (n=10) group (see recruitment details in Figure 2.1 Chapter 2). Twenty subjects completed the 8-week intervention and post-assessments. Baseline demographic, social, and clinical characteristics are presented in Table 2.1 in Chapter 2. All baseline characteristics were similar between the two groups.

The most common goals related to physical activity and daily life were in the play/school domain (e.g., playing sports, throwing, climbing, and running, formal games) selected by 7 participants in the experimental group and 6 participants in the control group. In the active recreation domain, most goals of going to the movie, taking care of pets, and going the park or beach were selected by 6 participants in each group. The most common goal in socialization was visiting friends and family houses, selected by 6 participants in the experimental group and 5 participants in the control group.

The results of adherence rates and other feasibility measurements, COPM performance, and satisfaction have been reported elsewhere (see Chapters 2 and 3, respectively). In this report, we will present the results of correlational analysis between each of PAQ-A, CP-QOL, PACES, and COPM outcomes.

There were no significant differences between the two groups in baseline scores of PAQ-A, PACES, and CP-QOL (Table 4.1). There were significant changes in post-intervention scores of PAQ-A ($p<0.001$), PACES ($p<0.001$), overall CP-QOL ($p<0.001$), general wellbeing ($p<0.001$), communication ($p<0.001$), school wellbeing ($p<0.10$), and social wellbeing ($p<0.05$), and feeling about function ($p<0.001$), respectively, compared to baseline scores in the experimental group. The control group has shown significant changes in post-intervention scores PAQ-A ($p<0.05$), PACES ($p<0.05$), overall CP-QOL ($p<0.001$), general wellbeing ($p<.001$), communication ($p=.001$), and feeling about function ($p<0.001$), respectively.

The experimental group showed a significantly greater change in PAQ-A score by 0.24 ($p<0.05$), overall CP-QOL score by 2.11 ($p<0.001$), general wellbeing score by 3.1 ($p<0.05$), communication score by 2.4 ($p<0.05$) and feeling about function score by 4 ($p<0.001$), but not in PACES, social wellbeing, or school wellbeing.

The correlational analysis revealed that the change in PAQ-A was significantly correlated with change in overall CP-QOL ($r=0.63$, $p<0.05$), change in COPM-performance ($r=0.48$, $p<0.05$), and change in COPM-satisfaction ($r=0.51$, $p<0.05$). The change in overall CP-QOL score was significantly correlated with adherence rate ($r=0.656$, $p<0.05$), change in COPM-performance ($r=0.695$, $p<0.001$), and change in COPM-satisfaction ($r=0.7$, $p<0.001$).

4.5. Discussion

This pilot RCT is the first study to utilize the telerehabilitation platform to deliver an individualized home exercise program with tele-coaching in adolescents with spastic CP. The results of this study are promising for the use of telerehabilitation plus tele-coaching in a home exercise program in adolescents with CP, as shown in the improvement in physical activity level and quality of life.

Both groups showed a significant improvement from the baseline evaluation in PAQ-A, PACES, and overall CP-QOL scores. The improved PAQ-A (2.47) in the experimental group approached normal values of typically developing adolescents (≥2.9 for boys and ≥2.7 for girls).[35] The improvement in physical activity and quality of life in the control group agreed with the similar results reported in past studies.[18,36] However, Mitchell et al. (2017) and Baque et al. (2017) observed no significant differences in activity performance compared to the usual care group in children with CP who received a web-based intervention.[19,20] The mixed results in the literature could be attributed to different characteristics of study participants and variation in outcome measures.

The further improvements in the experimental group are in the same line with findings from previous studies that reported additional benefits of adding tele-coaching in telerehabilitation programs in children or adults with various types of disabilities.[24,37-39] For example, Lai et al. (2018) observed more remarkable improvement in physical activity in the adult with Parkinson's disease who exercised under tele-coaching supervision compared to self-managed exercise through online resources.[40] Furthermore, our data showed that the increases in COPM scores were significant correlated with changes in physical activity levels and changes in quality of life measurement. Those connections highlight the effectiveness of goal-directed HEP in improving functional performance, physical activity, and quality of life.

