Factors Affecting Lifelong Participation in Physical Activity for Adults with Cerebral Palsy

by

Larken R. Marra

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Doctoral Committee:

Associate Professor Susan H. Brown, Co-Chair
Professor Emeritus Dale A. Ulrich, Co-Chair
Associate Professor Min-Hui Huang
Professor Edward A. Hurvitz
Associate Professor Mark Peterson

Larken R. Marra

lrmarra@umich.edu

ORCID iD: 0000-0001-5177-3546

Dedication

This dissertation is dedicated to my father. A man who has shown me nothing but love and support throughout a journey he didn’t fully understand. Thank you for everything you have given me over the years, the warm embraces, the sound advice, and often, a swift kick in the butt. This is for you, Big R.

I further dedicate this dissertation to my mother in heaven. I hope that I have made you proud.

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Abstract

Cerebral palsy (CP) is a non-progressive disorder caused by trauma to or malformation of the developing brain which leads to limitations in motor planning, posture, perception, and sensation. Due to the pediatric onset of CP, much of the current research focuses on childhood outcomes even though 90% of children with CP age into adulthood with life expectancies similar to that of the general population. It is well established that adults with CP experience several barriers to lifelong participation in physical activity (PA) and many of these barriers are related to physical limitations. An understanding of the factors that keep adults with CP from remaining physically active throughout the course of their lives is still largely unknown. The purpose of this dissertation is to obtain a better understanding of these factors and how they may affect the lifelong participation in PA among adults with CP.

The first study examined how attitudes and experiences with lifelong PA opportunities affected adult PA trajectory. Participants (n= 68) were categorized according to age (young, middle, or older adults). A new survey was created and validated that asked adults with CP to recall their experiences with PA at different developmental stages of life. Additionally, they were asked to reflect on how those experiences affected their current levels of physical activity. Participants also engaged in a semi-structured recall interview that focused on type and intensity of activity completed over three days. All surveys and interviews were conducted via teleconferencing software. Regardless of age, adults with CP had relatively positive attitudes towards past experiences with PA. However, positive attitudes towards PA were negatively correlated with time spent in moderate activities of daily living. These findings suggest that the

PA opportunities offered to individuals with CP are sufficient to create positive associations with PA but may require additional effort to impact PA trajectory.

The second study examined the factors that may facilitate ongoing participation in PA. Surveys of pain, quality of life, self-perception and independence were administered concurrently with the survey and interview conducted in study one. The current level of activity that was determined using the semi-structured interviews was used again in this study. Factor domain contributions of self-perception and pain were strongly associated with activities of high perceived exertion, whether it was required tasks of daily living or self-selected leisure activities. Self-perception of athletic ability, pain severity, affective distress, and pain associated with general activities were significant predictors of time spent in leisure activities.

The final study addressed the need to enhance the healthcare reach for adults with CP. This study tested the feasibility of assessing physical function, encompassing mobility, functional leg strength, balance, sensory integration, and gait speed, using a telehealth approach. From the original sample, twenty participants were randomly selected to take part in this study. Most participants were able to complete the assessments, demonstrating the feasibility of using a telehealth model to monitor physical function in adults with CP.

Collectively, these findings illustrate the importance of continuous monitoring of adults with CP to maintain function. Adults with CP have positive attitudes towards lifetime PA but are still less active than the general population. Functional maintenance through telehealth-based assessments may facilitate increased physical and psychological well-being while indirectly increasing lifetime participation in PA.

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Chapter 1 Background

1.1 Physical Activity and Health

The body of evidence supporting the positive associations between physical activity (PA; defined as: *"any body movement that is produced by the contraction of skeletal muscles and that increases energy expenditure"* (Chodzko-Zajko et al., 2009)) and health has been growing exponentially over the last century (Vanhees et al., 2005). Regular participation in PA has been shown to decrease the risk of premature mortality and mitigates the onset and/or effect of cardiovascular disease, hypertension, stroke (Chodzko-Zajko et al., 2009), osteoporosis, Type II diabetes, obesity, cancer, depression (Gremeaux et al., 2012), functional decline, and cognitive function (Lee et al., 2012) while increasing one's emotional and social well-being (Bloemen et al., 2015). Additionally, regular participation in PA has also demonstrated protective effects on the body, including but not limited to reduction in systematic inflammation, reduction body fat mass, and improved muscle mass and strength (Gremeaux et al., 2012; Vanhees et al., 2005). As a result of the work done in this area, and in an effort to increase public awareness, the Center for Disease Control (CDC) and the American College of Sport Medicine (ACSM) released recommendations in 1995 for U.S. adults to "accumulate 30 minutes or more of moderate PA on most, preferably all, days of the week" (Chodzko-Zajko et al., 2009). While the guidelines have been updated in recent years to include specific recommendations for cardiovascular, resistance, balance, and flexibility training, the overall goal of improving health through PA remains the same.

Despite the growing evidence in support of continued PA throughout the lifespan, many Americans fail to meet the minimum PA guidelines and as a result, the United States of America has some of the highest prevalence of obesity, secondary health conditions, and premature mortality within developed countries (Lee et al., 2012; Olshansky et al., 2005; Rimmer et al., 2001). While PA and lifestyle patterns are often discussed for adults, research related to childhood PA has shown that many adult patterns of inactivity are developed in childhood that, in turn, can either positively or negatively impact adult PA trajectories later in life (Robinson et al., 2015). PA trajectory is defined as the level and change in PA over age and time (Nagata et al., 2021).

1.2 Theories of Child Development

The role of childhood PA and its impact on PA trajectory is a widely researched topic in the field of motor development. In the early years of child development, pioneering investigators including Piaget, Geselle, and McGraw speculated that motor development was “hard-wired” within every child and that the acquisition of new skills were “prescriptive”; occurring only after the preceding skill has been mastered (Thelen et al., 1991). For example, children must have head control before sitting, sitting before standing, standing with support before walking, etc.

Work in child development has moved away from a hierarchal model of skill acquisition to one that is more dynamic. Esther Thelen is one of the most recognized researchers in motor development whose work used Dynamic Systems Theory (DST) as a theoretical framework. Known more widely in mathematics and physics as “chaos theory”, this theory states that organisms are viewed as complex, thermodynamic, multi-component systems that spontaneously self-organize into meaningful behaviors or patterns assembled in response to environmental demands. DST supports the notion that the process of motor development is both context-specific (assembled from component systems that are free to re-assemble in functional ways in different contexts) and non-linear, and only through exploration and practice can an organism settle into patterns of behavior that are functional to their needs (Teulier et al., 2015; Thelen et al., 1991). DST and the work done by Thelen, Ulrich, and others supports the idea that early opportunities to explore through tactile stimulation of the surrounding environment leads to greater gains in motor development over time (Johnson, 2010; Teulier et al., 2015; Ulrich, 2010).

The previously mentioned aspects of DST work harmoniously with the model of Perceived Motor Competency (PMC) proposed by David Stodden and colleagues in 2008. While DST discusses the importance of early opportunities to move, Stodden's model presses the importance of "learning to move" as a necessary skill underlying lifelong participation in PA. Early childhood consists of learning fundamental motor skills (FMS) that form the foundation for future physical activity (Haywood & Getchell, n.d.; Stodden et al., 2008). Stodden and colleagues propose that the individual level of competency (high or low) in these motor skills can either encourage or discourage PA levels. Furthermore, the development of motor competency is vital in understanding why individuals choose to be physically active or not (Robinson et al., 2015; Stodden et al., 2014). By combining the fundamental components of DST and PMC, it can be safely assumed that a child who is given more opportunities to move and explore in infancy will have greater gains in motor development than a child who was not afforded the same opportunities. Given these early opportunities to move, the child moves more often and perceives themselves as a competent mover. With high levels of PMC, the child enjoys and engages more in PA early and more often. Developing a child's desire to move and increasing their enjoyment in moving can assist in establishing positive PA patterns early in life that are likely to carry-on into adulthood. While this is a relatively safe assumption for individuals with typical development, individuals with developmental disabilities, like cerebral palsy, face greater challenges when it comes to positive and ongoing opportunities to be physically active throughout the course of their lives.

1.3 Overview of Cerebral Palsy

Cerebral palsy (CP) is the most common pediatric onset physical disability with a U.S. prevalence of 2-3 out of 1,000 live births (Paneth et al., 2006). CP is a non-progressive disorder caused by trauma to or malformation of the developing brain (Ross et al., 2016) which leads to limitations in motor planning (Verschuren et al., 2018), posture (Mezaal et al., 2009), perception and sensation (Haak et al., 2009); including movement related somatosensory feedback (Auld et al., 2012; Goble et al., 2009; Langan et al., 2014). Even with advances in medicine to prevent malformation in utero (i.e., magnesium sulfate for preeclampsia, corticosteroids for inflammation, and early detection and vigorous treatment of infection) (Rogers & Wong, 2018; Usuba et al., 2014) the prevalence of children born with CP has remained stable since the 1970's (Strauss et al., 2007). This is likely due to the risk of CP associated with pre-term, very pre-term, and low birth weight infants that now have improved survival, albeit with disability (Reddihough & Collins, 2003).

CP is classified by the neuroanatomical location of the damage (i.e. basal ganglia, cerebellum, or motor cortex) resulting in neurologic dysfunction (i.e. spastic, hypotonic, athetoid, dystonic, or a combination) and extremity involvement (i.e. monoplegia, diplegia, hemiplegia, quadriplegia, etc.) (Graham et al., 2016; Turk & Fortuna, 2019; Zaffuto-Sforza, 2005). Additionally, a classification system based on disability and functional limitations was created by Palisano and colleagues in 1997 known as the Gross Motor Function Classification System (GMFCS). This classification system allows for comparison and generalizability among this highly heterogenous population. The GMFCS classifies individuals on a scale of I-V, with a GMFCS score of "I" indicating the highest level of gross motor function and independence and "V" indicating no independent mobility (Jahnsen et al., 2007; Palisano et al., 1997; Rosenbaum et al., 2003). While CP is a non-progressive disorder in terms of brain damage severity, gross motor function can decrease significantly with age especially in the absence of continued participation in PA (Palisano et al., 2000). This is why it is important to understand the interaction of multiple domains within a person's life that may optimize or reduce their ability to remain physically active throughout their life (Benner et al., 2019).

As previously mentioned, CP is a heterogenous disability which means that two individuals with the same CP classifications can present with completely different motor patterns and limitations. This problem is well addressed by the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO) (Benner et al., 2019; Frisch & Msall, 2013; Liptak, 2008). Figure 1 depicts the ICF framework which examines the interaction between health condition, environment, and personal factors with body function and structure, activities and participation (Frisch & Msall, 2013; Liptak, 2008). This internationally accepted standard allows for universal language regarding the impact of disability or disease on a person's life (Benner et al., 2019) and is widely used in both research and clinical settings (Liptak, 2008).

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1.4 Physical Activity for Children with Cerebral Palsy

Since CP is a pediatric onset disability, much of the work being done in CP and PA participation focuses on childhood and adolescence (Cremer et al., 2017; Turk, 2009). Early intervention is of the upmost importance when discussing PA for infants who are at risk (i.e. preterm, low birth weight, asphyxia at birth, postnatal meningitis, etc.) (Maitre et al., 2021) or those with an early diagnosis of CP (Graham et al., 2019). As discussed earlier, opportunities for children to move and explore their environment is vital to development, however, the importance of beginning this practice in infancy was not previously mentioned. At this age, these movements and explorations are generated spontaneously, which unlike reflexes, are not initiated by any obvious external stimuli. These movements generally disappear by the age of one, but they play an integral role in the development of mobility (Piek & Carman, 1994). Variations to these general infant movements often depict underlying concerns within the developing nervous system (Kanemaru et al., 2014; Kwong et al., 2018). There are no standardized clinical guidelines for using motor impairment predictions for diagnosis of high risk infants (Marcroft et al., 2015). And yet, the presence of writhing movements at 9-20 weeks post-term versus fidgety yet elegant movements is often a powerful predictor of CP (Kanemaru et al., 2014). This is important for early identification because definitive diagnosis and classification of CP stabilizes after 2 years of age, with most diagnoses happening by 19 months. Withholding early intervention until a medical diagnosis has been given may result in missed opportunities to implement interventions during a time of high infant neural plasticity in which to maximize functional outcomes (Kwong et al., 2018). In addition to early intervention, most individuals with CP will continue in therapy and habilitation for most of their childhood and adolescence.

Clinicians and researchers have switched their focus from “normalizing motor patterns” in children with CP to interventions that help strengthen supporting systems that allow that child to be more mobile, and ultimately, more independent (Rosenbaum & Gorter, 2012). For a given individual there are a number of factors that can be intervened upon, but it is in the best interest of the provider to target the areas that are most functional to the individual (Teulier et al., 2015).

For example, hippotherapy is commonly used to strengthen postural control (Dewar et al., 2015) and general motor function (Park et al., 2014). Further examples of therapeutic interventions that increase motor function include aquatic therapy (Lai et al., 2015) and task-oriented training (Salem & Godwin, 2009). General mobility efficiency and gait speed can be increased using gait and resistance training, and electrical stimulation (Moreau et al., 2016). While most therapeutic interventions are conducted in a clinical setting with adult clinicians, children and adolescents with CP can also benefit from structured physical education (PE) classes and other forms of PA with their peers.

PE can be defined as instruction in physical and motor fitness, fundamental motor skills and patterns, and skills in aquatics, dance, games and sports in either an integrated (general education environment) or self-contained (including only students with disabilities) setting (Haegele & Kirk, 2018). In recent years, educational research for individuals with disabilities has switched focus from objective measures of physical prowess and game-play ability to subjective attitudes towards PE and PA participation (Haegele & Kirk, 2018; Haegele & Sutherland, 2015; Haegele & Zhu, 2017; Lauruschkus et al., 2015; Leo et al., 2018; Li & Chen, 2012; Nyquist et al., 2019; Sienko, 2019).

Lauruschkus et al (2015) reported that students with disabilities enjoyed the sensation of speed that came with activities like running, swimming, dancing, biking, or playing active video games. Students also expressed that they enjoyed “getting tired the fun way”, participating in activities that were engaging to them and allowed them to be competitive or show off to their peers. Lee et al (2018) reported positive affective attitudes towards PA in individuals with disabilities; however, boys generally reported more positive affective attitudes than girls. The thematic analysis of in-depth interviews conducted by Nyquist et al (2019) revealed five main themes in regard to participants subjective experiences with PE and PA. These children enjoyed 1.) the ability to self-select their own activities as opposed to withdrawing from an activity that they are unable to perform; 2.) the feeling of belonging and feeling equal to others; 3.) the sense of joy and fulfillment that came with participating in self-selected activities; 4.) being free from the worries of their disabilities and of not "being good enough"; 5.) finding novel "cool activities" that can be done at home with friends.

Even with a growing compilation of traditional and alternative interventions aimed to meet the motor development needs of children with CP, supplemented by the positive attitudes towards PE classes and other PA opportunities, these children are still less active than their same-aged peers without CP (Shields et al., 2012; Shields & Synnot, 2016; Sienko, 2019). The reasons for low levels of PA participation in children with CP are complex (Shields et al., 2012). The youth in this population have less variety in their recreation and leisure participation and as a result, they spend more time in slower-tempo skilled based activities and sports, or in sedentary recreational activities (Sienko, 2019). Research in this area has shown that children with CP experience a number of barriers to continued PA with the most notable being pain and fatigue (Vogtle et al., 2014).

In children with cerebral palsy, the prevalence of pain ranges from 14 to 76% and is more common in those who are non-ambulatory (79%) (Jersak & Noritz, 2021). The musculoskeletal limitations in CP suggest that pain is the result of the movement disorder itself (Vogtle, 2009), however, pain can occur acutely, recurrently, or chronically (Turk, 2009), and for this reason the true etiology of pain in CP is unclear (Peterson et al., 2021). Fatigue, or the feeling of exhaustion or lacking energy (Opheim et al., 2009), of all types (i.e., mental, physical, etc.) is more prevalent in CP than the general population (Jahnsen, et al., 2007) and is often linked with pain in a perpetual loop. Fatigue incites pain, but pain subsides with PA which is difficult when fatigued (Turk, 2009). This relationship is not well understood (Vogtle, 2009), but the two play a role in the overall deterioration of functional mobility over time (Opheim et al., 2009). Other barriers of continued physical activity for children with CP can be physical (i.e., GMFCS level, low motor skill, etc.)(Bloemen et al., 2015), psychological (i.e., awareness of individual differences, embarrassment, fear, etc.)(Shields & Synnot, 2016) or societal (i.e., lack of professional assistance, lack of adapted equipment, negative societal attitudes, etc.)(Sienko, 2019) and vary by individual (Bloemen et al., 2015; Shields & Synnot, 2016).

1.5 Aging with Cerebral Palsy

While CP is often referred to as a disorder involving only children, 90% of children with CP will age into adulthood (Zaffuto-Sforza, 2005). As a result, there is an increase in the importance of understanding the life course changes associated with CP, including musculoskeletal, cardiorespiratory, and mental health, and the onset of comorbidities (Yi et al., 2019). Moll & Cott (2013) stressed the importance of a life course perspective especially as it relates to preparing individuals with CP to manage their bodies and move in ways that are effective and efficient for participation. In one of the earliest papers examining changes associated with aging with CP, Zaffuto-Sforza (2005) reported on these changes with an emphasis on lifetime care and general aging effects on major bodily systems (i.e., respiratory, endocrine, etc.), while further discussing the medical and social issues unique to adults with CP. Mudge et al (2016) conducted interviews with adults with CP to understand their experiences of aging with CP, primarily their experiences with health services. Furthermore, the ongoing interactions with health care providers to manage these changes have the potential to positively or negatively impact the individual’s experience with healthcare.

The literature regarding the risk of chronic disease and multimorbidity among adults with CP is continuing to grow. Whitney et al (2018a) used an electronic cohort query tool to examine the medical records of hospital patients with CP between the ages of 18 and 30. Of interest was the diagnosis of or family history of musculoskeletal (i.e., osteopenia, osteoporosis, osteoarthritis, etc.), cardiometabolic (i.e., stroke, hypertension, type 2 diabetes, etc.), or pulmonary morbidity (i.e., asthma, pulmonary embolism, etc.). Their findings demonstrate that adults with CP have a higher prevalence of noncommunicable diseases and multimorbidity than the general population. The odds of disease onset increased with very low weight, obesity, and higher levels of motor limitation. These results are similar to others who have used large electronic databases to access medical records and have found a higher prevalence of musculoskeletal and cardiometabolic morbidity among adults with CP (Peterson et al., 2021). In further agreement, Cremer et al (2017) determined that middle-aged adults with CP have a high prevalence of multimorbidity which further increase with higher gross motor classifications (i.e., those who require additional assistance for mobility). Usuba et al (2014) conducted an 8-year longitudinal look at changes in gross motor function by age. Despite the emphasis on habilitation during the transition years from school to community, findings suggested that the biggest change in gross motor function was seen in the late 20’s and 30’s. This is consistent with work that notes changes in functional mobility as young as 35 years (Jahnsen et al., 2004) and demonstrates the array of challenges faced by adults aging with CP.

Several factors lead to the deterioration of motor function in adults with CP, including musculoskeletal structure and morbidity. A review done by Verschuren et al (2018) describes the differences in muscle size and composition of individuals with CP compared to those without CP. They reported that muscle cross-sectional area and accompanying force production is substantially smaller in those with CP (Graham et al., 2016). Furthermore, the mobility limitations associated with the accelerated musculoskeletal aging seen in CP was comparable to the mobility limitations that result from sarcopenia (i.e., age-related loss of muscle mass and strength) experienced by older adults without CP, suggesting that the fluctuation in musculoskeletal health among individuals with CP is a lifelong concern not one limited to adulthood. Whitney et al (2018b) examined the age-related changes in musculoskeletal morbidity in adults with CP. With a sample of over 1000 participants aged 18 years and older, it was determined that adults with CP are at high risk for musculoskeletal multimorbidity regardless of age. These findings were recently confirmed by Thorpe et al (2021) that adults with CP have higher rates of musculoskeletal morbidity than older adults without CP. These authors have also found that adults with CP typically experience varying degrees of osteoarthritis. Finally, in one of the largest cohort studies with a sample of 1,705 participants with CP, O'Connell et al (2019) determined that adults with CP have higher incidence of osteoporosis and osteoarthritis compared to adults without CP. The evidence supporting the prevalence of musculoskeletal morbidity among this population continues to grow, but this is not the only area of concern for adults aging with CP.

Cardiometabolic morbidity among adults with CP boasts additional concern. Peterson et al (2020) found that adults with CP had a higher incidence of all cardiometabolic morbidities as compared to adults without CP. They further determined that these diseases were occurring earlier in life for adults with CP compared to the age-matched control group. Eighty percent of the sample younger than 65 years of age and approximately 40% between the ages of 18 and 44. Earlier work by Peterson et al (2019) also showed a higher incidence of cardiometabolic disease among adults with CP and observed that disease-free survival significantly shortens with an increase in age. It was further demonstrated that the highest rates of cardiometabolic morbidity observed were hypercholesterolemia and hypertension, and these rates were similar to that of the general population. Ryan et al (2014) explored the relationship between physical activity, sedentary behavior, and the risk of cardiometabolic disease among adults with CP. They determined that moderate PA was negatively associated with the number of cardiometabolic risk factors, suggesting that adults with CP were at an increased risk of developing chronic disease due to reduced levels of PA participation. Similarly, Whitney et al (2020) also concluded that middle-aged adults with functional disabilities had a higher prevalence of cardiometabolic morbidity that was more pronounced in those with more physical limitations. While it was determined that this sample had increased prevalence of depressive symptoms and sleep disorders, these secondary issues were independent of the increased cardiometabolic risk factors. A common conclusion from the cardiometabolic morbidity literature is the importance of early and continued monitoring of disease risk for adults with CP as these issues tend to arise earlier than the general population (Peterson et al., 2019; Ryan et al., 2014; Whitney et al., 2020).

Monitoring adults with CP for disease risk should extend beyond musculoskeletal and cardiometabolic concerns to include screenings for psychological risk factors as well due to the high prevalence among this group. In a large retrospective cohort study of 15,000 participants using a national database of private insurance claims, Peterson et al (2021) determined that adults with CP (and spina bifida) had a higher incidence of all psychological morbidities (i.e., insomnia, anxiety, post-traumatic stress disorder, dementia, etc.) than adults without disability. Previous work completed by Smith et al (2019) and Whitney et al (2019) reported that depression and anxiety have higher levels of prevalence and incidence among adults with CP compared to the general population. Fortuna et al (2018) also determined that there is a high prevalence of anxiety and depression among their cohort of 229 adults with CP. Mental health in adults with CP is an area of increased awareness and warrants continued monitoring for a better understanding of how issues in this area may prevent participation in PA. The overall research on aging with CP has increased over the last 15 years, but much remains to be learned about promoting healthy aging for this group using physical activity (Thorpe, 2009).

1.6 Physical Activity for Adults with Cerebral Palsy

It is important to mention again that adults with CP have a normal life expectancy, however, they are overall less active than their same-aged peers without disabilities (Heller et al., 2002; Rimmer et al., 2001; Thorpe, 2009; Turk, 2009; Zaffuto-Sforza, 2005). This is due in large part to the smaller variety of activities designed/adapted for this population as well as the slower tempo at which these activities are performed (Cremer et al., 2017). Additionally, increased rates of sedentary lifestyles lead to increased body fat composition (Thorpe, 2009; Whitney et al., 2018) and decreased lean muscle mass (Ross et al., 2016; Verschuren et al., 2018). This cascading effect of inactivity can lead to declines in mobility, functional status, musculoskeletal changes, and the occurrence of comorbidities such as hypertension and diabetes (Roebroeck et al., 2009; Thorpe, 2009; Turk, 2009).

To combat the negative relationship between physical inactivity and health, Piercy et al (2018) describe the physical activity guidelines for Americans that were established in 2008. It was suggested that adults engage in at least 150 minutes of moderate intensity aerobic activity a week as well as two days of muscle strengthening activities. These guidelines were updated in 2018 to include adults with chronic conditions and disabilities. The new suggestions include at least 150-300 minutes a week of moderate intensity activity or 75-100 minutes of heavy intensity activities a week, or a combination of the two. Additionally, muscle strengthening activities within the moderate-to-heavy intensity for large muscle groups should be done two or more days a week. For those unable to meet these guidelines, it is suggested that they engage in regular PA participation at their level of ability and avoid long bouts of inactivity. Despite established PA guidelines for adults with CP (Verschuren et al., 2016), they remain less physically active than the general population (Ryan et al., 2014; Sienko, 2019).

Adults with CP have expressed their desire to remain physically active as they age (Moll & Cott, 2013; Mudge et al., 2016), and yet similarly to children with CP, they face barriers that can be difficult to overcome. One of the largest barriers for adults with CP is access. Access refers not only to the built environment (buildings, ground around buildings, layout of communities, transportation infrastructure, and parks and trails) (Sallis et al., 2012), but societal attitudes towards disabilities, knowledge of needs for people with disabilities (Heller et al., 2002), and continued healthcare maintenance (Hurvitz et al., 2021; Smith et al., 2021).

Rimmer et al. (2004) conducted focus groups involving individuals with disabilities and professionals from across the U.S. to determine barriers and facilitators to participation in PA. In terms of access to the built environment, individuals with CP and healthcare professionals reported that PA is inherently inaccessible for individuals with disabilities. The lack of accessibility is due to a multitude of reasons including inefficient curb cuts on sidewalks leading to the street, inaccessible sidewalk routes for wheelchairs or other assistive devices, lack of elevators, and lack of space between equipment to allow for wheelchairs. Barriers related to societal attitudes towards disability included feeling self-conscious for the attention being drawn toward disability, and concerns regarding the need and request for assistance. Rimmer et al. (2004) also discussed “knowledge of needs” as a barrier to participation, and this can be in reference to lack of knowledge of the individual with disabilities themselves or the lack of knowledge from fitness and recreational professionals. The largest barriers were seen in lack of adaptive and/or accessible equipment and lack of professional knowledge, education, and training regarding working with individuals with disabilities. PA limitations do to access are still ongoing and have been illustrated again recently (Aviram et al., 2021; Sienko, 2019; Wright et al., 2019). Most of these barriers could be eliminated with additional training by professionals in the field, but some participation limitations are due primarily to the brain damage suffered in infancy.

When considering the concerns related to access to healthcare, Hurvitz et al (2021) discuss a number of ongoing challenges faced by adults with CP. The first factor is a lack of providers who work with the adult population of CP. Adults with CP require complex care that often requires longer appointment times that are difficult to incorporate into schedules already at capacity. Furthermore, there is lack of training in medical school as it pertains to individuals with disabilities. Given that adults with CP represent a specialized clinical population there is little published guidance on how to effectively manage their unique and varied needs. Preventative care used within the general population differs substantially for those aging with CP. Common preventative and monitoring methods such as body mass index, glomerular filtration rate, and bone mineral density are impacted by physiological aspects of CP and may not allow for the accurate interpretation of results. Finally, there is a lack of equitable access for individuals with CP regarding healthcare needs and community factors that may influence the desire to seek out supportive healthcare (i.e., the cost to travel, taking time off work, attaining support staff, etc.). Increased access to healthcare monitoring and maintenance would provide more knowledge about the process of aging with CP while also coordinating care leading to an increase in PA participation and overall quality of life (QOL).

Pain is the most researched and discussed secondary condition that acts as a barrier to continued participation in PA for adults with CP (Roebroeck et al., 2009; Turk, 2009; Yi et al., 2019). Secondary conditions are injuries, impairments, or functional limitations that occur as a result of a primary condition like CP (Gajdosik & Cicirello, 2002). As discussed, the high prevalence and epidemiology of pain in CP is not fully understood, but it can be associated with contractures, orthopedic deformities, weakness, falls, or muscle spasticity (Gajdosik & Cicirello, 2002; Turk, 2009; Yi et al., 2019). Additionally, pain prevalence appears to be similar in adolescence and adulthood which suggests that the presence of pain begins early in life and continues to progress with age (Jersak & Noritz, 2021; van der Slot et al., 2021). Pain in adults with CP is seen predominantly in the lower back, hip, and legs (Roebroeck et al., 2009; Turk, 2009; Zaffuto-Sforza, 2005). Moreover, pain can be defined as either acute, recurrent, or chronic (Gajdosik & Cicirello, 2002; Turk, 2009; Yi et al., 2019; Zaffuto-Sforza, 2005). While there is lack of consensus about the definition of chronic pain, which can make comparison across studies difficult (Roebroeck et al., 2009), it is reported most often with 75% of adults experiencing some form of chronic pain throughout their lives (Yi et al., 2019).

Recently, Peterson et al (2021) differentiated pain subtypes in a sample of over 22,000 participants accessed through a nationwide insurance claims database. They discuss three pain subtypes: nociceptive, neuropathic, and nociplastic pain. Nociceptive pain is pain due to direct tissue damage and is commonly referred to as muscular pain in CP, often because of physical deformities or physical exertion/overuse. Neuropathic pain is pain due to damage to the somatosensory system of the body and peripheral neuropathy is one of the most common examples of neuropathic pain. Finally, nociplastic pain is due to central sensitization, more commonly known as centralized pain or central hyperalgesia, this pain sensation stems from the overamplification of pain processing in the central nervous system. Common examples of nociplastic pain include fibromyalgia, chronic migraine, and irritable bowel syndrome. Peterson and colleagues further determined that 60% of their sample experienced pain of any kind. The results of these findings illustrate the importance of understanding the phenotype of individual pain to provide appropriate treatment and care.

Despite the high prevalence and incidence of pain found amongst those with CP, it has been shown that less than half of this population will seek out medical care to help manage their pain (Liptak, 2008; Zaffuto-Sforza, 2005). PA has been shown to be one of the most common and cost-effective relievers of pain (Schwartz et al., 1999; Turk, 2009). For adults with CP, the literature surrounding aging continues to grow, but there are still large gaps in our understanding of what keeps adults with CP active throughout their lifespan. Implementing a method of longitudinal physical functioning surveillance and maintenance would be beneficial to track a variety of individuals over an extended period.

1.7 Using Telehealth to Increase Access

Adults with CP could benefit from a method of healthcare delivery that increases clinician reach and promotes monitoring of physical function from afar (Robinson et al., 2017). Care for adults with CP utilizes a variety of specialized disciplines (Graham et al., 2019; Kantarcigil et al., 2016). However, access to such specialized care can be difficult especially for those living in rural areas or in lower income communities (Annaswamy et al., 2020). In response to the recent COVID-19 pandemic, non-essential face-to-face care was suspended, leaving many individuals with CP without services. To counter these issues, many providers began using telehealth (Maitre et al., 2021).

Telehealth is the delivery of health care to a patient from a distance using technology (Dorsey et al., 2020). By delivering care remotely, individuals with disabilities like CP can easily access the specialized care they require (Dorsey et al., 2020). For instance, Yeroushalmi et al (2020) found that 31% of patients with multiple sclerosis do not have access to specialized care and yet, after a review of literature they concluded that telehealth provides affordable access to clinical care especially in terms of clinical examinations, longitudinal management and telerehabilitation. The issues of patient location and distance to specialized care are vast and this issue is not faced by adults with CP alone (Rimmer et al., 2013; Sutter et al., 2021; Yeroushalmi et al., 2020). Twenty-five percent of individuals with amyotrophic lateral sclerosis (ALS) live more than 100 miles from their nearest ALS clinic (Howard & Kaufman, 2018). Furthermore, the cost to attend the appointment often exceeds the amount issued by insurance copay (Dorsey et al., 2020). Work done by Dorsey et al. (2020) shows that a 30-minute doctor’s appointment for an individual with Parkinson’s disease could take up to 4 hours between travel, parking, mobility, and wait time. More than anything, telehealth could make care for patients and caregivers more convenient (Kantarcigil et al., 2016).

By utilizing telehealth as a primary mode for delivering healthcare the overhead cost to the providers is reduced by limiting staff and space requirements (Miller et al., 2006), furthermore, telehealth all but eliminates the out-of-pocket cost for the patient in terms of travel and the need for an aide (Howard & Kaufman, 2018). Telehealth delivery also decreases the risk of falls and other accidents (Dorsey et al., 2020) while also decreasing a patient’s exposure to other illnesses (i.e., Covid-19)(Annaswamy et al., 2020).

Providers and patients may be more comfortable using telehealth approaches if they considered the process “new age” house calls. In the 1930’s, physician home-visits accounted for

40% of healthcare delivery, but as a society we have since moved away from that practice, opting instead for more face-to-face care (Dorsey et al., 2020). Dorsey et al. (2020) suggests that these small glimpses into the patients natural setting is a better insight into the individual's true function compared to a controlled clinic environment. Additionally, telehealth reduces power asymmetry among the patient and provider. It increases comfort and convenience for the patient while also increasing patient confidentially by eliminating societal preconceptions of disability.

While many are still wading through the nuances of telehealth others have implemented telehealth delivery with promising outcomes. Kantarcigil et al. (2016) tested the reliability of an asynchronous telehealth delivery of standardized clinical assessments to evaluate dysphagia in children with CP. They found that the asynchronous evaluations had acceptable levels of agreement with face-to-face evaluations and were an acceptable alternative for children with inadequate access to expert swallowing care. Harper et al. (2021) evaluated the use of telehealth as a screening tool for spasticity and compared it to direct patient assessments in a long-term care facility. This study utilized a telepresenter, or someone on the patient's end of the call that can assist with the visit (i.e., give physical assistance, assist with communication in cases of decreased cognition, ask clarifying questions, etc.). In this instance the telepresenters were nurses working in the long-term care facility. After evaluation and agreement by two teleneurologists it was determined that telehealth may be a useful and efficient method of identifying individuals who would benefit from a referral for spasticity evaluation.

When working with infants from the neonatal intensive care unit surveillance of neurodevelopmental risks is crucial. Early and accurate detection of developmental concerns leads to diagnostic assessments. In the wake of Covid-19 restrictions, Maitre et al. (2021) developed a telehealth neurodevelopmental surveillance program for infants at high risk. They discovered that the program provided standardized and timely care to the infants during “shelter in place” orders. The authors believe that broadening telehealth applications will assist in overcoming access barriers in the field of neurodevelopmental surveillance. Graham et al. (2019) published a scoping review of the effects and processes of telehealth wheelchair and seating assessment. Wheelchair assessment is generally complex, costly, and requires input from numerous specialists. It was determined, however, that telewheelchair assessment may be a feasible delivery format especially for follow-up after initial assessment and delivery of wheelchair.

For individuals with disabilities, the rates of obesity are higher than those without disabilities. To target this underrepresented population, Rimmer et al. (2013) designed a 9-month remote, telephone-based weight management program for people with physical disabilities. They determined that a telephone intervention supported by web-based remote coaching was an effective strategy for weight maintenance or body weight reduction among individuals with physical disabilities. As evident by these examples, telehealth has a promising role in healthcare and participation, but like any new approach to services it has its limitations.

A large limitation of telehealth is that it is not generally covered or reimbursed by insurance companies (Yeroushalmi et al., 2020). Furthermore, there are restrictions if the provider is in a different state (Annaswamy et al., 2020), which is one of the most appealing aspects of telehealth for those who live in areas with limited or no availability to doctors (Howard & Kaufman, 2018). This limitation could be mitigated if the U.S. would implement a national telehealth regulatory framework which would allow insurance companies and providers to monitor patients across state lines (Annaswamy et al., 2020).

Another roadblock of telehealth is infrastructure, that is broadband high speed internet access to rural and low economic communities who would likely utilize telehealth most frequently (Annaswamy et al., 2020; Sutter et al., 2021). While internet access has become less of an issue over the last 20 years (Howard & Kaufman, 2018), access still plays role in the disparities of healthcare access and pleads for infrastructure reform (Kantarcigil et al., 2016). Along the lines of access comes interface and communication barriers with telehealth. Annaswamy et al.(2020) note that issues such as lack of document magnification or poor screen contrast can make a telehealth appointment more stress inducing for patients than traditional in=-person visits. They further explain that the Americans with Disabilities Act does not address internet accessibility, so a telehealth platform for those who are blind, deaf, or use augmented assisted communication may not be as efficient as a traditional practice. Finally, for providers, telehealth comes with an inherent risk of "liability for negligence"; this occurs when reasonable care is not provided to the patient. This can come about by something as simple as malfunctioning equipment or if the patient/caregiver does not know how to operate or monitor equipment correctly (Miller et al., 2006). Understandably, this is a foremost barrier to the global adoption of telehealth by practitioners.

1.8 Dissertation Statement of Purpose

An understanding of the factors that keep adults with CP from remaining physically active throughout the course of their lives is still largely unknown. Therefore, the purpose of this dissertation is to obtain a better understanding of the factors in one's life that may affect their lifelong participation in PA. The first two aims utilized remote questionnaires that have been validated to use within this population. Additionally, semi-structured interviews were conducted to determine the current level of PA engagement by the participants. The same participant sample was used for the first two studies. The final aim is a feasibility study to determine if assessing physical function in adults with CP using a telehealth delivery is practical. This sample was comprised of 20 participants randomly selected from the participants of the first two studies.

Presented earlier were the attitudes of children with CP towards their current opportunities to be physically active. Of greater interest, however, is the association between life course experiences with PA and adult PA behaviors. These experiences are not limited to PE, but all forms of PA including therapy (physical or occupational), adapted physical activity, inclusive and competitive sport, and community programs. The only work done in the adult CP population is looking at attitudes towards adult healthcare (Mudge et al., 2016), health and self-efficacy (Becker & Schaller, 1995), and living with and managing a disability (Nieuwenhuijsen et al., 2009). Nothing explicitly asks adults with CP about their attitudes towards previous opportunities to be active. Furthermore, it would be interesting to see if adults with CP can recall PA opportunities with peers and how that may have motivated them to continue to be physically active.

Of additional interest are factors within an individual’s life that may facilitate or hinder their ongoing participation in PA. These factors are within the personal factor’s domain of the ICF. Exploring the relationships between individual factors and their interactions on continued participation in PA may provide clinicians with a prescriptive approach to services based on current levels of PA of their individual patients. Factors that have been known to influence levels of PA were used and include quality of life, self-perception, pain, and functional independence.

And finally, with an ever-growing population of adults aging with CP and a finite number of physicians that work with them, it seems highly beneficial to establish a collection of assessments that measure current levels of physical function in adults with CP using a telehealth model. This would allow physicians to monitor more patients over an extended period with greater ease. Ultimately the goal of this dissertation is to better understand the lived experience of PA participation across the lifespan of individuals aging with CP.

1.8.1 Specific Aims

Aim 1.1: Determine if attitudes towards experiences with lifelong PA differ with age.

Hypothesis: Attitude scores towards lifetime experiences in PA participation for older adults with CP will be significantly lower than the attitude scores of the younger adults with CP.

Aim 1.2: Determine if attitudes towards experiences with lifelong PA affect current levels of PA.

Hypothesis: Positive attitude scores will be related to more time spent in moderate and heavy leisure time PA (LTPA). Negative attitude scores will be related to more time spent in activities of daily living (ADL) versus LTPA, as well as mild intensities.

Aim 2.1: Identify the relationship between ICF domains and the current type and intensity of activity chosen.

Hypothesis: Domains of pain will be associated with low intensities of self-selected LTPA. High scores within the domains of QOL and self-perception will be associated with higher intensities of self-selected LTPA. Functional independence will be associated with high intensities of ADL and moderate-high intensities of self-selected LTPA.

Aim 2.2: Explore which ICF domains have the greatest influence on self-selected types of PA and if that factor is affected by age.