The add-on benefits of tele-coaching in multiple measurements of physical activity and quality of life could be attributed to different causes. The tele-coaching group had weekly interaction with the study therapist, who provided motivation and correction of performance to help participants to improve functional performance, which might improve in getting around from place to place or around the neighborhood and hanging out with friends. Furthermore, supervision and motivation provided by the therapist might increase the engagement in exercise, getting along with adults, and communication about their physical health, and improve their plans for the future. Furthermore, the weekly interaction might help participants to increase their positive attitude and confidence on themselves and their abilities to participate in sport, social, or community events.[41]

The non-significant difference between the two groups in school wellbeing and social wellbeing domains of quality of life could be partially because our participants were close at their ceiling values in both groups. Furthermore, the COVID-19 pandemic could impact our findings due to changes in school setting (in-person vs Online vs Hybrid) and work from home for most caregivers, which might alter the support provided by teachers, school therapists or caregivers, and limit the interaction of our participants with teachers, other students, and school staff.[42] Our results showed a quite large mean differences between groups in PACES, school well-being, and social well-being outcome measures, however, the differences were not statistically significant. The issue in the present pilot study could be attributed to the low statistical power for those variables. Our post-hoc power analyses showed a statistical power of 29.8% for PACES, 6.3% for social well-being, and 3% for school well-being. Future studies with a larger sample size are suggested to improve the statistical power.

No significant difference between the two groups in PACES could be attributed to moderately high levels of exercise enjoyment among both groups at the start and end of the intervention. It appears that participants in both groups started the trial already having a positive attitude toward exercise, and the HEPs for either group did not cause a change in this existing state.[43] Future studies may include outcome assessment with more enjoyment elements, such as competitions and feeling of reward.[44,45]

This pilot study had some limitations. The small sample size and limited age range may limit the generalization of our findings. It was impossible to blind our participants from their intervention allocation or blind our researchers. We did not include objective outcome measures of physical activity, which may provide a better explanation of differences between the two groups. We did not collect data about variations in physical or occupational therapy provided to our participants during the study period. Furthermore, we did not control for school settings between groups. Different school settings, such as in-person or online settings, might influence the physical activities, social interaction, communication, and school wellbeing of our participants.

4.6. Conclusion

Our pilot RCT study suggests that using Physitrack to prescribe individualized HEP and to provide tele-coaching sessions for children with spastic CP could result in better improvement in physical activity and quality of life compared to self-monitored HEP. Our study is the first to investigate outcomes of additional tele-coaching in physical activity and quality of life in adolescents with spastic CP. Further research with large sample size is required to confirm our pilot findings.

Table 4.1: Physical activity level (PAQ-A) and enjoyment (PACES) and quality of life (CP-QOL) outcomes measured at baseline and post-intervention evaluations.

	Experimental group (n=10) Mean (SD)		**Control group (n=10) Mean (SD)**		**Between groups difference**	***p*-value**
	Pre	**Post**	**Pre**	**Post**		
PAQ-A	2.06 (.55)	2.47 (.62) *	2.04 (.48)	2.20(.54) *	0.24	***p*=.002**
PACES	2.97 (.26)	3.30 (.39) *	2.73 (.31)	3.06 (.36) *	0.006	*p*=.956
CP-QOL						
Overall score	56.8 (6.0)	60.7 (5.9) *	54.9 (8.5)	56.7 (8.2) *	2.1	***p*<.001**
General wellbeing	58.6 (13.4)	64.6 (13.3) *	55.8 (13.3)	58.7 (12.75) *	3.1	***p*=.02**
Communication	60.7 (10.9)	65.7 (11.5) *	57.4 (14.7)	59.9 (14.5) *	2.4	***p*=.002**
School wellbeing	52.3 (9.5)	53.03 (9.08) *	52.5 (9.7)	53.2 (9.6)	0.08	*p*=.919
Social wellbeing	60.7 (12.1)	62.6 (11.9) *	59.4 (15.1)	60.1 (13.9)	1.3	*p*=.186
Feeling about function	56.7 (10.6)	62.2 (11.2) *	55.4 (10.3)	57.0 (10.2) *	3.9	***p*<.001**

**Significant within-group change from baseline measured by paired t-test.*

p-value represents between-group differences compared using independent t-test.

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Chapter 5: Discussion and Conclusion

5.1 Summary of findings

This dissertation project investigated the feasibility and trend of outcomes of an 8-week individualized home exercise program with tele-coaching delivered through a telerehabilitation platform. This is the first study to examine the impact of tele-coaching in promoting adherence to HEP and improving functional performance, physical activity, and quality of life in adolescents with cerebral palsy (CP). We found that participants in our experimental group who received tele-coaching reported significantly higher adherence rates and greater improvements in COPM performance and satisfaction, physical activity, and quality of life in comparison to a control group with the same HEP but no tele-coaching. Furthermore, our secondary outcome of correctness of exercise performance showed a greater improvement in the tele-coaching group than the control group. This work provides insight into the importance of tele-coaching that provides ongoing feedback and correction of performance to adolescents with CP.