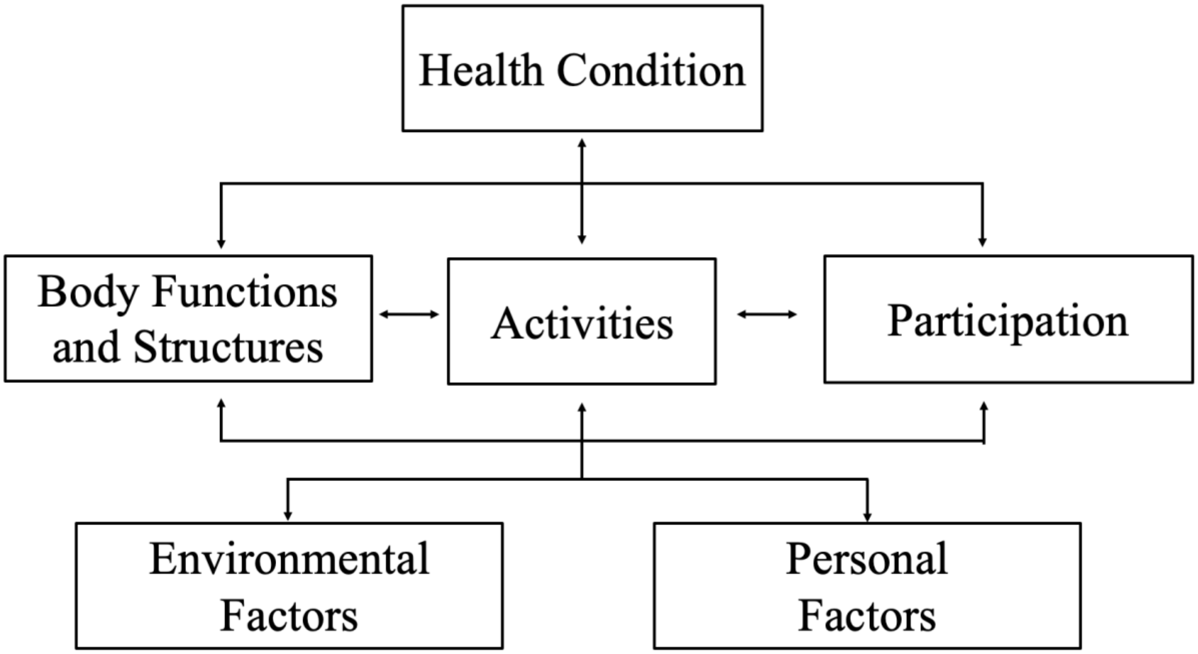
Hypothesis: Domains of pain will be the leading factor affecting self-selected types of LTPA. Independence scores will affect self-selected PA the least.

Aim 3.1: Establish the feasibility of using telehealth to assess physical function remotely.

Hypothesis: Telehealth assessments will be feasible based on the proportion of participants who complete the assessment and do so safety.

1.9 Figure

Figure 1. The International Classification of Functioning, Disability, and Health Framework (World Health Organization, 2001)



Chapter 2 Attitudes and Perceptions Towards Lifetime Physical Activity and the Effect on Current Levels of Physical Activity

2.1 Abstract

Introduction: Childhood is an important period to introduce new types of physical activity (PA) as it is a time where both attitude development and skill development are high; both of which are important for shaping adult PA behaviors. Children with cerebral palsy (CP) may experience more negative opportunities with PA such as early, frequent, and intense therapy sessions, or poorly conceptualized and implemented adapted physical education. While the benefit of continued PA is comprehensive, how past experiences and attitudes with PA shape adult PA behavior for individuals with CP is not well understood.

Methods: Adults with CP who were ambulatory, with or without assisted devices, completed the Assessment of Attitudes Towards Lifetime Physical Activity (AATLPA). This newly created and validated survey asks adults with CP to recall their experiences with PA in different developmental stages of life and reflect on how that may affect their current levels of activity. Participants further participated in a semi-structured interview known as the PARA-Sci which recalls the type, intensity, and frequency of activity done in a three-day period of time.

Results: A total of 68 adults with CP participated in the study and were split into three age groups; younger, middle, and older adults. When looking at attitudes towards lifetime PA opportunities, there was no significant difference in attitude scores among the three age groups, p= .26. Approximately three fourths of the population had between positive and very positive attitudes towards lifetime PA opportunities (72% ≥48). A correlation existed between the age of the participant and their self-assessment of movement quality (r= -.32, p= .02). Finally, Spearman’s rho correlations identified two negative relationships between AATLPA scores, and time spent in moderate ADLs for young adults (r= -0.54, p=.01) and middle adults (r= -0.55, p=.01).

<u>Conclusions:</u> Attitudes towards lifetime PA opportunities do not change with an increase in age. Adults with CP from this sample, appear to have relatively positive attitudes towards past experiences with PA. Attitudes towards the self-assessment of movement quality become increasingly negative as they get older, and attitudes are negatively associated with time spent in moderate ADL’s. These findings underscore the importance of offering more meaningful opportunities for PA that are specifically designed or adapted towards the movement quality of individuals with CP. This should extend beyond the currently established early therapeutic opportunities to more lifelong opportunities that allow adults with CP to maintain and build off the foundation created in childhood. Future studies should examine this interaction between attitudes towards lifetime PA and current levels of PA using objective measures of PA as opposed to semi-structured interviews.

2.2 Introduction

Cerebral palsy (CP) is the most common pediatric onset disability and can be the result of many things including a complicated or preterm birth (Graham et al., 2016). Postural and motor concerns related to CP can manifest between 6 and 9 months when babies with typical development begin grasping, sitting up without support, or rolling over (Krigger, 2006). A great deal of time and resources are dedicated to habilitation in the early stages of life for those with CP (Aisen et al., 2011), in order to increase individual functional ability and introduce patterns of adaptation that can increase independence. This often requires the involvement of more than one mode of therapy such as physical, occupational, or speech therapy, multiple times a week (Moll & Cott, 2013). To eventually increase physical functioning, children with CP must actively participate in the habilitation process.

Actively participating in intense physical therapy sessions multiple times a week throughout childhood and adolescence can be challenging. Children with CP, in general, understand why they have to attend therapy but they do not enjoy it and feel they have no choice but to attend (Houx et al., 2021). Furthermore, routine physical therapy can cause pain beyond what is experienced daily as a result of CP (Houx et al., 2021). Therefore, an association between either boredom or pain and movement during therapy can negatively impact activity levels over time (Redmond & Parrish, 2008).

Social barriers to activity participation can come in the form of school-based PA or other childhood-based recreation (i.e., physical education or group sport). One common perspective of school-based PA that occurs for many children with disabilities is the interaction with neurotypical peers. Often students with disabilities will discuss positive interactions with their peers, suggesting that the feelings of inclusivity increased their desire to be physically active

(Haegele & Sutherland, 2015; Li & Chen, 2012). However, it has been shown that physical education contexts differentiate able and disabled bodies to an extent that leads to bullying (Haegele & Sutherland, 2015). Beyond the scope of bullying, students with disabilities often report feelings of exclusion in school-based PA (Haegele & Zhu, 2017; Lindsay & McPherson, 2012). These feelings can manifest through improper training of an educator (Li & Chen, 2012), discrimination due to disability (Haegele & Kirk, 2018), or lack-of or poor activity modifications (Haegele & Kirk, 2018). Again, a relationship is formed between PA and the experiences and attitudes associated with that activity.

Childhood is a pertinent stage to introduce different forms of PA as this is a time where both attitude development and skill development occur, both of which are important for regular adult PA. In a 10-year longitudinal study by Miller and Siegel (2017), it was determined that PA in childhood was a significant predictor of PA participation in young adulthood. The authors further suggested that the predictive value of childhood PA opportunities on adult participation is mediated by the perception of the experience itself, which can often be negative. Furthermore, Thompson and colleagues (2003), found that significant PA experiences in childhood and adolescence had lasting impact on adult preference for PA or inactivity.

Past experiences with PA on future opportunities to be physically active in adulthood are not well understood in developmental disabilities like CP. Attitudes towards previous opportunities and experiences with PA, primarily in childhood and adolescence, may have predictive value in determining the PA trajectory of adults with CP. In the past, qualitative studies have examined childhood experiences with PA for pediatric disabilities (Haegele & Kirk, 2018; Haegele & Sutherland, 2015; Haegele & Zhu, 2017; Lauruschkus et al., 2015; Leo et al., 2018; Li & Chen, 2012; Nyquist et al., 2019; Sienko, 2019), but research focused on the adult disability population primarily examines healthcare concerns (Becker & Schaller, 1995; Mudge et al., 2016; Nieuwenhuijsen et al., 2009), barriers and facilitators to PA (Buffart et al., 2009; Heller et al., 2002; Li & Chen, 2012; Rimmer et al., 2001; Sandström, 2007), or attitudes and experiences in adult PA opportunities (Jahnsen et al., 2003). Whether a relationship exists between attitudes towards previous childhood experiences with PA and current attitudes towards PA in adults with CP is unclear.

It may be also important to consider the age of the adult. Different experiences may have been available based on the age of the individuals. Older adults with CP may not have had access to inclusive sport or recreation and may have only been exposed to physical or occupational therapy services (Winnick, 2011). In contrast, younger adults with CP may have had more opportunities in adapted sports and recreation, adapted physical education classes, and inclusive classroom (S. M. Miller & Siegel, 2017; Sienko, 2019). Recalling these experiences may offer a better understanding of PA preferences for adults with CP.

Memory recall in adulthood is often met with skepticism, with many believing that older adults are unable to remember specific incidences that may have occurred in childhood (Kim & Welk, 2017). However, it has been shown that physical and psychological childhood events are important relays of adult behaviors (Smith, 2009). Therefore, the purpose of this study is to determine if lifelong attitudes towards PA influence adult behaviors. The results of this study will assist in pushing the importance of well-designed physical education and physical activity opportunities for individuals with CP across school and community contexts.

2.3 Methods

This study examined and compared the association between lifelong experiences and attitudes towards PA and how those experiences influence adult PA behavior. Data were collected using a newly designed and validated survey for lifelong experiences and attitudes with PA. Those responses were compared to scores of a 3-day recall of current levels of PA. The intended outcome of this study is to demonstrate the importance of providing meaningful and consistent opportunities for children and adolescents with CP to be physically active to encourage and support lifelong participation in PA. All study components were completed by the participants remotely due to the restrictions brought on by the COVID-19 pandemic. This study was approved by the Institutional Review Board at University of Michigan, Ann Arbor. Electronic informed consent was obtained from all study participants.

2.3.1 Study Population

Between February and July of 2021, adults with CP were recruited by flyers hanging in the Physical Medicine and Rehabilitation (PM&R) clinics at the University of Michigan, Ann Arbor. Further recruitment included electronic flyers posted to multiple CP support group social media platforms, such as Facebook, Instagram, Twitter, etc. Inclusion criteria included: 1.) 18 years of age or older; 2.) clinical diagnosis of CP; 3.) GMFCS level I-III (characterized by the ability to ambulate with or without assistive devices such as a posterior walker); 4.) Access to a laptop or other screening device, and internet access. Finally, the ability to complete the oral Trail B test in less than 273 seconds was a test of cognitive function. Participants were asked to count correctly from A1-L12 (i.e., A1, B2, C3, D4, etc.), but those who were unable to complete the oral Trail B in the allotted time were excluded from the study (Reitan, 1958).Topographical representation of CP was determined clinically and reported to the research team during participant screening.

Due to the large age range and subsequent variability among ages, the sample was trichotomized into age groups; young adults (YA) (ages 18-32), middle adults (MA) (ages 33-

49), and older adults (OA) (ages 50-70). Additional sociodemographic information was obtained including race, level of education, annual income, and status of a primary care provider.

2.3.2 Assessment of Attitudes Towards Lifelong Physical Activity (AATLPA)

The newly developed Assessment of Attitudes Towards Lifelong PA (AATLPA) is unlike other subjective recall measures because it focuses primarily on the attitudes and opportunities for PA throughout the life course for those with developmental disabilities. What makes this survey unique is its approach to recall for older individuals. The AATLPA attempts to mitigate recall limitations by asking respondents to recall the age of their first opportunity to be physically active, the context of the PA (i.e. playground, therapy, home, daycare, etc.), and who participated in the PA (i.e. parents, siblings, peers, therapists, etc.). This method allows participants to recall chronologically within specific times of their development and can help provide more accurate accounts.

Furthermore, the AATLPA requests that participants recall the interactions in PA they may have experienced as children. This can include professionals who have specific training working with individuals with disabilities (IwD) such as physical or occupational therapists, social workers, and direct support professionals, or meaningful interactions with those who do not have special training like peers, coaches, or grandparents. The AATLPA asks participants to consider how those interactions may have shaped their current attitudes towards PA. The AATLPA also has respondents recall PA interactions with peers both with and without disabilities and how those interactions may have swayed their attitudes towards PA. Finally, respondents are asked about their attitudes to PA in four developmental stages (i.e. early childhood, middle childhood, adolescents, and young adulthood), their current attitude towards PA, how they would rate themselves currently as movers, and how they think their past experiences and attitudes have influenced their current levels of physical activity. Altogether, the AATLPA paints a picture of the lived experience of participating in physical activity for someone with a developmental disability. A copy of the AATLPA instrument is in Appendix A. The highest possible score on the AATLPA is 84 while the lowest possible score is 12. Scores fall within one of four categories: 12-29 negative attitude, 30-47 moderate attitude, 48-66 positive attitude, and 67-84 very positive attitude.

2.3.3 Physical Activity Recall Assessment for Individuals with Spinal Cord Injury (PARA-Sci)

The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-Sci) (Martin Ginis & Latimer-Cheung, 2005) is a 3-day recall of activity, including both activities of daily living (ADL) and leisure time physical activity (LTPA). Participants are surveyed regarding activities performed in the last three days. It aims to measure the type (ADL vs. LTPA), frequency, duration (time in minutes), and intensity (mild vs. moderate vs. heavy) of physical activity. The PARA-Sci is sensitive enough to measure very low intensity activities expected of people who have disabilities with physical limitations. This semi-structured interview has been designed to be conducted over the phone or using other methods of face-to-face communication such as Zoom, Facetime, or Skype. This instrument has been used in populations of CP and other disabilities with physical limitations (Claridge et al., 2015).

2.3.4 AALTPA Tests of Validity and Reliability

Reliability

To assess the test-retest reliability of the AALTPA, calculations between 2 AALTPA scores were taken using an intraclass coefficient (ICC $_{3,1}$) with consistency, single measure, and 95% CI (Koo & Li, 2016) as well as a paired t-test for the mean difference in responses. A convenience sample of 20 participants from the study were retested between 40 and 70 days after the first test (Shore et al., 2019; Vasudevan et al., 2015; J. Verbunt, 2008; Washburn et al., 2002). Absolute reliability was assessed by the following equation for standard error of measurement (SEM): $SEM = SD \times \sqrt{(1- ICC)}$, with SD reflecting the pooled standard deviation of the two measurements and ICC of the test-retest analysis (Portney, 2020). Internal consistency using Cronbach's alpha was measured with a minimum, acceptable alpha score of 0.70. If a question resulted in an alpha score of less than 0.70, that question would be removed.

Minimal Detectable Change

To interpret changes in test scores, the minimal detectable change (MDC^{95}) at 95% CI was calculated using the equation: $MDC^{95} = SEM \times 1.96 \times \sqrt{2}$ (Portney, 2020). SEM was determined based on the standard deviation while the ICC was determined from the test-retest analysis. The MDC^{95} determines the minimal amount of change in outcome scores not due to subject variability or measurement error. Therefore, a true change in a person's attitude is determined when a score exceeds the MDC, and this is with 95% confidence.

Factor Analysis

Construct validity was measured using methods similar to those described by Washburn et al in 2002. The current construct of PA opportunities and attitudes in childhood is theoretical. Therefore, a factory analysis was deployed to determine if responses to the AALTPA grouped together in meaningful and foretelling ways. After completing an exploratory factor analysis on the data it was determined that a principal component extraction with Varimax orthogonal rotation based on Kaiser's criterion of on an eigenvalue ≥ 1 and a factor loading $\geq .40$ was the most appropriate analytical approach (Rimmer et al., 2001; Vasudevan et al., 2015; Washburn et al., 2002).

Internal Consistency

Once factors were identified, internal consistency was tested using Cronbach's α for items within each factor. This helps explain the degree of homogeneity within instrument questions (Rimmer et al., 2001; Vasudevan et al., 2015; J. Verbunt, 2008; Washburn et al., 2002).

Criterion Validity

The AALTPA was designed to be used as a tool to understand PA patterns in adults with disabilities. It is expected that more active adults will have higher AALTPA scores while less active adults will have lower AALTPA scores. Spearman correlation was used to examine criterion validity of the AALTPA with PARA-Sci (gold standard reference measure) responses (in minutes) by age group. Recommendations for correlation strength are as follows: little-none ($p < 0.25$), poor ($p= 0.25-0.50$), moderate-good ($p= 0.50-0.75$), and good-excellent ($p > 0.75$) (Portney, 2020).

Floor-and-ceiling effects

The presence of either a floor or ceiling effect may sway the reliability and validity of this measure. Therefore, if 15% or more of respondents scored either the highest or the lowest ACPAR score possible, we would know an effect had emerged (Verbunt, 2008).

2.3.5 Statistical Analysis

To determine if attitudes towards lifelong PA opportunities change with age, a one-way ANOVA was conducted with the AALTPA score as the dependent variable and age group as the independent variable. The three age groups of the participants are categorical variables, while the AALTPA score is discrete with no temporal sequence. For this reason, Spearman's rho correlations were used to determine if there is a relationship between the age of the individual and their attitudes towards lifelong PA based on their AALTPA score. A further understanding of the association between age and individual survey questions was also of interest to see if a particular question may be associated with overall attitude scores more than others. Spearman's rho correlations were conducted again using age and individual survey question scores.

Of further interest was to see if there was a relationship between attitudes and perceptions towards lifelong participation in PA and current levels of self-selected activity by age group. Again, because the AATLPA score is a discrete variable this relationship was determined using Spearman's rho correlations. All statistical analyses were completed with IBM-SPSS version 28 and a two tailed significance level of ($p<0.05$).

2.4 Results

2.4.1 Psychometric Properties of the AALTPA

Reliability

The $ICC_{3,1}$ of the two AATLPA test-retest scores was high (ICC= 0.98), with a 95% CI of 0.96-0.99. The SEM (1.63) and MDC^{95} (4.52) were small of this assessment. According to the paired t-test, there was no significant difference in AATLPA scores between time periods ($M_1 = 53.24 \pm 11.28$; $M_2 = 53.82 \pm 11.73$), which demonstrates that the AATLPA has good test-retest reliability ($p = .17$; effect size $d = 1.7$). The Cronbach's alpha of the total AATLPA score was

0.75, which indicates an acceptable internal consistency. No significant change to the alpha score was observed when items were removed.

Factor Analysis

The mean score for all 13-items of the AATLPA, correlations between each item and the total AATLPA score, eigenvalues, factor loadings, percentage of variance explained, and Cronbach's alpha coefficients are presented in Table 1. Six out of the 13-items significantly correlated ($p < .05$) with the total AATLPA score. According to the Kaiser criterion described earlier, four latent factors were identified: factor 1, *attitudes towards physical activity in early childhood* ("early childhood attitude"; items 2, 5, 10a, 10b); factor 2, *attitudes towards physical activity in the transition years ("transition years attitude";* items 4, 10c, 10d); factor 3, *current attitudes towards physical activity ("current attitude";* items 11, 12, 13); factor 4, *interactions within opportunities to be physically active* ("interactions"; items 8, 9).

Each factor had the following percent variance explained; early childhood attitude (30.6%), transition years attitude (15.4%), current attitude (12.5%), and interactions (10.9%) Altogether, these factors accounted for 69.4% of the total item variance. Cronbach alpha for each factor are as follows: early childhood attitude $\alpha = 0.76$, transition years attitude $\alpha = .56$, current attitude $\alpha = .74$, and interactions $\alpha = .83$, given the small number of items in each factor moderate-to-good internal consistency was observed. Removal of item 4 in the transition years attitude factor led to an increase in alpha from .56 to .81, for this reason, and because the response to item 4 is dependent on the answer to a preceding, unscored question, it was removed from the subscale. This validation provides empirical evidence that the scores from this instrument reflect the construct of interest. Furthermore, the results of the other psychometric properties of the AATLPA indicate that the survey has good reliability and no floor-or-ceiling effects.

--- Table 1 ---

Criterion Validity

The correlation summary of the PARA-Sci responses by age and the total AATLPA score are shown in Table 2. Moderate intensity ADLs were negatively correlated with both young (moderate correlation) and middle adults (strong correlation).

--- Table 2 ---

Floor-and-Ceiling Effects

Of the 68 participants in this study, not one scored the highest (84) or lowest (12) score on the AATLPA. The highest individual score on the ACPAR was 77 and the lowest was 31. Demonstrating that this measure is sensitive enough to capture increases and decreases in participant responses over time.

2.4.2 Study Results

The sociodemographic descriptive characteristics of the 68 adults with CP that were recruited into the study is depicted in Table 3. Of the whole sample, the mean age was 41.84 ± 13.70 years. Approximately 62% of participants had a topographical representation of CP as diplegia, while the remainder had hemiplegia. Most of the sample was both female (76.5%) and Caucasian (86.8). Only 85.7% of YA had a Primary Care Physician (PCP) and of that, 19% of PCP's were pediatricians. An overwhelming 89.7% of participants had experienced a major surgery in their lifetime, which includes but is not limited to Botox injections, tendon lengthening/release, and dorsal rhizotomy. Of the YA group, a majority were single (95.2%) and as expected, marriage and divorce increased with age groups; MA married (68.2%), OA married

(40%), MA divorced (4.5%), OA divorced (20%). In terms of education for the sample, 94.2% had at least some college experience with 41.2% receiving graduate level education. However, 76% of the sample population did not make over $60,000 annually despite being a highly educated group.

--- Table 3 ---

A one-way ANOVA revealed that there was no statistically significant difference in attitudes or perceptions towards lifelong participation in PA across age groups ($p= .26$, $\eta^2= .04$). However, 72% of the sample scored a 48 out of 84 or higher. A single sample t-test supports that the sample population had more positive attitudes towards lifelong participation in PA (M= 56.1, S.D.= 11.9) than the general population, ($p< .001$). The Spearman's rho correlation between age and the total AATLPA score was non-significant ($p= .66$). When looking at individual survey questions, however, a significant correlation did emerge. There is a moderate negative correlation between age and self-assessment of current movement quality ($r= -.34$, $p= .03$) such that as the age of the sample increases, self-assessment of movement quality goes down.

Table 4 depicts the responses to the PARA-Sci by age group, intensity (mild, moderate, or heavy), and type (activities of daily living (ADL) or leisure-time physical activity (LTPA)). Figures2-4 are graphical representations of time spent within activities and intensities, by individual age groups. Despite the large amount of variability among time spent in activities and intensities across the age groups, there were no statistically significant differences between groups. Spearman's rho correlations identified two significant relationships. The first is a strong negative relationship between AATLPA scores and time spent in moderate ADLs for young adults ($r= -.54$, $p=.01$) and the second a strong negative relationship between AATLPA scores and time spent in moderate ADLs for middle adults ($r= -.55$, $p=.01$). There were no significant relationships among the older adults, however, there was a trending moderate negative relationship between AATLPA scores, and time spent in heavy LTPA (r= -.39, p= .05).

--- Table 4 & Figures 2-4 ---

2.5 Discussion

This study examined how lifelong attitudes towards PA in adults with CP may affect adult PA behavior. Years of participating in therapy, or facing social challenges in school recreation contexts, can lead to negative associations between past experiences with PA and adult behaviors. The AATLPA was created to better understand how early opportunities and attitudes towards PA may impact the participation trajectory of adults with CP. This instrument would be a viable addition to other lifespan PA studies where participation is the outcome of interest. The AATLPA was determined to be a valid and reliable measure of attitudes and perceptions towards lifelong participation in PA.

Based on survey results, attitudes towards lifetime PA did not vary among age groups. Furthermore, nearly 75% of the study sample scored within the positive-to-very positive attitude range for the survey. This indicates that a positive attitude towards PA does not change as the population ages. This phenomenon could be due in large part to the fact that CP is a pediatric onset-disability and adults with CP have spent their lives modifying and adapting PA to their needs and goals (Jahnsen et al., 2004). In contrast, a physical disability that was acquired later in life would require significant changes to one’s well-learned movement repertoire. Those sudden changes and need to adapt may generate negative attitudes more than past experiences alone (Morris et al., 2017). An additional explanation for positive attitudes across age groups is that the PA opportunities provided to individuals with CP over the course of their lives were impactful enough to establish positive associations with PA. Perhaps issues with bullying, acceptance, and access in childhood is not as impactful on attitudes and perceptions towards PA in adulthood as originally hypothesized (Deighton et al., 2018).

The significant negative relationship between age and the self-assessment of movement extends the previous work examining the progressive loss of function common in individuals with CP (Andersson & Mattsson, 2001; Benner et al., 2017; Jahnsen, Villien, Egeland, et al., 2004; Lawrence et al., 2016; Strauss et al., 2004). Much of this work looks at the general age onset of mobility difficulty and walking cessation, with many researchers supporting the notion that individuals with CP begin to report changes in their mobility as young as 25 years old.

Based on the findings from the PARA-Sci semi-structured interview, a substantial amount of time was spent within low intensity activities regardless of age group, particularly mild activities of daily living (ADL). The creators of the PARA-Sci included ADLs because they are a part of one's daily routine and therefore, a relevant indication of daily activity (Martin Ginis & Latimer-Cheung, 2005). Responses from the PARA-Sci further depicted that as the age of the groups increased the time spent in moderate and heavy intensity ADLs also increased. This is likely because as individuals with CP age and detect the changes in their mobility, tasks take longer to complete and require additional energy expenditure (Hess et al., 2016).

For the younger and middle adult groups, significant negative correlations occurred between attitude scores and time spent in moderate ADL, such that as attitude scores increased time spent in moderate ADL decreased. This phenomenon is again due to how individuals perceive the intensity of the activity. The PARA-Sci's script does offer suggestions as to what intensities particular tasks are usually completed in (i.e., brushing teeth = mild ADL, moving clothes from the washing machine to the dryer = heavy ADL, walking the dog on a flat road = moderate LTPA, 3o-minute spin class = heavy LTPA, etc.). And yet, intensity is subjective and changes with everyone. Younger and middle adults may not have reported much time spent in moderate ADLs because their perception of working intensity was different from that of the older adults (Hess et al., 2021).

Leisure-time physical activity (LTPA), the other outcome of interest in the PARA-Sci, are activities that one chooses to do in their free time and includes organized sports and planned physical activity (i.e., working out at the gym, group fitness classes, personal training, etc.)(Martin Ginis & Latimer-Cheung, 2005). The responses for time spent in overall LTPA depicted low levels of LTPA participation across all intensities. These results indicate that adults with CP are spending more time completing tasks of daily living than participating in LTPA (Carlon et al., 2013). One possible explanation for this occurrence is that adults with CP participate in LTPA because of the known physiological benefits not necessarily because they enjoy PA (Usuba, 2013). A more reasonable explanation for low levels of LTPA relate to COVID-19. The interviews were conducted in the middle of the “shelter in place” protocol initiated by the United States Center for Disease Control and significantly limited access to LTPA for all, but especially adults with CP who rely heavily on the community for services (i.e., support aides, transportation, etc.)(Dogruoz Karatekin et al., 2021).

2.5.1 Practical Implications and Future Research

The findings from this study illustrate positive attitudes towards PA among adults with CP regardless of age. This demonstrates the importance of creating PA opportunities that are truly representative of individuals with CP that extend beyond early habilitation interventions designed to increase individual movement effectiveness. While individuals within this sample appear to have positive attitudes towards lifetime PA overall, that was not captured in the amount of time spent in ADL or LTPA. For older adults, more time was spent in higher intensity ADL and less time was spent overall in LTPA. If carefully curated adapted PA opportunities extended beyond adolescence and met the needs of bodies aging with CP (i.e., age-appropriate PA community programs, programs designed to mediate onset of comorbidities, etc.), we could minimize those physical changes to mobility which would allow individuals to be more efficient in their ADL's while increasing time and intensity in LTPA.

Future work in this area should attempt a truly longitudinal approach to lifelong attitudes towards PA and the effects on adult PA behavior. The practical application of truly understanding individual mobility changes with age is limitless. Often in CP research there is a degree of generalizability due to the heterogeneity of the population. Following a cohort over an extended period allows for a nuanced account of experienced changes and how they affect daily participation. Furthermore, this work would benefit from an objective measure of current levels of physical activity such as accelerometry. The PARA-Sci is an efficient measure but allows for quite a bit of subjective freedom; accelerometry would allow for a monitored account of how much activity an individual was completing.

2.5.2 Study Limitations

It is important to consider the limitations of this study when interpreting the results as they were obtained from a sample of predominantly Caucasian females with high levels of education. This may make generalizability with other demographics difficult and warrants additional work with a larger and more diverse sample. As for the design of the AATLPA, with any recall instrument, there are limitations as to how much an individual can remember. By asking grown adults (some in their 60's and older) to recall PA opportunities and attitudes from childhood there will be inherent gaps in memory. However, many of the participants of this study were so impacted by early PA interactions that they were able recall them more easily.

The shelter in place restrictions further limited this study because participants were not as active as they usually would have been. Many of our participants relied on third party transpiration or gym access to stay active. With these restrictions put into place, many participants were limited in their options to be physically active.

2.5.3 Conclusion

This study examined lifelong attitudes towards PA in adults with CP and how those attitudes may affect adult PA behavior. While it was determined that attitudes towards PA did not change significantly with an increase in age, the study did show positive attitudes towards PA opportunities across the lifespan. Furthermore, PA behavior was significantly correlated with an individual’s self-assessment of movement quality. Future research should use objective measures of PA such accelerometry to further examine how attitudes towards lifetime PA may affect adult PA behaviors.

2.6 Figures & Tables

Table 1. Survey Item Correlation to Total AATLPA Score and Factor Analysis for AATLPA

Item	Correlation with Total Score	*Factor Loading* ☨ Factor 1: Early Childhood Attitude	Factor 2: Transition Years Attitude	Factor 3: Current Attitudes	Factor 4: Interactions
Question 10a	0.48**	0.83	--	--	--
Question 2	0.63**	0.80	--	--	--
Question 5	0.57**	0.73	--	--	--
Question 10b	0.64**	0.58	--	--	--
Question 10c	0.65**	--	0.89	--	--
Question 10d	0.54**	--	0.83	--	--
Question 4	0.28 *	--	0.42	--	--
Question 12	0.33**	--	--	0.89	--
Question 11	0.58**	--	--	0.80	--
Question 13	0.60**	--	--	0.59	--
Question 8	0.54**	--	--	--	0.91
Question 9	0.55**	--	--	--	0.89
Eigenvalue	--	3.67	1.84	1.51	1.30
% Variance	--	30.6	15.4	12.5	10.9
Cumulative % variance	--	30.6	46.1	58.6	69.4
Cronbach's α	--	0.76	0.56	0.74	0.83

** Correlation is significant at the level of 0.01

* Correlation is significant at the level of 0.05

☨ Items are arranged by factor and by descending order of factor loading

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Table 2. Survey Score Correlations by Age Group

Intensity	Type	**YA (n=21)**	**MA (n=22)**	**OA (n=25)**
Mild				
	ADL	-0.16	0.23	0.14
	LTPA	0.37	-0.05	-0.18
Moderate				
	ADL	**-0.54***	**-0.55***	-0.35
	LTPA	0.23	0.24	-0.17
Heavy				
	ADL	-0.19	-0.16	-0.10
	LTPA	-0.12	0.19	-0.39

ADL = activity of daily living; LTPA = leisure time physical activity
YA = young adult; MA= middle adult; OA = older adult
* Correlation is significant at the level of 0.05

Table 3. Descriptive Characteristics

Variable	Total Sample (n=68)	YA (n=21)	MA (n=22)	OA (n=25)
Age (y)	**41.84 ± 13.70**	26.14 ±2.60	39.82 ± 5.83	56.80 ±5.99
Gender (%)				
Male	**23.5**	33.3	18.2	20.0
Female	**76.5**	66.7	81.8	80.0
Topography (%)				
Hemiplegia	**38.2**	33.3	40.9	40.0
Diplegia	**61.8**	66.7	59.1	60.0
Race (%)				
Asian	**1.5**	4.8	--	--
African American	**2.9**	9.5	--	--
Hispanic/Latino	**8.9**	9.5	4.5	12.0
Caucasian	**86.8**	76.2	95.5	88.0
Access to Primary Care Physician (PCP) (%)				
Yes	**94.1**	85.7	100.0	96.0
No	**5.9**	14.3	--	4.0
Pediatric PCP (%)				
Yes	**8.8**	19.0	9.1	--
No	**91.2**	81.0	90.9	100.0
Major Surgeries (%)				
Yes	**89.7**	85.7	95.5	88.0
No	**10.3**	14.3	4.5	12.0
Relationship Status (%)				
Single	**50.0**	95.2	27.3	32.0
Married	**38.2**	4.8	68.2	40.0
Divorced	**8.8**	--	4.5	20.0
Widowed	**2.9**	--	--	8.0
Highest Level of Education (%)				
High School	**5.9**	14.3	4.5	--
Trade School	**--**	--	--	--
Some College	**10.3**	14.3	4.5	12.0
2-Year College Graduate	**7.4**	4.8	4.5	12.0
4-Year College Graduate	**35.3**	52.4	18.2	36.0
Graduate Level	**41.2**	14.3	68.2	40.0
Annual Income (%)				
<$20,000	**35.8**	66.7	27.3	16.7
$20,000-$40,000	**23.9**	19	22.7	29.2
$40,000-$60,000	**16.4**	14.9	22.7	12.5
$60,000-$80,000	**9.0**	--	9.1	16.7
$80,000-$100,000	**4.5**	--	9.1	4.2
>$100,000	**10.4**	--	9.1	20.8

Bold print represents the full sample of n=68

Age is reported in mean (S.D.) and all other values reported as percentage of population

ADL = activity of daily living; LTPA = leisure time physical activity

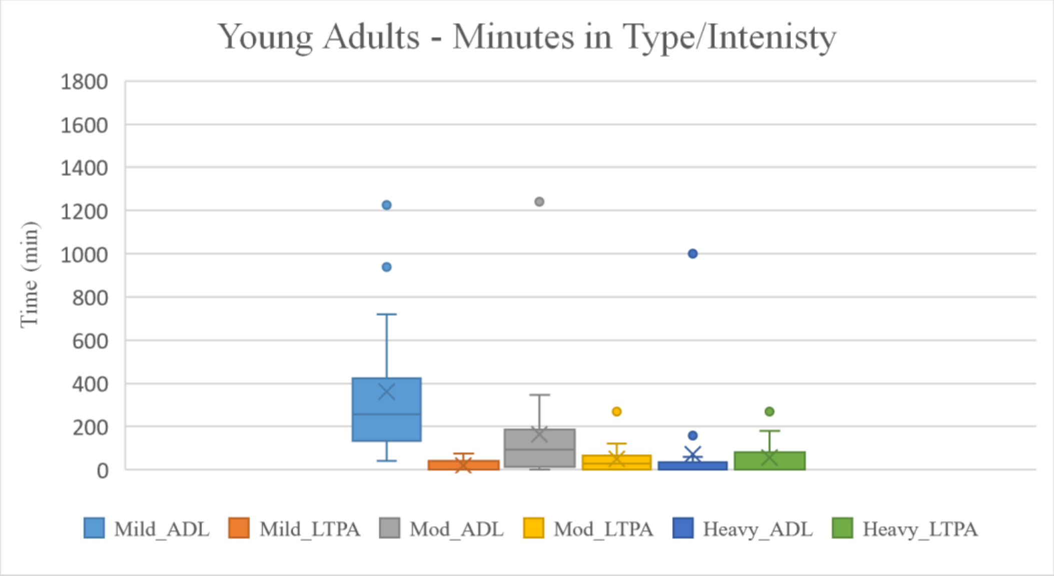
YA = young adult; MA= middle adult; OA = older adult

Table 4. PARA-Sci Activity Type and Intensity by Age Group

Intensity	Type	YA (n=21)	MA (n=22)	OA (n=25)
Mild				
	ADL	473.20 (384.22)	529.17 (396.04)	556.45 (445.60)
	LTPA	39.51 (124.80)	67.50 (193.06)	22.75 (38.54)
Moderate				
	ADL	178.90 (233.47)	185.17 (225.23)	134.00 (184.76)
	LTPA	62.50 (137.24)	106.67 (209.85)	73.00 (114.0)
Heavy				
	ADL	66.17 (164.65)	22.94 (54.67)	56.20 (148.83)
	LTPA	60.42 (105.65)	84.44 (105.02)	60.50 (126.26)

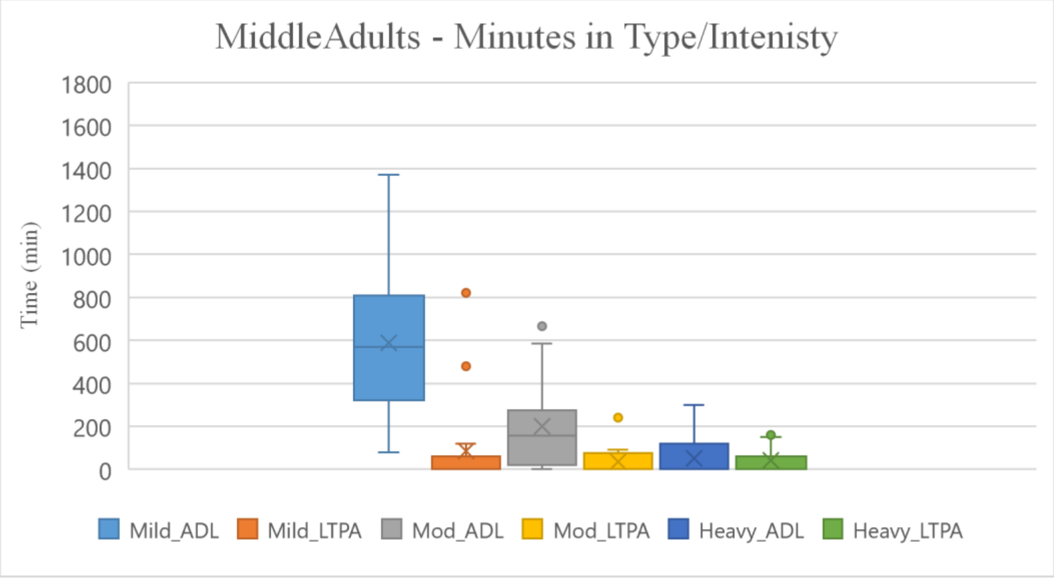
Values are mean (S.D.) minutes of activity over three consecutive days.
ADL = activity of daily living; LTPA = leisure time physical activity
YA = young adult; MA= middle adult; OA = older adult

Figure 2. Box and Whisker Plot: Minutes Spent in Activity Type and Intensity for Young Adults



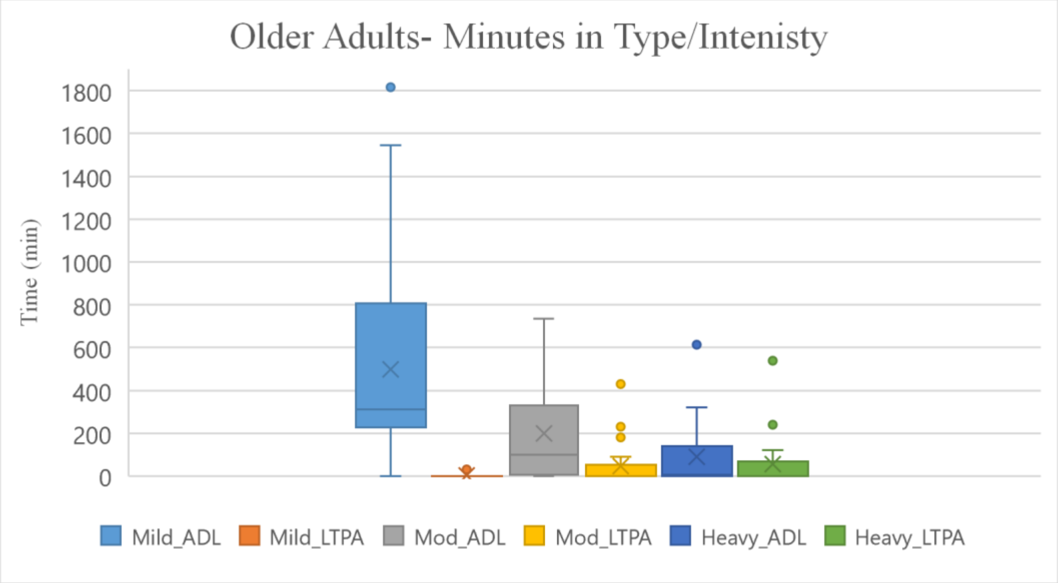
ADL = activity of daily living; LTPA = leisure time physical activity
Boxes represent upper and lower quartile of time spent in each type/intensity of PA.
Horizontal line within each box is the median time and X is the mean time.
Whiskers depict upper and lower extremes.
Outliers are represented by individual dots.

Figure 3. Box and Whisker Plot: Minutes Spent in Activity Type and Intensity for Middle Adults



ADL = activity of daily living; LTPA = leisure time physical activity
Boxes represent upper and lower quartile of time spent in each type/intensity of PA.
Horizontal line within each box is the median time and X is the mean time.
Whiskers depict upper and lower extremes.
Outliers are represented by individual dots.

Figure 4. Box and Whisker Plot: Minutes Spent in Activity Type and Intensity for Older Adults



ADL = activity of daily living; LTPA = leisure time physical activity
Boxes represent upper and lower quartile of time spent in each type/intensity of PA.
Horizontal line within each box is the median time and X is the mean time.
Whiskers depict upper and lower extremes.
Outliers are represented by individual dots.