In chapter one, we described the definition, classification, primary and secondary complications of the condition of CP, focusing on the decline in motor function and physical activity. We further elaborated health-related issues in patients with CP during adolescence age. We then introduced the current evidence on adolescents' adherence to therapeutic interventions and the barriers that impact adherence and compliance. We reviewed home exercise programs (HEP) for adolescents with CP in general, and specifically the HEPs that utilized telehealth technology, including types of telehealth technologies. Finally, we explained the significance of this dissertation project and listed specific aims and hypotheses.

In chapter two, we reported results of our pilot randomized clinical trial on the feasibility, including adherence rate of an 8-week HEP using telerehabilitation technology to deliver an individualized HEP with or without tele-coaching sessions in adolescents with

Spastic CP. In this pilot trial, twenty participants with Gross Motor Function Classification System (GMFCS) I-III spastic CP were recruited and randomly allocated to an experimental group or a control group. The experimental group received 8 weeks of individualized HEP with 30-60 minutes per exercise session, three sessions in each week. The last exercise session within each week was a tele-coaching exercise session. The control group receiving the same 8 weeks of individualized HEP without tele-coaching. The experimental group showed a significantly higher rate of completed sessions ($p<0.001$), completed exercises ($p<0.05$) and completed repetitions ($p<0.05$) compared to the control group. The experimental group also showed a significantly higher acceptance rate for the exercise program and use of Physitrack (M= 6.6, SD=0.33) compared to the control group (M= 5.28, SD=0.77) ($p<0.05$). Our pilot study suggests the use of telerehabilitation to prescribe HEP with addition of tele-coaching for adolescents with spastic CP could further improve adherence rates.

In chapter 3, we reported the results of our pilot trial in occupational performance and satisfaction measured by COPM and quality of exercise performance measured by COEP. The experimental group showed significantly higher mean-differences in Performance score (0.82, $p<0.001$) and Satisfaction score (0.76, $p<0.001$) compared to the control group. Four participants in the experimental group showed a clinically meaningful change in COPM scores, while only one subject showed it in the control group. The experimental group showed a significantly higher percentage of exercise completed correctly and scored “1” on COEP at 4^{th} week ($p<0.05$) and at the end of 8-week ($p<0.001$) compared to the control group. Our pilot RCT suggests that the individualized home exercise program with tele-coaching could result in further improvement in reaching the individualized goals and in quality of exercise performance in adolescents with spastic CP.

In chapter 4, we reported the results of our pilot trial in physical activity level, physical activity enjoyment, and quality of life. Both groups showed significant changes in PAQ-A scores from baseline to end of the intervention. The experimental group showed significantly higher mean-differences in PAQ-A (0.24, $p<0.05$) and QOL (2.1, $p<0.001$) compared to the control group. Our pilot RCT suggests that an individualized goal-directed home exercise program with tele-coaching could result in better improvement in physical activity level and quality of life in adolescents with spastic CP.

5.2 Lessons learned from this project and knowledge sharing

The use of telehealth in-home exercises may increase adherence and effectiveness of home exercise programs. Throughout the current project, we have learned some lessons and accumulated some experience on the topic, as summarized in the following. Those experiences and lessons may help people in the field to further develop clinical guidelines for using tele-health techniques to implement home exercise programs in people with various health conditions. Following a structured guideline for coaching sessions was essential to ensure the consistency of feedback and instructions provided to participants. Furthermore, mediation of the instructions through caregivers for younger or more disabled participants could help significantly in reaching the goals of specific exercises. , The utilization of small number of exercises within each coaching session, could also help participants feeling confident in carrying out the exercise safely and incorporating activities or exercises into the daily routine of family and child and help to increase exercise enjoyment and engagement.

The therapist, caregivers, and participants should ensure enough space to conduct the intervention at home, besides the availability of equipment and tools for exercise programs. The therapist should emphasize the importance of the presence of parents during exercise sessions to ensure safety and help participants be more engaged in the exercise program.

It is important to familiarize caregivers and participants with telehealth platform and technology troubleshooting, especially at the beginning of the intervention. High-quality video and audio are important tools for the correct delivery of instructions and feedback and to increase engagement in telehealth programs. In the current project, our team members made a significant effort to learn and familiarize themselves with the technology. It is worthwhile to mention that in the present study, technical issues did not necessitate the cancelation of any exercise session.