Chapter 3 The Effects of Contextual Factors on Participation in Physical Activity

3.1 Abstract

Introduction: Adults with cerebral palsy (CP) experience fluctuations in their participation in PA like the general population, however, they experience age-related physiological changes to their health earlier than the general population. It is well understood that this deterioration in functional ability is associated with decreased participation in CP. What is less clear is how contextual factors such as pain, quality of life (QOL), self-perception, and independence impact the selection of and participation in PA.

Methods: Adults with CP who were self-ambulatory, with or without assisted devices, completed remote versions of the following surveys related to personal factors: the West Haven-Yale Multidisciplinary Pain Inventory (WHYMPI), the World Health Organization Quality of Life – Brief (WHOQOL-BREF), the Self-Perception Profile for Adults (SPPA), and the Barthel Index. Each of these factors were chosen because of their known impact on PA participation. Participants further completed a semi-structured interview known as the Physical Activity Recall Assessment of Individuals with Spinal Cord Injury (PARA-Sci) which recalls the type, intensity, and frequency of activity done in a three-day period.

Results: A total of 68 adults with CP participated in the study. A Chi-Square Test of Independence concluded that the physical and psychological domains of QOL, plus the self-perception of athletic ability had the most associations between type and intensity of PA chosen. Pain interference and severity were associated with moderate ADL and moderate LTPA, respectively, while functional independence was only associated with mild LTPA. A multivariable regression analysis on time spent in overall LTPA determined that self-perception of athletic ability, pain severity, and affective distress were all positive predictors while pain associated with completing general activities was a negative predictor of time spent in overall LTPA; overall time in LTPA = -786.58 + (155.78 athletic ability) + (698. 22 pain severity) + (993. 42 affective distress) + (-1912.82 general activities).

Conclusions: Physical and psychological QOL and self-perception of athletic ability had the most associations with PA types and intensities. Time in overall LTPA is predicted positively by self-perception of athletic ability, pain severity, and affective stress while negatively by pain associated with the completion of general activities. Future work should look more closely at the interplay between pain severity and affective distress and the impact on PA participation.

3.2 Introduction

The general population of adults often experience ebbs and flows in their effort to maintain health through physical activity (PA)(Heller et al., 2002; Lineweaver et al., 2018; Vanhees et al., 2005) and many factors (i.e. motivation, self-perception, etc.) contribute to these fluctuations (Chodzko-Zajko et al., 2009; Jiang et al., 2016; Stewart & King, 1991). Individuals aging with CP may experience similar patterns but for different reasons (Benner et al., 2019; Usuba et al., 2014). While the brain damage associated with CP is static (Palisano et al., 2000; Thorpe, 2009; Turk, 2009), functional ability changes throughout the lifespan. Consequently, adults with CP report that they experience age-related changes to their functional health earlier than the general population (Mudge et al., 2016). These accelerated changes are further impacted by factors within the ICF model (Gajdosik & Cicirello, 2002) and exploring these factors to determine their impact on continuing participation in PA is of great interest.

Pain is a widely researched topic in CP as a majority of individuals report some level of pain throughout their lives (Turk, 2009; Yi et al., 2019; Zaffuto-Sforza, 2005). Musculoskeletal pain is often referenced as the primary reason for walking cessation in former self-ambulatory adults with CP (Roebroeck et al., 2009). However, there are conflicting reports on whether pain is age-dependent. Schwartz et al. (1999) reported that more than half of their participants with CP experienced moderate to severe pain daily. The older the participants age was indicative of pain intensity. Van der Slot et al. (2020) found that pain in the arms increased with age and was likely due to overuse related to reduced walking ability and supplemental use of mobility aids. Jahnsen et al. (2004) compared musculoskeletal pain in adults with CP to that of the general population and found that pain was associated with age for the control group, but not adults with CP. Similarly, Riquelme et al. (2011) reported that pain intensity was differentially modulated by age in both participants with CP and the control group. Age-related differences in current pain, however, only appeared for the control group.

Despite differing opinions about the age effect on pain, there is consensus that individuals with CP experience more pain in their lower limbs (Riquelme et al., 2011), women experience more pain than men (Jahnsen et al., 2004), and pain begins in childhood (van der Slot et al., 2020), but with minimal interference on their activity levels and social functioning (Engel et al., 2003). It is suspected that this phenomenon is due to already low functional levels typical of individuals with CP (Schwartz et al., 1999). Riquelme et al. (2011) further suggest that individuals with CP are involved in repeated painful experiences during times of neurological development (i.e., physical therapy, stretching, bracing, etc.), which could lead to relative changes in pain threshold and tolerance throughout the course of a person's life. Additionally, the early onset of pain may allow an individual to modify, or eliminate, activities in a way that helps manage their pain (van der Slot et al., 2020).

Pain is a contributing factor to the decrease in quality of life (QOL) for individuals with CP (Lundh et al., 2018). Moreover, QOL is considered the most important adaptation outcome to assess in CP (Alves-Nogueira et al., 2020). The World Health Organization reports QOL as an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (Jiang et al., 2016; Skevington et al., 2004; "The World Health Organization Quality of Life Assessment

(WHOQOL),” 1995) and includes physical, psychological, social and environmental dimensions (Alves-Nogueira et al., 2020). QOL appears to be predicted by level of impairment, age, independence, education, income, and employment (Alves-Nogueira et al., 2020).

QOL for adults with CP can be influenced by impaired or declining functional capacity (Lundh et al., 2018) which is common among this population. Usuba et al. (2014) determined that over an 8-year period, 27% of the participants in their study reported deterioration in GMFCS level which was consistent with work done by Sandström et al. (30%) and McCormick et al. (23%). Jahnsen et al. (2004) also described walking deterioration occurring between the ages of 25 and 35 years. A review by Alves-Nogueira et al. (2020) found that high QOL is associated with increased levels of physical activity, but low levels of QOL were associated with higher levels of impairment, increased pain intensity and sites. Despite these findings, Gannotti et al. (2021) concluded that 80% of their participants reported good to excellent QOL. While there appears to be inconsistent evidence surrounding decreased QOL due to disability (Jiang et al., 2016), assessing QOL is an important consideration of participant’s own perception of their well-being (Alves-Nogueira et al., 2020).

An individual’s QOL, physical functioning, and PA participation are all influenced by self-perception (Causgrove Dunn, 2017). Self-perception, or a person’s sense of worth, value, and adequacy (Gannotti et al., 2011), is assumed to be low for individuals with CP, especially in those with increased severity (Gannotti et al., 2011; Ziebell et al., 2009). For individuals without CP, self-perception trajectory evolves throughout the course of their lives as a result of the experiences they encounter (Cheong et al., 2018). This should theoretically be true for individuals with CP as well, however, research related to self-perception in adults with CP is limited. There are mixed findings on whether reported levels of self-perception in CP are like that of individuals without CP. Ziebell et al. (2009) found that children with CP had lower perceived self-competence compared to their school-aged peers without CP. These participants did attend a mainstream school in which their benchmark of “normal” were their peers without CP. It is speculated that if the participants attended a school designed for children with disabilities that there may be an increase in self-perception. Conversely, Shields et al. (2007) determined that individuals with CP do not have lower self-perception of global self-worth even though they may feel less competent in certain aspects of life like athletic ability or communication.

Moreover, the perception of individuals with CP by their parents or caregivers is generally lower than the individuals perception of themselves (Dunn et al., 2007). Adults with CP likely conceptualize self-perception differently as a result of a lifetime of atypical experiences across different environments (Cheong et al., 2018; Ziebell et al., 2009). Bonnefoy-Mazure et al. (2020) determined that self-perception of gait quality was influenced by CP severity (i.e., GMFCS) not CP type (i.e., dyskinetic vs. spastic). Walking speed and distance positively influenced self-perception of gait, with the former having a direct impact on functional independence. Finally, decreased gait quality (i.e., hip adduction/abduction, knew flexion/extension, etc.) was associated with lower self-perception. From a sample of 102 adults with CP Gannotti et al. (2011) found that a majority had average or above average self-perception and that there was no relationship between self-perception and severity of CP.

Additionally, of the less that 15% of the sample that had low self-perception there was no relationship with gender, severity, or levels of PA.

There is a strong relationship between QOL and functional independence (Chulliyil et al., 2014). Functional independence is the level of functioning that allows an individual to be self-reliant and independent in ADLs and self-selected recreational activities (Posłuszny et al., 2017). A decrease in QOL can be seen with loss of mobility and leads to low levels of participation in social relationships and low percentages of independent living (Lennon et al., 2018). A review by Posłuszny et al. (2017) defined the factors that determine functional independence as internal (direct result of CP) and external (impact of environment). The type and severity of CP have the greatest internal impact on functional independence. Work by Fortuna et al. (2018) demonstrated the impact of age and health condition on functional independence in 229 adults with CP. They determined that functional independence decreases with an increase in age. They further explained that functional independence may be dependent of health condition but note an association between decreased independence and seizure disorders, urinary incontinence, and intellectual disability.

External factors of functional independence (i.e., environmental factors like access, transportation, support staff, etc.) are modifiable. In fact, independence is not just adapting an individual to their environment, but modifying the environment to meet the person's capabilities (Posłuszny et al., 2017). A five year follow-up study on 31 community dwelling adults with developmental disabilities conducted found an increase in individuals living independently with a partner and a decrease of individuals living with their parents (Andrén & Grimby, 2004). They further noted that indoor mobility among the sample over five years did not change and there was a 10% increase in employment among the sample. In general, it was found that modifications or adaptations to the individual's environment likely influenced these areas of independence, which emphasizes the importance of continued monitoring and assessment of functional independence (Fortuna et al., 2018). Ultimately, the more independent the individual feels, the more likely they are to participate socially (i.e., PA) which has a considerable influence on life-satisfaction (Posłuszny et al., 2017; van der Dussen et al., 2001)

It is evident that the four factors discussed (pain, QOL, self-perception, and functional independence) interact and influence the lives of adults with CP to some extent. Therefore, the purpose of this is study is to explore the impact of these individual factors on the continued participation in PA throughout the life course of adults with CP. Each factor has multiple domains, and this study will assist in delineating the dimensions that influence PA participation the most. By truly understanding the factors that drive adult PA behavior, researchers and clinicians can monitor and intervene in areas that are the most valuable to the individual and their life goals. Theoretically, this will lead to positive changes within the other factors as well.

3.3 Methods

This study examined the influence of pain, QOL, self-perception, and independence on PA behaviors of adults with CP. Data were collected using validated and reliable surveys related to the factors of interest (Benner et al., 2017; Burckhardt & Anderson, 2003; Jiang et al., 2016; Stewart & King, 1991). Those replies and the responses to a 3-day recall of current levels of PA were used to look at significant relationships. All study components were completed by the participants remotely due to the restrictions brought on by the COVID-19 pandemic. This study was approved by the Institutional Review Board at University of Michigan, Ann Arbor. Electronic informed consent was obtained from all study participants.

3.3.1 Study Population

The same sample (n= 68) from the second chapter was used for this study as well. Between February and July of 2021, adults with CP were recruited by flyers placed in the Physical Medicine and Rehabilitation (PM&R) clinics at the University of Michigan, Ann Arbor. Further recruitment included electronic flyers posted to several CP support group social media platforms, including Facebook, Instagram, Twitter, etc. Inclusion criteria included: 1.) 18 years of age or older; 2.) clinical diagnosis of CP; 3.) GMFCS level I-III (characterized by the ability to self-ambulate with or without assistive devices such as a posterior walker); 4.) Access to a laptop or other screening device, and internet access. Finally, the ability to complete the oral Trail B test in less than 273 seconds, as described in the testing criteria, was a test of cognitive function and involves counting alphanumerically from A1-L12 (Reitan, 1958). Those unable to complete the oral Trail B in the allotted time were excluded from the study. Additional sociodemographic information was obtained including race, level of education, annual income, and status of a primary care provider.

3.3.2 West Haven- Yale Multidimensional Pain Inventory (WHYMPI)

This self-report questionnaire was designed to measure severity and interference of pain with specific interest on pain response and impact on ADLs. (Burckhardt & Jones, 2003). The version used is comprised of 52 items across three sections and each item is rated on a 0-6 Likert scale. The WHYMPI has 12 dimensions, or subscales: interference, support, pain severity, life control, affective distress, household chores, outdoor work, activities away from home, social activities, and general activities. Subscale scores are computed from the sum of individual subscale items divided by the number of items in the subscale to provide a mean. The internal reliability coefficients of all WHYMPI scales range from .70 to .90; the test-retest reliabilities of these scales over a 2-week interval range from .62 to .91 (Kerns et al., 1986). The WHYMPI has been used with older adults (Burckhardt & Anderson, 2003) and other disabilities with physical limitations (Raichle et al., 2007).

3.3.3 World Health Organization Quality of Life – Brief (WHOQOL-BREF)

This survey was developed as a short version of the WHOQOL-100 to use when time is restricted, or to minimize participant burden and asks individuals how they feel about their quality of life, health, and other areas of life ("The World Health Organization Quality of Life Assessment (WHOQOL)," 1995). WHOQOL-BREF utilizes a four-domain structure as opposed to the original six-domain structure of the WHOQOL. The four domains of QOL withing the WHOQOL-BREF are physical, psychological, social, and environmental. WHOLQOL-BREF uses 5-point Likert scales that reflect intensity, capacity, frequency, and evaluation, such as "how much", "how often", "how satisfied", participants felt in the last two weeks. Scores were computed by summing the scale scores of each domain and dividing by the number of items in the domain. Internal reliability for the WHOQOL-BREF is acceptable for domains 1-physical(α=0.82), 2-psychological (α=0.81), and 4-enivronmental (α=0.80), and marginal for domain 3-social (α=0.68)(Skevington et al., 2004). The WHOQOL-BREF has been used as an assessment measure in CP (Colver, 2012).

3.3.4 The Self-Perception Profile for Adults (SPPA)

This questionnaire is a multidimensional reflection of one's self-esteem, self-image, and perceived competence. It was created in response to the idea that an individual is not uniform in their feelings of adequacy in any given domain of their life (Messer & Harter, 2012). The SPPA examines the individual's profile of perceived competencies across different domains. There are twelve domains within the SPPA and include sociability, job competence, nurturance, athletic abilities, physical appearance, adequate provider, morality, household management, intimate relationships, intelligence, sense of humor, and global self-worth. The questions are formatted as forced choice on a 4-point scale in which two statements are made and respondents are asked to select which type of adult they are most like as "sort of true for me" or "really true for me". The wording of items is counterbalanced and the score of each item ranges from 1-4, where a score of 1 indicates low perceived competence/adequacy and a score of 4 reflects high perceived competence/adequacy. The SPPA's sensitivity to change and to individual differences across a diverse dimensions allows for its application in both therapeutic and research settings (Messer &

Harter, 2012). Internal reliability for the twelve domains of the SPPA are acceptable with Cronbach alpha ranges of 0.65-0.90.

3.3.5 Barthel Index

This self-report survey is a measure of functional independence in those with neuromuscular and musculoskeletal conditions (Sainsbury et al., 2005). The main aim is to establish a degree of independence from any help, physical or verbal, however minor and for whatever reason (Benner et al., 2017). This ordinal scale is comprised of ten ADLs that are scored in steps of five for a maximum score of 100. This measure was chosen because it was found to be reliable when administered face-to-face or remotely (ICC 0.89) and on testing by different observers (ICC 0.95–0.97)(Sainsbury et al., 2005). The Barthel Index has been used to assess independence in adults with CP (Benner et al., 2017).

3.3.6 PARA-Sci

The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-Sci) is a 3-day recall of activity, including both activities of daily living (ADL) and leisure time physical activity (LTPA)(Martin Ginis & Latimer-Cheung, 2005). Participants are surveyed regarding activities performed in the last three days. It aims to measure the type (ADL vs. LTPA), frequency, duration (time in minutes), and intensity (mild vs. moderate vs. heavy) of physical activity. The PARA-Sci is sensitive enough to measure very low intensity activities expected of people who have disabilities with physical limitations. This semi-structured interview has been designed to be conducted over the phone or using other methods of face-to-face communication such as Zoom, Facetime, or Skype. This instrument has been validated for use in CP and other disabilities with physical limitations (Claridge et al., 2015; Martin Ginis et al., 2017).

3.3.7 Survey Administration

Surveys were delivered to participants via a password protected Qualtrics link once Informed Consent was received. Surveys were read and completed by each participant in the order of QOL, self-perception, pain, and independence. Participants were allotted as much time as needed to complete the surveys; however, the surveys were completed in an average of 20 minutes.

3.3.8 Statistical Analysis

To determine the relationship between factors and the selection of PA, individual Pearson's Chi-Square Test of Independence were conducted between each factor domain, and the type and intensity of activity chosen for a total of 29 tests. These analyses determine whether variables within a contingency table are associated. Chi-square is a significance statistic and does not necessarily imply clinical importance. Therefore, the use of statistical strength test is essential and Cramer's V test is the most common (McHugh, 2013). Minutes of time spent in each type and intensity of PA (i.e., mild ADL, mild LTPA, moderate ADL, etc.) were the dependent variables in this analysis while the scores of the factor domains were the independent variables.

A forward regression approach was employed to construct a multivariable model that would determine if a particular factor had the greatest influence on self-selected types of PA. The PA intensities collected from the PARA-Sci were collapsed across PA type for an overall amount of time (in minutes) spent in ADL and LTPA (dependent variables). Estimates of effect size were reported as the standardized coefficients (β) for the independent variables. A strong effect of the independent variable on the outcome of interest corresponds with a larger beta coefficient with $\beta \geq 0.50$ representing a large effect (Kelley & Preacher, 2012). Interaction variables were created between participant's age and each factor domain to determine if there is an age effect on the factor that influences PA behavior the greatest. All statistical analyses were completed with IBM-SPSS version 28 and a two tailed significance level of ($p<0.05$).

3.4 Results

Table 5 illustrates the significant relationships from the Chi-Square tests and the accompanying Cramer's V. There were strong associations throughout the significant results demonstrated by all Cramer's V values of 0.52 or higher. No significant relationships existed between time spent in mild activities of daily living and factor domains. This finding is interesting because more time was reported in mild ADLs than any other type or intensity of PA (Figures 2-4 from Chapter 2). Pain interference was only associated with time spent in moderate ADLs. Time spent in heavy ADLs had the most significant associations with factors which were predominately from the domains of self-perception and pain.

In terms of time spent in leisure-time PA, psychological QOL and self-perception of athletic ability had the most associations with time spent in leisure activities regardless of intensity. The physical QOL domain and functional independence were associated with mild intensities of leisure activity, but no other intensities. Heavy intensities of leisure activity had more association with domains of self-perception than any other factor. Severity of pain only had one association and it was with time spent in moderate leisure activities. In general, self-perception and pain domains were associated with activities of high perceived exertion, both required daily tasks and self-selected activities of enjoyment. No associations were seen for the environment domain of QOL, self-perception of sociability, job competence, morality, intelligence and sense of humor, or pain in terms of support, life control, affective distress, household chores, or social activities.

--- Table 5 ---

For the multivariable regression analyses all the personal factor domains were entered into the model first, followed by the interaction variables. Table 6 depicts the final forward regression models for time spent in overall activities of daily living and leisure-time physical activity, respectively. When looking at time spent in overall ADLs, the first entry only explained 44.4% of the variance in the model ($F_{27,40}$= 1.19, p=.31). Despite the second entry increasing the variance explained to 75.2% ($F_{52,15}$= .88, p=.75) neither of the models were significant. This finding demonstrates that the factors chosen for this model do not accurately predict time spent in activities of daily living, nor is age an effect.

Conversely, the factor domains accounted for 63.5% of the variance in time spent in overall LTPA ($F_{27,40}$= 2.58, p=.003) with significant predictors including self-perception of athletic ability (β= .41, p= .004), severity of pain (β= 2.92, p= .01), affective distress (β= 2.66, p= .02), and pain associated with general activities (β= -4.73, p= .04). Again, the entry of the interaction variables increased the variance explained by the model, but this was not significant ($F_{52,15}$= 2.39, p=.24). This finding depicts the four factor domains that predict time spent in leisure time PA and these factors are not affected by age.

--- Table 6 ---

3.5 Discussion

The purpose of this study was to look at different factors and determine the impact on two types of PA, activities required for independence and activities chosen for enjoyment. It was determined that the factors associated with all intensities of leisure PA were psychological QOL and self-perception of athletic ability. It is not unexpected that self-perception of athletic ability has strong associations with all intensities of LTPA. However, the finding that psychological QOL contributes to LTPA demonstrates the importance of psychological health. These findings combined suggest that psychological well-being plays a large role in self-selected LTPA (Ferkel et al., 2017).

Independence and physical QOL were strongly associated with mild LTPA. Independence is highly correlated with QOL (Chulliyil et al., 2014), and in this sample QOL has strong associations with higher intensity activity selection. Despite the association between physical functioning and independence, perception of independence versus actual functional ability may influence QOL to a greater degree (Causgrove Dunn, 2017; Cheong et al., 2018). There were few relationships between moderate activity levels and pain severity and pain interference. While it was hypothesized that pain would be strongly associated with self-selected PA, these findings are in line with reports that pain in CP, while extremely common, does not interfere with the selection of activities (Jahnsen et al., 2004; van der Slot et al., 2020). Independence and physical QOL were strongly associated with mild LTPA.

Physical QOL was strongly associated with moderate and high intensities of ADL. This suggests that the ability to exert oneself at such high intensities of ADL relies heavily on physical QOL. This is interesting because unlike all intensities of LTPA, it appears that the execution of ADL is perceived to be more physically demanding than LTPA. This finding suggest that adults with CP are perceiving their physical abilities to be higher than they are which would support other research on self-perception and CP (Dunn et al., 2007).

Time spent in heavy ADLs had the most associations with factor domains and many of the domains have to do with the perception of interactions with other people. This phenomenon may be in large part due the high intensities of activities required to maintain a household. The findings further consider the level of intensity that is required to complete activities outside of typical day-to-day ADLs. These domains may be outside of the individual’s typical repertoire and may require higher intensities of participation (van der Slot et al., 2020).

While the Chi-Square Test looked at the possible associations among personal factor domains and PA type and intensity, a forward multivariable regression determined which factor domains influenced the selection of PA the greatest. The first set of models entered into the regression were concerned with time spent in overall ADL. Neither the factor domains nor the interaction variables were significant in the model, despite high percentages of variance explained. This is likely because ADLs are socially mandatory whereas leisurely PA is a personal choice. Furthermore, the factor domains chosen may not impact the completion of ADLs because individuals with CP have spent their lives compensating these movements or eliminating them completely from their movement repertoire (Jahnsen., 2004). Conversely, the second set of models computed with regards to time spend in overall LTPA had a significant relationship with factor domains. Significant and independent predictors of time spent in overall LTPA were perception of athletic ability, pain severity, affective distress associated with pain, and pain associated with completing general activities.

Self-perception of athletic ability was strongly associated with all intensities of LTPA, therefore, its role as a significant predictor in the regression model is not surprising. However, it had the smallest effect in terms of the standardized coefficient (β= .41) which suggests that it is not the most impactful predictor. This could be due to the difference in conceptualization of ability by individuals with CP compared to the general population (Cheong et al., 2018). Pain severity was only associated with time spent in moderate LTPA in the Chi-Square Test but is the strongest positive predictor (β= 2.92) of time spent in overall LTPA. It is well established that PA is the most accessible and cost-effective approach to pain management in CP (Schwartz et al., 1999; Zaffuto-Sforza, 2005). This finding is likely a result of adults with CP managing their pain with movement especially when considering the intensity, they are working within. Mild

LTPA may not increase energy expenditure beyond typical mobility while heavy intensity LTPA may exacerbate the pain in the perpetual activity loop discussed earlier (Turk, 2009).

Affective distress, as it relates to pain, is the second strongest positive predictor of time spent in overall LTPA (β= 2.66). It has been reported that mood affective disorder (MAD) is the most common mental health disorder among adults with CP (Whitney et al., 2019) and that MAD is increased by the presence of pain (Whitney, Bell, et al., 2020). Combined with the findings of this regression, it is suggested that pain severity and affective distress are the two leading positive predictors of time spent in overall LTPA. The last predictor of time spent in overall LTPA was pain associated with completing general activities and it was negative (β= -4.73). This domain is different from the pain interference domain. It is fair to assume that if an individual is in pain when completing general daily activities then they would participate less in planned PA, regardless of the positive outcomes that can come from increased PA participation.

The final predictive model is as follows, overall time in LTPA = -786.58 + (155.78 athletic ability) + (698. 22 pain severity) + (993. 42 affective distress) + (-1912.82 general activities). Where a one unit increase in the independent variable is associated with the given change of time (in minutes) spent in LTPA. For example, a one unit increase in self-perception of athletic ability results in a 155.78-minute increase in time spent in LTPA. This would be over three days as per the methodology of the PARA-Sci. Despite the large negative effect of pain associated with completing general activities, the combination of the other three positive factors can outweigh the negative factor. This highlights the importance of properly managing pain, and indirectly affective distress, while increasing positive self-perception as well. The fact that this regression model was no longer significant with the addition of the interaction variables suggests that the predictors of time spent in overall LTPA are not affected by age. More importantly, the predictive value of these factor domains remains constant throughout the life course of this population of adults with CP.

3.5.1 Practical Implications and Future Research

Findings from this study have significant implications for habilitation and future research. Firstly, there is a strong association psychological QOL and self-perception of athletic ability with all intensities of leisure PA. There is a psychological component to PA participation that plays a larger role in intensity of activity chosen than physical ability or pain. Practitioners should aim to increase their assessment and monitoring of psychological outcomes, such as self-perception, to ensure that adults with CP have positive associations with their body’s structures and functions. Even if the perceived abilities are higher than the objective abilities, psychological health and perception are still strong associates of activity participation.

Next, the multivariable regression provided a predictive model of time spent in overall LTPA. The model stresses the importance of monitoring and managing pain as a method of increasing time spent in LTPA. The inclusion of self-perception of athletic ability in the model supports the prospect of PA as a mode to decrease pain and affective distress. Practitioners should offer PA suggestions that maintain a moderate level of intensity to help alleviate any pain that accompanies the completion of general activities. Future work in this area should use another method to capture the current level of PA participation other than a semi-structured interview. Activity trackers, or other objective measures of PA, would allow for a more precise association with personal factors and may alter which personal factors are predictive of participation. Future work should also look more closely at the interaction between pain and affective distress, how that phenomenon possibly changes throughout the life course, and what affects the association has on participation.

3.5.2 Study Limitations

As with all research, there are limitations to this study. The most notable limitations are the surveys used to capture the domains of factors. It is difficult to find consensus on which surveys are better equipped to detect changes in particular outcome measures, making it difficult to compare and generalize the results of this study to others like it. Another limitation of this study comes within the Barthel Index. While this survey is commonly used to determine level of independence, unlike the other surveys, the Barthel Index is not comprised of domains. Components of independence (i.e., ability to transfer oneself) may be associated with different types and intensities of PA, but because the concept of independence was not subcategorized those associations may not have been revealed.

3.5.3 Conclusions

This study examined the possible relationships between personal factors and participation in type and intensity of PA. Additionally, this study explored the predictive nature of these personal factors. Physical and psychological quality of life and self-perception of athletic ability had the most associations with PA types and intensities. Time in overall leisure-time PA is predicted positively by self-perception of athletic ability, pain severity, and affective stress while negatively by pain associated with the completion of general activities. Future work should look more closely at the interplay between pain severity and affective distress and the impact on PA participation.

3.6 Tables

Table 5. Chi-Square Tests of Independence

Factor *Domain*	Mild ADL	Mild LTPA	Moderate ADL	Moderate LTPA	Heavy ADL	Heavy LTPA
Quality of Life						
Physical		p= .03, V= .58	p= .03, V= .83		p= .03, V= .58	
Psychological		p= .003, V= .54		p= .03, V= .59		p= .05, V= .53
Social			p= .04, V= .84			
Self-Perception						
Athletic Ability		p< .001, V= .58		p= .04, V= .63		p< .001, V= .60
Nurturance			p= .002, V= .86		p= .003, V= .62	
Household Management			p= .04, V= .84		p< .001, V= .63	
Physical Appearance				p= .03, V= .59	p= .02, V= .59	
Intimate Relationships					p= .04, V= .59	p= .003, V= .56
Adequate Provider						p= .03, V= .53
Global Self Worth			p= .04, V= .83			
Pain						
Interference			p= .02, V=. 83			
Severity				p= .01, V= .76		
Outdoor Activities					p= .01, V= .79	
Activities Away from Home		p= .02, V= .75			p= .01, V= .75	p< .001, V= .81
General Activities			p= .02, V= .88		p< .001, V= .94	
Independence						
Barthel Index		p= .002, V= .52				

Significant (p< 0.05) associations between time spent in type/intensity of physical activity and individuals factor domains.
ADL = activity of daily living; LTPA = leisure time physical activity

Table 6. Multivariable Regression Model for Time Spent in Leisure-Time Physical Activity

Variable	**Standardized coefficients (β)**	**Sig. (*p*)**
Self-perception of athletic ability	0.41	.004
Pain severity	2.92	.01
Affective distress	2.66	.02
Pain associated with completing general activities	-4.73	.04
Model Statistic: $F_{52,15}$= 2.39, p=.24; R^2= .64		

Chapter 4 The Feasibility of Using Assessments of Physical Function via Teledelivery

4.1 Abstract

Introduction: In pediatric-onset conditions such as cerebral palsy (CP), physical function may continue to decline with age. For many individuals, however, these changes may not be addressed by health care providers once patients transition to adulthood. This has been further exacerbated by COVID-19 which has limited or suspended non-essential, in person clinical visits. As a result, remote delivery of health care has taken on greater importance. The purpose of this study was to determine the feasibility of assessing physical function in adults with cerebral palsy using a telehealth model of delivery.

Methods: Twenty adults with CP (mean age = 44.1 ± 10.8 years) completed all components of the SPPB, including timed measures of balance (side by side, semi-tandem, tandem), gait speed, and repeated chair stand. Additional tests included the Timed Up and Go, the Romberg Test, four reaching and manipulation components of the Streamlined Wolf Motor Function Test (WMFT) and the bimanual upper extremity assessment ABILHAND.

Results: Feasibility was assessed based on the number of participants who were able to complete all assessments, do so safely without any adverse events such as loss of balance, and complete the assessments so that their scores fell within the standardized norms. Average testing time was 32 ±6.9 min. Most adults completed all assessments. Seventeen adults were able to complete the assessments without any adverse events (momentary loss of balance). Ten adults had SPPB scores that fell within the normative SPPB range. Lower SPPB scores were indicative of a slower

working pace or use of an assistive device (e.g., posterior walker). All 20 participants fell within the normative values for the 9 WMFT items.

Conclusions: This feasibility study shows that remote assessment of physical function can be performed accurately and efficiently in adults with CP. Balance assessments that challenge the base of support and utilize lower limb muscle strength are meaningful predictors of physical function.

4.2 Introduction

Because CP is a pediatric onset disability, research on functional outcomes is often limited to childhood and adolescence (Benner et al., 2019). Unfortunately, it has been suggested that the transition to adulthood is the end of progressive gains in functional ability for individuals with CP and emphasis should be placed on maintaining the functionality that has already been established (Rosenbaum & Gorter, 2012). However, individuals with CP have life expectancies similar to those without CP (Turk & Fortuna, 2019). Thus, there is a growing number of adults with CP who would benefit from a better understanding of what to expect about aging with a pediatric onset disability.

CP is often described as non-progressive. While it is true that the trauma sustained to the brain that resulted in CP does not progress (Mezaal et al., 2009; Turk & Fortuna, 2019), adults with CP would likely argue that the functional aspects of their disability have indeed progressed as they have aged. In fact, it is likely that adults with CP are experiencing a more rapid progression in their aging compared to those born neurotypically (Benner et al., 2017; Liptak, 2008; Mudge et al., 2016; Turk, 2009; Usuba et al., 2014; Yi et al., 2019). Adults with CP can expect to encounter common secondary health conditions, such as pain and fatigue (Haak et al., 2009; Turk & Fortuna, 2019). However, adults with CP are also at an increased risk of additional comorbid conditions such as diabetes, hypertension, and stroke (Cremer et al., 2017; Peterson et al., 2015). While these conditions are often seen in the general population, adults with CP may be more prone to health due to a natural predisposition or the presence of underlying risk factors (Turk, 2009; Turk & Fortuna, 2019). There is an even greater prevalence of multimorbidity among the obese and higher GMFCS levels of this population (Cremer et al., 2017). Beyond these secondary and multimorbid conditions, adults with CP also experience deterioration in their physical functioning as well (Benner et al., 2017, 2019; Hurvitz et al., 2021; Peterson et al., 2015). With aging, there is a decrease in muscle flexibility, strength, and endurance. This leads to a limitation in weight bearing activities which can impact the efficiency and overall ability to maintain upright mobility(Frisch & Msall, 2013; Nieuwenhuijsen et al., 2009).

Locomotor activities among adults with CP cause physical strain and it has been shown that those who experience high levels of strain when walking will walk less in their daily life (Slaman et al., 2013). A review by Morgan & McGinley (2014) demonstrated that over twenty-five percent of individuals with CP experience walking declines in early adulthood which worsen with increasing age. In a similar longitudinal study by Opheim et al. (2009) on walking cessation in CP revealed that 79% of those with bilateral CP and 37% with unilateral CP reported deteriorated walking that was associated with greater pain intensity and frequency, physical fatigue, and reduced balance.

Loss of balance and the subsequent risk of falling is a growing concern for adults with CP. Balance dysfunction has been reported as the leading cause of self-reported decline in mobility throughout adulthood for those with CP (Morgan & McGinley, 2013). Morgan & McGinley (2013) found that 40% of adults with CP fell monthly, while 75% fell at least every two months. Morgan et al. (2016) found that nearly all participants reported a fall in the previous year, and more than half reported near falls. Falls often occurred indoors, at the participants' home, and while performing nonhazardous activities. It is clear to see the cascading effects the aging CP body can have on health, physical function, and mobility. Ultimately, the fear of falling can contribute to a reduction in mobility for adults with CP (Morgan & McGinley, 2013).

Adults with CP have preventative health opportunities that differ from the general public. Turk & Fortuna (2019) suggest several preventative and treatment strategies for common health conditions seen in adults with CP. For musculoskeletal concerns such as contractures and foot or ankle pain, physical therapy and orthoses or wheelchair adjustments are suggested as treatment strategies. Bone health in CP is prevented through routine exercise and bone density evaluation. Common complaints of pain and fatigue can be prevented through routine exercise and progressive pain management programs.

Methods for managing the most influential health concerns associated with CP and aging have progressed, and yet, adults with CP are underserved in health care. The ability for adults with CP to access appropriate healthcare is a unique challenge. (Haak et al., 2009; Hurvitz et al., 2021; Turk, 2009). First and foremost, for the number of individuals with CP in the United States, there is an underwhelming number of professionals who work with the adult end of this population. Pediatricians work with children and often their best practices do not transfer to adult care. Adult providers are not as knowledgeable about CP due to its pediatric nature and best practices for this age group are just beginning to emerge (Hurvitz et al., 2021; Mudge et al., 2016; Young et al., 2005). Further, a childhood filled with hospital visits and habilitation may lead to negative attitudes towards the health care system and may impede health and wellness maintenance (Liptak, 2008). Other barriers to regular health care maintenance may include inaccessible health care facilities due to distance (Hurvitz et al., 2021), cost to travel or accessibility of ride share companies (Young et al., 2005), need and accessibility of support staff (Mudge et al., 2016), lack of resources to help manage life independently (Freeman et al., 2018; Frisch & Msall, 2013), or social attitudes and assumptions towards a visible disability (Mudge et al., 2016). By incorporating technology in the form of telehealth, it is possible to increase the scope and reach of healthcare for those aging with CP.

The ease and usefulness of health care delivered via telehealth has become increasingly apparent in the wake of COVID-19 restrictions. A review by Mauldin et al. (2021) examining evidence-based approaches to conducting nutrition assessments remotely found that telehealth consultations are effective for those seeking nutritional intervention. Moreover, patients preferred the telehealth modality over the face-to-face assessment process. There has even been a push for telehealth physical therapy delivery. Delivery of physical therapy via telehealth is expanding. Miller et al. (2021) evaluated the feasibility of implementing physical therapy remotely based on reach, effectiveness, adoption, implementation, and maintenance of the program. It was determined that the implementation of telehealth physical therapy was both feasible and acceptable.

With the acceptance of telehealth gaining traction, it is reasonable to assume that the physical function of adults with CP could be assessed and monitored through a telehealth model. Physical function is described as an individual’s ability to perform everyday physical activities that build the foundation for more discretionary activities of daily living and leisure, such as self-care, meal prepping, or hiking (Stewart & King, 1991). Therefore, the goal of this study was to determine the feasibility of assessing physical function via a remote platform. To accomplish this goal, a sample of adults with CP completed a series of assessments to measure domains of function. This study aimed to provide support for telehealth as a mechanism to increase the breadth of health and wellness maintenance for adults with CP.

4.3 Methods

4.3.1 Study Population

All methods and procedures were approved by the Health Sciences Institutional Review Board of The University of Michigan and all participants signed electronic informed consent prior to the start of the study. Due to the pilot nature of this study, 20 participants (mean age = 44.1 ± 10.8; female = 75%) from the previous studies were randomly recruited into this final study. Participants were 18 years of age and older, had a medical diagnosis of cerebral palsy, fall within categories I-III of the GMFCS (diplegia = 85%) indicating the ability to ambulate independently or with the use of an assistive device (i.e. walker or forearm crutches) (Palisano et al., 2008; Palisano et al., 2000; Rosenbaum et al., 2003), and were able to stand with minimal assistance for 15 minutes. If a participant used assisted devices for mobility in their daily life (i.e., posterior walker or forearm crutches), they were encouraged to do so in the assessments as well. The average time to complete all but the ABILHAND assessment was 32 ± 6.9 minutes. The ABILHAND survey was delivered electronically when participants signed the Informed Consent and completed before the schedule telehealth assessment.

4.3.2 Assessments of Physical Function

Participants were given written instructions, complete with pictures, as to how to set up their “at-home testing area” so that the assessments could be properly observed by the investigator as seen in Figure 6. Due to the remote nature of these assessments, safety measures were put into place to assure safety of the participants. Participants were asked to remove all possible hazards from the testing area and were told that balance tests could be completed next to a wall or chair to maintain balance if needed. Participants were asked before every task if they felt comfortable performing the task. If safety was a concern, the assessment was not performed. Five domains of physical function were of interest: mobility, functional leg strength, balance, sensory integration, and gait speed. Additionally, observed and participant reported outocme measures of upper extremity mobility were assessed.

--- Figure 5 ---

Short Physical Performance Battery

The Short Physical Performance Battery (SPPB) is a measure of functional status and physical performance that was first described in 1994 (Treacy & Hassett, 2018). The SPPB is a good predictor of fall risk, frailty, and cessation of walking (Ortega-Pérez de Villar et al., 2018; Pavasini et al., 2016; Vasunilashorn et al., 2009). This battery was used as a sounding board for the compilation of assessments due to its ability to detect decreases in functional strength and mobility. The SPPB is based on three timed tasks: 1. balance tests, 2. the repeated chair stand test and 3. gait speed test (See below). The timed results of each task fall within ranges of predefined cut points for obtaining a score. These total scores can range from 0 (worst performance) to 12 (best performance).

1. Balance Tests

Participants were asked to stand with their feet in three different positions: side-by-side, semi-tandem, and tandem. The participant attempted to hold the stance for 10 seconds, in which time they are allowed to bend their knees, use their arms, or move their body to maintain balance. Their time was recorded and matched against a 2 or 3-point scale (Treacy & Hassett, 2018).

2. Chair Stand:

Participants were asked to stand in front of the armchair as if they were about to sit. They fold their arms across their chest and sit keeping their feet flat on the floor and then proceed to stand back up. If the participant was able complete the Chair Stand, they moved onto the Repeated Chair Stand in which the move is performed again five times in a row without stopping. The time was recorded in seconds and matched against a 5-point grading scale. If either the Chair Stand or Repeated Chair Stand were unsuccessful, the participant received a zero (Treacy & Hassett, 2018).

3. Gait Speed

The participant was instructed to walk a 3-meter line at their typical walking speed. At the end of the route the participant was instructed to turn-around and reset themselves. When instructed again, they returned to their beginning point. Walking once again at their typical speed. The test was terminated when the participant completed two 3-meter walks. The time was recorded in seconds and the average of two times was taken then compared against a 4-point scale (Treacy & Hassett, 2018).