We observed that using telehealth platforms was sufficient for conducting the semi-structured interview with caregivers and participants to set up goals of the intervention. Keeping the exercise area quiet with minimal distraction could help to increase the focus of participants and improve their interaction with therapists and caregivers. Furthermore, the presence of parents/caregivers to mediate instructions was important to keep participants engaged. In selecting exercises for individualized goals, we targeted either task-specific training or training for gloss motor function and were successful in helping our participants to improve their exercise performance and satisfaction. We started with a small number of exercises and gradually increased the exercise intensity to help participants to be more engaged with confident. During tele-coaching therapist could also address issues directly or indirectly related to the cognitive and behavioral aspects of participants by motivating, building trust bonds, and being aware of their interests, orientations, and cultures.

The experiences as mentioned earlier, may help clinicians in their early attempt to utilize telehealth technology to deliver their rehabilitation service to their patients. Those experiences may help clinicians to adapt our approaches to their practice, especially during particular time periods such as the COVID-19 pandemic, when only essential face-to-face visits are allowed. We were contacted, during the COVID-19 pandemic shut down between March and July 2020, by physical therapists who wanted to implement telerehabilitation in their clinic for children with disabilities. We offered them consultation, which helped them to utilize our platform and adapt our intervention to their patients. It is also important to share our experience from this project with individuals with CP and families to provide them with a better understanding of technology-based intervention.

5.3 Limitations

A small sample size with only teenagers spastic CP may limit the results to be generalized to other types of CP or different age ranges. It was impossible to blind the participants to the intervention's allocation, and it was impossible to blind the examiner to participants' allocation due to the shortage of research staff in this pilot study.

We did not collect data about variations in physical or occupational therapy provided to our participants during the study period. Furthermore, we did not control for school settings between groups. Different school setting, such as in-person or online settings, might influence the physical activities, social interaction, communication, and school wellbeing of our participants. Moreover, we did not systematically document the needed assistance from caregivers in tele-coaching sessions, in posture alignment, delivery of exercises, and in the motivation of participants, which could influence participants' performance and response to the therapist's feedback.

We did not control for potential influences of important covariates, including Gross Motor Functional Classification System (GMFCS) levels, age, gender, BMI, ethnicity, and medications. We did not have a long-term follow-up assessment to investigate the long-term effect of our intervention.

We did not include any objective measures of physical activity or other outcome measures related to gross motor function, which may limit our ability to explain the differences between the two groups.

5.4 Future directions

A randomized controlled trial with blinded assessors and a long-term follow-up assessment is needed to investigate the effectiveness of individualized HEP with tele-coaching. Furthermore, future trials are required in order to examine the feasibility of tele-assessment of gross motor function mediated by caregivers and to examine of reliability of virtual assessment tools such as virtual goniometers in children and adolescents with CP. Replication of this study for children with other disabilities may help expand the knowledge about the feasibility and effectiveness of tele-coaching.

Future trials may examine the use of telerehabilitation programs for non-English speakers by designing a platform including different language options. Developing a telehealth app with the incorporation of games or rewards may also help to increase enjoyment of the physical activity.

Future trials may need to examine the influence of covariates, including age, gender, ethnicity, and medications. Furthermore, future studies may examine the feasibility of using a telerehabilitation platform to deliver interventions combining cognitive-behavioral therapy and exercise programs and to investigate the interaction between 2 therapies among adolescents with CP. Future studies may include additional outcome measures such as gross motor function measure (GMFM), sleep quality and pain, and objective measures of physical activity such as Active-pal accelerometer or motion sensors. It would be interesting to examine whether tele-coaching could affect those measurements in adolescents with CP.

5.5 Conclusion

The findings of this dissertation project have proven the feasibility and acceptance of using a telerehabilitation platform to deliver tele-coaching among adolescents with spastic CP. Furthermore, promising results showed in adherence rate, occupational performance, physical activity, and quality of life in adolescents with spastic CP after the 8-week individualized HEP with tele-coaching compared to the same HEP without tele-coaching. Future studies may utilize the data from this pilot project to design large-scale randomized control trials to understand better the effectiveness of tele-coaching on function, physical activity, and quality of life in adolescents with CP. Future studies could also utilize other relevant outcome measures related to gross motor function, sleep quality, and pain to detect the effectiveness of tele-coaching. Future studies may use different intervention duration/frequency as well. Future studies are needed to create a guideline for tele-coaching in HEP with different age ranges, disability levels and to incorporate different durations and frequency of exercises.