Timed Up and Go (TUG)

This mobility assessment is often used in older populations and is a good predictor of fall risk (CDC, 2017). The test is completed on a 3-meter line with a standard armchair at one end. The participant began by sitting in the chair facing the assessment area. On “Go” the participant stood up from the chair and walked the line at normal pace. Once they reached the 3-meter mark they turned around and walked back to the chair. The test was terminated when the participant sat back down in the char. The time it took to complete the task was recorded in seconds and anything less than 11 seconds was considered good.

Romberg Test

This assessment of sensory integration looks primarily for dysfunction within the cerebellum and vestibular systems. A common diagnostic tool among clinicians, the test requires participants to stand with their feet together, arms by their side, and eyes closed. It is scored simply as negative or positive results, with negative indicating minimal sway and a termination after 20 seconds. Positive results would indicate failure to keep eyes close, loss of balance requiring the displacement of the feet or the participant falls completely (Busti, 2015).

Streamlined Wolf Motor Function Test (SWMFT)

This upper extremity motor assessment was utilized for its streamlined reaching and manipulation components. Participants were asked to lift a can, lift a pencil, turn a key, and fold a towel. These tasks were scored on a scale of 0 to 5 based on ability to perform and fluidity of movements (Wolf et al., 2001; Wu et al., 2011). Depending on whether participants had hemiplegia or diplegia, they were asked to perform the SWMFT with either their more affected side (hemi) or their non-dominant side (di) to introduce a level of standardization into the assessment. This assessment was completed remotely using objects the participants had in their home, some of the manipulative objects were different (i.e., soda pop can vs. soup can, or a pencil vs. a pen) but maintained the weight and grip necessary to capture the movement quality of interest.

ABILHAND

This semi-structured response questionnaire measures manual ability according to an individual's perceived difficulty performing daily bimanual tasks. For this study, ABILHAND was used as a patient reported outcome (PRO) measure and it is scored from 0-2 based on ability to execute the given tasks. The ABILHAND has been modified for several conditions including neuromuscular conditions like CP (Vandervelde et al., 2010).

4.3.3 Determining Feasibility

Feasibility was assessed based on the proportion of participants who were able to complete all of the assessments (i.e. upper and lower extremity, objective vs. subjective UE assessments), do so safely without any adverse events such as falling, and complete the assessments so that their scores fall within the reference data for that particular assessment (Douma et al., 2018; Lauzé et al., 2017; Marini et al., 2019; Preston et al., 2017).

4.3.4 Statistical Analysis

Of interest was determining if there was an age effect on upper or lower extremity function. Therefore, Pearson's correlations based on assessment score and age were conducted. Additional interest was in determining if there was a relationship between the two upper extremity measures. More specifically if participant reported perception of function differed significantly from the researcher's observational assessment. All statistics were performed on SPSS v28; significance was set at $p< .05$.

4.4 Results

4.4.1 Feasibility

Sixteen out of the 20 participants were able to complete all the assessments. For the remaining four participants only one was unable to physically complete the lower extremity assessments, but the other three did not have adequate space to perform the TUG or gait speed assessments safely. A small number of participants (n=3) had momentary losses in balance when completing the semi-tandem and tandem stances and required holding onto an object to regain balance.

When looking at the scores for the SPPB (M= 5.4 ± 2.8) all but one participant failed to reach the cut-off score of 10 (Halaweh et al., 2016). This indicates that these participants are at a high risk for mobility limitations. The TUG test resulted in 85% of participants taking longer than 11 seconds to complete the assessment. This categorizes those adults as high risk for falling. Conversely, 90% of participants were able to complete the Romberg test which means that they have good overall vestibular and proprioceptive sense.

The upper extremity scores showed that 100% of participants were able to complete the four tasks of the SWMFT (M= 16.1 ± 3.5). The ABILHAND does not have cut-off scores, but higher overall scores are associated with greater perceived performance. With that, 75% of the participants scored higher than 30 out of 36 (M= 33.3 ± 3.2) on the ABILHAND.

4.4.2 Outcomes

The total score of the SPPB was correlated with the Romberg test (r= .47, p= .04). There was no correlation between SPPB scores and the time it took to complete the TUG (r= .23, p= .33). The scores from the SWMFT and the ABILHAND were highly correlated (r= .76, p< .001). No significant correlations existed between age and any of the assessments.

4.5 Discussion

The telehealth model of service delivery has grown significantly over the last ten years (Zischke et al., 2021), and more so in light of Covid-19 (Ben-Pazi et al., 2020). Within pediatric

CP, telehealth has been shown to be an effective method for monitoring and assessing infants at high risk (Maitre et al., 2021; Schlichting et al., 2022), providing upper extremity interventions for infants (Pietruszewski et al., 2020), conducting swallowing evaluations (Kantarcigil et al., 2016), maintaining continuous care through medication management (Ben-Pazi et al., 2020) and physical therapy (Zischke et al., 2021), and delivering at home exercise programs (Ben-Pazi et al., 2020). Adults with CP experience several challenges regarding ongoing healthcare access (Hurvitz et al., 2021), and yet, adults with CP experience progressive deterioration in function throughout the course of their lives and would benefit from ongoing maintenance and monitoring (Benner et al., 2017).

This study, to our knowledge, was the first to determine the feasibility of assessing physical function in adults with CP using a telehealth model. The overall feasibility was established as all but one participant was able to complete all the assessments. Other researchers who have conducted telehealth interventions have noted that it takes longer for participants to set-up and perform interventions at home than is usually required in the clinic setting (Richardson et al., 2017). However, in this study the average time to complete the assessments was 32 minutes (S.D. 6.9 minutes) and participants were asked to set-up their assessment space prior to the Zoom call. The time it took participants to set-up was not assessed in this study, however, it is assumed that the possible time commitment associated with telehealth still outweighs the limitations associated with face-to-face care (i.e., travel time, cost of travel, loss of income due to time off work, risk of exposure to disease, etc.). Overall, the reliability between face-to-face assessments and telehealth assessments has been determined (Ben-Pazi et al., 2020;

Cabrera-Martos et al., 2019) and overall satisfaction with telehealth is high (Chaudhry et al., 2021).

Balance is the most self-reported predictor of decline in functional mobility (Morgan & McGinley, 2013) and contributes to all the assessments used in this study. Yet, momentary loss of balance was only seen in three participants during the semi-tandem and tandem stance in the SPPB. Additionally, only one participant completed the TUG within the given timeframe while most of the sample successfully completed the Romberg test. These preliminary findings suggest that adults with CP have difficulty integrating and compensating a narrow base of support, likely due to decreased muscular strength in the lower limbs (Ross et al., 2016). The static standing aspects of the SPPB and the TUG challenge balance by altering the base of support while the Romberg removes visual feedback. In the assessment of impaired balance control, it appears that assessments which stress the base of support and muscle activation of the lower limbs may be more meaningful predictors of function than static balance.

4.5.1 Practical Implications

The purpose of this study was to determine if it was feasible to assess motor function remotely via a teleconference platform like Zoom. As discussed in the opening of this study, the move to telehealth care delivery was on a rise before the global pandemic and has only increased further in response. By testing the feasibility of such assessments, we can add to the growing body of support that telehealth care delivery is a reasonable and timely way to support or substitute face-to-face care. Furthermore, medical practitioners and researchers are consistently motivated to reach more individuals aging with CP who may require specialized care and who may not be able to seek the care that they need. Telehealth care delivery essentially removes the barriers of distance, time, and cost of traveling to see a healthcare provider. This approach allows professionals to continuously monitor individuals from afar while remaining present in the day-to-day maintenance of aging with CP.

4.5.2 Study Limitations and a Call for Future Research

The first limitation of this study is the sample size. While this study was preliminary and exploratory, the small sample size makes it difficult to come to conclusions regarding the results of statistical analyses. Furthermore, the study participants were all categorized as GMFCS I-III. The group of assessments chosen for this study may not be feasible for those with more severe CP who may have additional intellectual disability or difficulty with communication or executive function. While this study was strictly a feasibility study, there was no assessment on participant satisfaction with the delivery of telehealth assessments. Future work in this area should integrate satisfaction assessments into the assessment protocol.

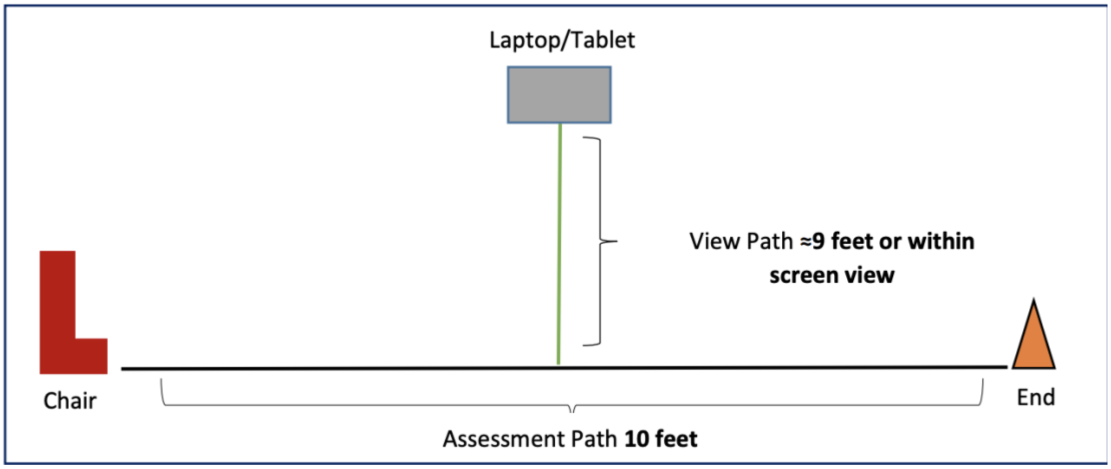
Future studies using telehealth to monitor and assess physical function in CP should compare results of assessments done in a face-to-face clinic setting to the remote assessments to assure reliability. This course of action was not taken in this study because of the restrictions implemented to mitigate the spread of Covid-19. Further considerations for future work are related to the standardization of assessment set-up. There is inherent variability among participants when establishing their assessment area and this makes it difficult to compare across measures. Care must be taken to control for as much variation in the environment as possible to maintain reliable data across assessments.

4.5.3 Conclusion

This feasibility study shows that remote assessment of physical function can be performed accurately and efficiently in adults with CP. Balance assessments that challenge the base of support and utilize lower limb muscle strength are meaningful predictors of physical function. Future work in this area should test the reliability among face-to-face and telehealth assessment results, quantify participant satisfaction with telehealth delivery, and standardize assessment space set-up to decrease variability among participants.

4.6 Figure

Figure 5. Visual Instructions for Participants to Set-up Assessment Space



Chapter 5 Discussion

Aging with cerebral palsy (CP) has become an area of great interest over the years due to the growing number of adults with CP. The overall prevalence of CP is reported as 2-3 out of 1000 live births (Oskoui et al., 2013), which has remained stable for years due to increased survival of at-risk infants born prematurely (Turk & Fortuna, 2019). Between 1983 and 2010 the mortality rates of children with CP decreased 2.5% per year (Brooks et al., 2014) and it is estimated that the worldwide prevalence of CP is 17 million people (Graham et al., 2016). The prevalence of CP among non-Hispanic black infants is higher than non-Hispanic white infants (Van Naarden Braun et al., 2016) which suggests that there is an inequity of health care access for minorities (Wheeler & Bryant, 2017). The issue with access is further underscored by emerging research related to the broad impact of CP across the lifespan (Hurvitz et al., 2021; Peterson et al., 2015). Secondary health conditions (i.e., pain and fatigue,) and multimorbidity are not uncommon concerns (Cremer et al., 2017), while age related changes in bone and muscle health further impact adults with CP (Whitney et al., 2018). Together, these issues can lead to reduced participation in daily, leisure, or social activities.

Physical activity (PA) for years has been shown to positively affect health and mitigate the onset of secondary conditions in the public, including those with disabilities (Piercy et al., 2018). The phrase “exercise is medicine” illustrates the important impact PA can have on cardiovascular disease, metabolic disease, musculoskeletal disorders, psychiatric disease, cancer, and others common diseases (Carroll et al., 2021). In the second study of this dissertation, it was determined that participation in PA among adults with CP can be impacted by several factors.

Specifically, these factors included physical and psychological quality of life, self- perception of athletic ability, and pain when completing general activities. In contrast, study 1 showed that despite low participation in PA among adults with CP, they still had positive attitudes and perceptions towards lifelong PA opportunities. Study 1 further revealed, however, that as the age of participants increased, self-assessment of movement quality decreased. The combined results of studies 1 and 2 demonstrate the importance of perception and how an individual's evaluation of their own ability can act as a barrier to ongoing participation in PA.

There is much emphasis placed on early efforts to enhance childhood mobility for those with CP, with a goal of increasing movement quality and overall independence (Rosenbaum & Gorter, 2012). This is understandable as this is a time when the capacity to enhance neural connections in the brain are high, facilitating the development of meaningful motor patterns (Kwong et al., 2018). However, this typically leads to extensive time spent in in habilitation, which, in turn, can often be accompanied by painful experiences such as stretching, bracing, or functional electrical stimulation (Houx et al., 2021). School-based PA such as physical education classes or organized sports can present their own barriers among children with CP. While both are further opportunities for children with CP to be physically active and socialize with their neurotypical classmates, these environments also have the potential to negatively promote differences among peers, such as focusing on an individual's need for assistance. Unfortunately, bullying and feelings of isolation can come from such interactions (Haegele & Sutherland, 2015).

Adverse childhood events, such as painful therapeutic experiences or bullying, have been linked to long-term poor health outcomes such as obesity (Schiff et al., 2021), cardiometabolic diseases and cancer (Deighton et al., 2018). The Assessment of Attitudes towards Lifelong Physical Activity survey was created as part of this dissertation to meet a gap in the understanding of how lifelong opportunities in PA may affect adult behaviors, especially among those with disabilities. Prior to this survey, qualitative work examined experiences in childhood PA among children with disabilities (Leo et al., 2018; Nyquist et al., 2019), and adult disability work focused on healthcare concerns (Mudge et al., 2016), barriers to PA (Buffart et al., 2009), or adult attitudes towards current PA opportunities (Jahnsen et al., 2003). With an understanding of the possible bidirectional relationship between adverse childhood events related to PA with CP and long-term health outcomes, the survey developed here sought to determine how attitudes and perceptions of lifelong PA opportunities affected PA trajectory into adulthood. The findings indicate that adults with CP have positive attitudes regarding their childhood experiences with PA and, importantly these attitudes do not differ based on age. Combined these results suggest that attitudes alone are not a barrier to participation in PA. Thus, the opportunities for adults to be physically active need to be extended beyond childhood and school-aged years to encompass more of the life course.

Opportunities for adults with CP to remain physically active, while increasing in number, are relatively limited compared to opportunities provided to children with CP. Physical activity recommendations for adults with CP have been established (Piercy et al., 2018; Verschuren et al., 2016) and communities are increasing the amount of adapted recreational opportunities offered to adults, yet, PA prospects for adults with CP are still disproportionate to that of children with CP (Lai et al., 2021). Newly adapted activities such as rock climbing and sled hockey are becoming increasingly popular, but often these activities require special equipment that can be expensive to acquire. Furthermore, participation in the Paralympic or Special Olympic games is seen among adults with CP, but these events require elite training or specific classifications to participate (McNamee et al., 2021). The built environment also plays a large role in PA disparity between children and adults with CP with access as ultimately one of the biggest barriers (Rimmer et al., 2004). Access is not limited to the ability to enter a building; it includes how information is disseminated, knowledge of disability and activity modification, equipment designed specifically for mobility limitations, and solidarity among community members (Aviram et al., 2021; Sienko, 2019; Wright et al., 2019). This list is not exhaustive, and yet, it illustrates the need to increase access through novel approaches.

Great lengths have been taken to assure access to treatment for children with CP. For example, to increase intensity of traditional physical therapy, practitioners have considered utilizing web-based home training that implements video game style play. This relatively new approach has been shown to improve functional mobility and increase participation in daily activities (Lorentzen et al., 2015; Mitchell et al., 2016). Access to additional alternative treatments such as hippotherapy and aqua therapy have been shown to positively affect gross motor function (i.e., how the body moves) and functional performance (i.e., the ability to complete tasks) (Park et al., 2014) in children with CP. These PA contexts are employed to support traditional methods that build foundational movement patterns to increase healthy lifestyle choices into adulthood. However, the research on alternative and complimentary treatments for adults with CP is limited even though many adults with CP have expressed their willingness to pay out of pocket for these treatments (Oppenheim, 2009). Therefore, a logical next step would be adapting research-based pediatric programs designed to promote motor function performance for the population of adults aging with CP to increase lifelong PA opportunities and maintain overall function. Adults with CP would further benefit from a method of monitoring that could combat some of the barriers to sustained care.

Study 3 of this dissertation tested the feasibility of assessing motor function using a telehealth platform. The use of telehealth delivery is a potential direction to increase access for adults with CP. The use of web-based training has been established in pediatrics, more so as a result of Covid-19 (Lai et al., 2021; Sutter et al., 2021), and is suitable for adult populations as well (Brown et al., 2010). Beyond increasing access, a telehealth platform of service delivery essentially eliminates many of the environmental barriers of traditional care including the time and cost associated with transportation (Tenforde et al., 2017). Furthermore, telehealth has the potential to reduce burden for both the individuals with CP and the providers by removing the need for in-person supervision (Howard & Kaufman, 2018). More importantly, telehealth access to care allows for increased communication between the participant and several specialists at once. This not only encourages the participant to engage fully in their own care (O’Donovan et al., 2020), but also leads to an integrated and comprehensive healthcare model (Fleischman et al., 2016).

It is feasible to assess physical function remotely as 95% of participants were able to complete all the assessments. Therefore, telehealth has further potential to increase accessibility to continuous care as changes in physical function can be monitored from afar across the lifespan (Graham et al., 2019). For this study, five domains of physical function were assessed: mobility, functional leg strength, static balance, sensory integration, and gait speed. However, it is important to choose appropriate assessments to capture outcomes. For example, in this study 15% of the participants experienced a momentary loss of balance. While no one fell, care must be taken when determining what and how specific aspects of physical function are assessed remotely, particularly as it relates to varying presentations of CP.

By determining the feasibility of using such remote assessments, interventions targeted towards increasing physical function among adults with CP can be continuously monitored for effectiveness. The assessments selected for this study provided useful information regarding participants' functional abilities, but care should be taken when designing remote assessments for those who have more limited mobility or communication. For example, individuals with gross motor classification requiring greater dependence on assistance, may have additional limitations in intellectual capacity or executive functioning, and therefore may require assistance from a caregiver to provide accurate accounts of ability. The reliability between face-to-face and telehealth delivery of assessment (Harper et al., 2021), intervention (Rimmer et al., 2013), physical therapy (Zischke et al., 2021), and leisure-time physical activity (Lai et al., 2021) have been demonstrated. Based on these findings and the results from this dissertation, it is clear to see that telehealth is a reasonable approach to increase access and monitor changes in physical function for adults with CP.

In summary, this dissertation has demonstrated that adults with CP have positive attitudes and perceptions towards lifetime opportunities to be physically active regardless of age. While attitudes and perceptions are positive, adults with CP are still less active than the general population and this was exacerbated by the restrictions of Covid-19. Domains within the factors of quality of life, self-perception, and pain had significant associations with type and intensity of activities chosen. This illustrates the importance of increasing PA opportunities and participation among adults with CP to maintain functional mobility throughout the lifespan. Access to such opportunities is limited for adults with CP. A telehealth approach to participation combined with the potential for continuous monitoring, provides infinite possibilities for this unique group. Ultimately, the telehealth model of service delivery can reduce PA disparity among children and adults with CP while providing a method of longitudinal monitoring among individuals aging with a pediatric onset disability.

Appendices

Appendix A: Assessment of Attitudes towards Lifelong Physical Activity (AATLPA)

This questionnaire was designed to get a better understanding of your lifelong experiences with physical activity and your attitude towards your participation engagement. For this questionnaire, **physical activity** is defined as "any bodily movement produced by skeletal muscles that require energy expenditure" and **attitude** is defined as "the degree to which a person has a favorable or unfavorable evaluation of their behavior.

1. Can you tell me about the first time you remember having an opportunity to be physically active?
    a. How old were you?
    b. What was the context/environment (park playground, home, therapy etc.)?
    c. Who were you with (i.e. parents, siblings, caretakers, etc.)?

2. What were your feelings towards physical activity during childhood??

1	**2**	**3**	**4**	**5**	**6**	**7**
Did not enjoy			*It was fine*			*Enjoyable*
Too hard			*It was necessary*			*Regular participation*

3. At what age did you participate in any form of physical activity with peers? **_____ years**
    a. Who did you participate with? Please check the answer that matches your experience.

Peers with disabilities ______ Peers without disabilities _______ Mix of both ______

4. If applicable, what was your attitude towards participating in physical activity with other peers with disabilities (i.e. Cerebral palsy, Autism, Down syndrome, etc)? **N/A _______**

1	**2**	**3**	**4**	**5**	**6**	**7**
Did not enjoy/			*No preference*			*Enjoyable/*
Prevented progression						*Learned from each other*

5. If applicable, what was your attitude towards participating in physical activity with peers of typical development? **N/A _______**

1	**2**	**3**	**4**	**5**	**6**	**7**
Did not enjoy			*No preference*			*Enjoyable*
Felt left behind						*Friendships formed*

Little/no instruction *Pushed me to try more/harder*

6. Did you encounter any individual(s) in your childhood who were <u>specifically trained</u> to work in physical activity with individuals with disabilities? **YES** **NO**
    a. **Please check all that apply:**

PT/OT ______ Other therapist _______ Teacher ________ Coach _________

Parent _______Personal Trainer _______ Direct Support Professional _______

Aide _______ Sibling _______ Peer _______ Social Worker ________

7. Based on your last response, which interaction do you think influenced (either positively or negatively) your desire to be physically active the most? _______________________

8. What was your attitude towards working with this individual?

1 **2** **3** **4** **5** **6** **7**
Did not enjoy *Neutral* *Positive interaction*
Got little from interaction *Pros and Cons* *Mutual respect/understanding*
Negative interaction *Enjoyed time together*

9. How much do you think the interaction with that individual influenced your desire to be physically active in your childhood?

1 **2** **3** **4** **5** **6** **7**
Negative impact *Some impact* *Positive impact/ability*
No desire *Neither positive nor negative* *to be physically active*

10. Did you enjoy physical activity during the following stages of development?

    a. Early childhood (2-9 yoa)

1 **2** **3** **4** **5** **6** **7**
Not at all *Some days more than others* *Yes, enjoyed it!*

    b. Middle childhood (10-13 yoa)

1 **2** **3** **4** **5** **6** **7**
Not at all *Some days more than others* *Yes, enjoyed it!*

c. Adolescence (14-17 yoa)

1 2 3 4 5 6 7
Not at all *Some days more than others* *Yes, enjoyed*
it!

d. Young adulthood (18-23 yoa)

1 2 3 4 5 6 7
Not at all *Some days more than others* *Yes, enjoyed*
it!

11. What is your current attitude towards physical activity?

1 2 3 4 5 6 7
Hate it *Do it because I must* *Love it!*
Painful *Necessity* *Part of my everyday*
Time consuming

12. How would you rate yourself as an everyday mover? (i.e. work, leisure, transportation, etc.)

1 2 3 4 5 6 7
Painful to move *Good days & bad days* *Fluid movements*
Fall often *Move as often as body allows* *Moves often*
Sedentary lifestyle *Slower but purposeful* *Active lifestyle*

13. Do you believe your past experiences and attitudes with physical activity have influenced your current level of physical activity?

1 2 3 4 5 6 7
Yes, negatively *Never considered it* *Yes, positively*
No influence

Bibliography

Aisen, M. L., Kerkovich, D., Mast, J., Mulroy, S., Wren, T. A., Kay, R. M., & Rethlefsen, S. A. (2011). Cerebral palsy: Clinical care and neurological rehabilitation. *The Lancet Neurology*, *10*(9), 844–852. https://doi.org/10.1016/S1474-4422(11)70176-4

Alves-Nogueira, A. C., Silva, N., McConachie, H., & Carona, C. (2020). A systematic review on quality of life assessment in adults with cerebral palsy: Challenging issues and a call for research. *Research in Developmental Disabilities*, *96*, 103514. https://doi.org/10.1016/j.ridd.2019.103514

Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: A survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine and Child Neurology*, *43*(02), 76. https://doi.org/10.1017/S0012162201

Andrén, E., & Grimby, G. (2004). Dependence in daily activities and life satisfaction in adult subjects with cerebral palsy or spina bifida: A follow-up study. *Disability and Rehabilitation*, *26*(9), 528–536. https://doi.org/10.1080/09638280410001672490

Annaswamy, T. M., Verduzco-Gutierrez, M., & Frieden, L. (2020). Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond. *Disability and Health Journal*, *13*(4), 100973. https://doi.org/10.1016/j.dhjo.2020.100973

Auld, M. L., Boyd, R., Moseley, G. L., Ware, R., & Johnston, L. M. (2012). Tactile function in children with unilateral cerebral palsy compared to typically developing children. *Disability and Rehabilitation*, *34*(17), 1488–1494. https://doi.org/10.3109/09638288.2011.650314

Aviram, R., Khvorostianov, N., Harries, N., & Bar-Haim, S. (2021). Perceived barriers and facilitators for increasing the physical activity of adolescents and young adults with cerebral palsy: A focus group study. *Disability and Rehabilitation*, 1–11. https://doi.org/10.1080/09638288.2021.1970252

Becker, H., & Schaller, J. (1995). Perceived Health and Self-Efficacy Among Adults with Cerebral Palsy. *Journal of Rehabilitation*, 36–42.

Benner, J. L., Hilberink, S. R., Veenis, T., Stam, H. J., van der Slot, W. M., & Roebroeck, M. E. (2017). Long-Term Deterioration of Perceived Health and Functioning in Adults With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, *98*(11), 2196-2205.e1. https://doi.org/10.1016/j.apmr.2017.03.013

Benner, J. L., Noten, S., Limsakul, C., Slot, W. M. A. V. D., Stam, H. J., Selb, M., Berg-Emons, R. J. G. V. D., & Roebroeck, M. E. (2019). Outcomes in adults with cerebral palsy: Systematic review using the International Classification of Functioning, Disability and Health. *Developmental Medicine & Child Neurology*, *61*(10), 1153–1161. https://doi.org/10.1111/dmcn.14247

Ben-Pazi, H., Beni-Adani, L., & Lamdan, R. (2020). Accelerating Telemedicine for Cerebral Palsy During the COVID-19 Pandemic and Beyond. *Frontiers in Neurology*, *11*, 746. https://doi.org/10.3389/fneur.2020.00746

Bloemen, M. A. T., Backx, F. J. G., Takken, T., Wittink, H., Benner, J., Mollema, J., & de Groot, J. F. (2015). Factors associated with physical activity in children and adolescents with a physical disability: A systematic review. *Developmental Medicine & Child Neurology*, *57*(2), 137–148. https://doi.org/10.1111/dmcn.12624

Bonnefoy-Mazure, A., De Coulon, G., & Armand, S. (2020). Self-perceived gait quality in young adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *62*(7), 868–873. https://doi.org/10.1111/dmcn.14504

Brooks, J. C., Strauss, D. J., Shavelle, R. M., Tran, L. M., Rosenbloom, L., & Wu, Y. W. (2014). Recent trends in cerebral palsy survival. Part I: Period and cohort effects. *Developmental Medicine & Child Neurology*, *56*(11), 1059–1064. https://doi.org/10.1111/dmcn.12520

Brown, S. H., Lewis, C. A., McCarthy, J. M., Doyle, S. T., & Hurvitz, E. A. (2010). The Effects of Internet-Based Home Training on Upper Limb Function in Adults With Cerebral Palsy. *Neurorehabilitation and Neural Repair*, *24*(6), 575–583. https://doi.org/10.1177/1545968310361956

Buffart, L., Westendorp, T., van den Berg-Emons, R., Stam, H., & Roebroeck, M. (2009). Perceived barriers to and facilitators of physical activity in young adults with childhood-onset physical disabilities. *Journal of Rehabilitation Medicine*, *41*(11), 881–885. https://doi.org/10.2340/16501977-0420

Burckhardt, C. S., & Anderson, K. L. (2003). The Quality of Life Scale (QOLS): Reliability, Validity, and Utilization. *Health and Quality of Life Outcomes*, 7.

Burckhardt, C. S., & Jones, K. D. (2003). Adult measures of pain: The McGill Pain Questionnaire (MPQ), Rheumatoid Arthritis Pain Scale (RAPS), Short-Form McGill Pain Questionnaire (SF-MPQ), Verbal Descriptive Scale (VDS), Visual Analog Scale (VAS), and West Haven-Yale Multidisciplinary Pain Inventory (WHYMPI). *Arthritis & Rheumatism*, *49*(S5), S96–S104. https://doi.org/10.1002/art.11440

Busti, A. J. (2015, July). *Romberg Test: Physical Exam*. Evidence-Based Medicine Consult. https://www.ebmconsult.com/articles/rphysical-exam-romberg-test

Cabrera-Martos, I., Ortiz-Rubio, A., Torres-Sánchez, I., López-López, L., Rodríguez-Torres, J., & Carmen Valenza, M. (2019). Agreement Between Face-to-Face and Tele-assessment of Upper Limb Functioning in Patients with Parkinson Disease. *PM&R*, *11*(6), 590–596. https://doi.org/10.1002/pmrj.12001

Carlon, S. L., Taylor, N. F., Dodd, K. J., & Shields, N. (2013). Differences in habitual physical activity levels of young people with cerebral palsy and their typically developing peers: A systematic review. *Disability and Rehabilitation*, *35*(8), 647–655. https://doi.org/10.3109/09638288.2012.715721

Carroll, A., Chan, D., Thorpe, D., Levin, I., & Bagatell, N. (2021). A Life Course Perspective on Growing Older With Cerebral Palsy. *Qualitative Health Research*, *31*(4), 654–664. https://doi.org/10.1177/1049732320971247

Causgrove Dunn, J. (2017). Self-concept research in cerebral palsy: Development of a population-specific measure. *Developmental Medicine & Child Neurology*, *59*(6), 573–573. https://doi.org/10.1111/dmcn.13407

CDC. (2017). *Assessment: Timed Up & Go Test (TUG)*. Centers for Disease Control and Prevention. https://www.cdc.gov/steadi/pdf/TUG_Test-print.pdf

Chaudhry, H., Nadeem, S., & Mundi, R. (2021). How Satisfied Are Patients and Surgeons with Telemedicine in Orthopaedic Care During the COVID-19 Pandemic? A Systematic Review and Meta-analysis. *Clinical Orthopaedics & Related Research*, *479*(1), 47–56. https://doi.org/10.1097/CORR.0000000000001494

Cheong, S. K., Lang, C. P., & Johnston, L. M. (2018). Self-concept of children with cerebral palsy measured using the population-specific myTREEHOUSE Self-Concept

Assessment. *Research in Developmental Disabilities*, *73*, 96–105. https://doi.org/10.1016/j.ridd.2017.12.001

Chodzko-Zajko, W. J., Proctor, D. N., Fiatarone Singh, M. A., Minson, C. T., Nigg, C. R., Salem, G. J., & Skinner, J. S. (2009). Exercise and Physical Activity for Older Adults: *Medicine & Science in Sports & Exercise*, *41*(7), 1510–1530. https://doi.org/10.1249/MSS.0b013e3181a0c95c

Chulliyil, S., Diwan, S., Sheth, M., & Vyas, N. (2014). Correlation of functional independence and quality of life in school aged children with cerebral palsy. *International Journal of Contemporary Pediatrics*, *1*(1), 32. https://doi.org/10.5455/2349-3291.ijcp20140510

Claridge, E. A., Mcphee, P. G., Timmons, B. W., Martin Ginis, K. A., Macdonald, M. J., & Gorter, J. W. (2015). Quantification of Physical Activity and Sedentary Time in Adults with Cerebral Palsy: *Medicine & Science in Sports & Exercise*, *47*(8), 1719–1726. https://doi.org/10.1249/MSS.0000000000000589

Colver, A. (2012). Outcomes for people with cerebral palsy: Life expectancy and quality of life. *Paediatrics and Child Health*, *22*(9), 384–387. https://doi.org/10.1016/j.paed.2012.03.003

Cremer, N., Hurvitz, E. A., & Peterson, M. D. (2017). Multimorbidity in Middle-Aged Adults with Cerebral Palsy. *The American Journal of Medicine*, *130*(6), 744.e9-744.e15. https://doi.org/10.1016/j.amjmed.2016.11.044

Deighton, S., Neville, A., Pusch, D., & Dobson, K. (2018). Biomarkers of adverse childhood experiences: A scoping review. *Psychiatry Research*, *269*, 719–732. https://doi.org/10.1016/j.psychres.2018.08.097

Dewar, R., Love, S., & Johnston, L. M. (2015). Exercise interventions improve postural control in children with cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology*, *57*(6), 504–520. https://doi.org/10.1111/dmcn.12660

Dogruoz Karatekin, B., İcagasioglu, A., Sahin, S. N., Kacar, G., & Bayram, F. (2021). How Did the Lockdown Imposed Due to COVID-19 Affect Patients With Cerebral Palsy? *Pediatric Physical Therapy*, *33*(4), 246–249. https://doi.org/10.1097/PEP.0000000000000818

Dorsey, E. R., Okun, M. S., & Bloem, B. R. (2020). Care, Convenience, Comfort, Confidentiality, and Contagion: The 5 C's that Will Shape the Future of Telemedicine. *Journal of Parkinson's Disease*, *10*(3), 893–897. https://doi.org/10.3233/JPD-202109

Douma, J. A. J., Verheul, H. M. W., & Buffart, L. M. (2018). Feasibility, validity and reliability of objective smartphone measurements of physical activity and fitness in patients with cancer. *BMC Cancer*, *18*(1), 1052. https://doi.org/10.1186/s12885-018-4983-4

Dunn, N., Shields, N., Taylor, N. F., & Dodd, K. J. (2007). A Systematic Review of the Self-Concept of Children with Cerebral Palsy and Perceptions of Parents and Teachers. *Physical & Occupational Therapy In Pediatrics*, *27*(3), 55–71. https://doi.org/10.1080/J006v27n03_05

Engel, J. M., Jensen, M. P., Hoffman, A. J., & Kartin, D. (2003). Pain in persons with cerebral palsy: Extension and cross validation11No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit upon the author(s) or upon any organization with which the author(s) is/are associated. *Archives of Physical Medicine and Rehabilitation*, *84*(8), 1125–1128. https://doi.org/10.1016/S0003-9993(03)00263-6

Ferkel, R. C., Razon, S., Judge, L. W., & True, L. (2017). Beyond “Fun”: The Real Need in Physical Education. *The Physical Educator*, *74*(2), 255–268. https://doi.org/10.18666/TPE-2017-V74-I2-7426

Fleischman, A., Hourigan, S. E., Lyon, H. N., Landry, M. G., Reynolds, J., Steltz, S. K., Robinson, L., Keating, S., Feldman, H. A., Antonelli, R. C., Ludwig, D. S., & Ebbeling, C. B. (2016). Creating an integrated care model for childhood obesity: A randomized pilot study utilizing telehealth in a community primary care setting: Creating an integrated care model using telehealth. *Clinical Obesity*, *6*(6), 380–388. https://doi.org/10.1111/cob.12166

Fortuna, R. J., Holub, A., Turk, M. A., Meccarello, J., & Davidson, P. W. (2018). Health conditions, functional status and health care utilization in adults with cerebral palsy. *Family Practice*, *35*(6), 661–670. https://doi.org/10.1093/fampra/cmy027

Freeman, M., Stewart, D., Cunningham, C. E., & Gorter, J. W. (2018). “If I had been given that information back then”: An interpretive description exploring the information needs of adults with cerebral palsy looking back on their transition to adulthood. *Child: Care, Health and Development*, *44*(5), 689–696. https://doi.org/10.1111/cch.12579

Frisch, D., & Msall, M. E. (2013). Health, functioning, and participation of adolescents and adults with cerebral palsy: A review of outcomes research. *Developmental Disabilities Research Reviews*, *18*(1), 84–94. https://doi.org/10.1002/ddrr.1131

Gajdosik, C. G., & Cicirello, N. (2002). Secondary Conditions of the Musculoskeletal System in Adolescents and Adults with Cerebral Palsy. *Physical & Occupational Therapy In Pediatrics*, *21*(4), 49–68. https://doi.org/10.1080/J006v21n04_04

Gannotti, M. E., Minter, C. L., Chambers, H. G., Smith, P. A., & Tylkowski, C. (2011). Self-concept of adults with cerebral palsy. *Disability and Rehabilitation*, *33*(10), 855–861. https://doi.org/10.3109/09638288.2010.514017

Gannotti, M. E., Wilson, J. L., Bagley, A. M., & Oeffinger, D. (2021). Adults with cerebral palsy rank factors associated with quality of life and perceived impact of childhood surgery on adult outcomes. *Disability and Rehabilitation*, *43*(17), 2431–2438. https://doi.org/10.1080/09638288.2019.1701718

Goble, D. J., Hurvitz, E. A., & Brown, S. H. (2009). Deficits in the ability to use proprioceptive feedback in children with hemiplegic cerebral palsy. *International Journal of Rehabilitation Research*, *32*(3), 267–269. https://doi.org/10.1097/MRR.0b013e32832a62d5

Graham, D., Paget, S. P., & Wimalasundera, N. (2019). Current thinking in the health care management of children with cerebral palsy. *Medical Journal of Australia*, *210*(3), 129–135. https://doi.org/10.5694/mja2.12106

Graham, F., Boland, P., Grainger, R., & Wallace, S. (2019). Telehealth delivery of remote assessment of wheelchair and seating needs for adults and children: A scoping review. *Disability and Rehabilitation*, *0*(0), 1–11. https://doi.org/10.1080/09638288.2019.1595180

Graham, H. K., Rosenbaum, P., Paneth, N., Dan, B., Lin, J.-P., Damiano, D. L., Becher, J. G., Gaebler-Spira, D., Colver, A., Reddihough, D. S., Crompton, K. E., & Lieber, R. L. (2016). Cerebral palsy. *Nature Reviews Disease Primers*, *2*(1), 15082. https://doi.org/10.1038/nrdp.2015.82

Gremeaux, V., Gayda, M., Lepers, R., Sosner, P., Juneau, M., & Nigam, A. (2012). Exercise and longevity. *Maturitas*, *73*(4), 312–317. https://doi.org/10.1016/j.maturitas.2012.09.012

Haak, P., Lenski, M., Hidecker, M. J. C., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine & Child Neurology*, *51*, 16–23. https://doi.org/10.1111/j.1469-8749.2009.03428.x

Haegele, J. A., & Kirk, T. N. (2018). Experiences in Physical Education: Exploring the Intersection of Visual Impairment and Maleness. *Adapted Physical Activity Quarterly*, *35*(2), 196–213. https://doi.org/10.1123/apaq.2017-0132

Haegele, J. A., & Sutherland, S. (2015). Perspectives of Students with Disabilities Toward Physical Education: A Qualitative Inquiry Review. *Quest*, *67*(3), 255–273. https://doi.org/10.1080/00336297.2015.1050118

Haegele, J. A., & Zhu, X. (2017). Experiences of Individuals With Visual Impairments in Integrated Physical Education: A Retrospective Study. *Research Quarterly for Exercise and Sport*, *88*(4), 425–435. https://doi.org/10.1080/02701367.2017.1346781

Halaweh, H., Willen, C., Grimby-Ekman, A., & Svantesson, U. (2016). Physical functioning and fall-related efficacy among community-dwelling elderly people. *European Journal of Physiotherapy*, *18*(1), 11–17. https://doi.org/10.3109/21679169.2015.1087591

Harper, K. A., Butler, E. C., Hacker, M. L., Naik, A., Eoff, B. R., Phibbs, F. T., Isaacs, D. A., Gallion, S. J., Thomas, E. P., Scott, J. L., Ploucher, S., Meystedt, J. C., McLeod, M. E., & Charles, P. D. (2021). A comparative evaluation of telehealth and direct assessment when screening for spasticity in residents of two long-term care facilities. *Clinical Rehabilitation*, *35*(4), 589–594. https://doi.org/10.1177/0269215520963845

Haywood, K. M., & Getchell, N. (n.d.). *Lifespan Motor Development* (4th ed.). Human Kinetics.

Heller, T., Ying, G., Rimmer, JamesbH., & Marks, B. A. (2002). Determinants of Exercise in Adults with Cerebral Palsy. *Public Health Nursing*, *19*(3), 223–231. https://doi.org/10.1046/j.0737-1209.2002.19311.x

Hess, T. M., Freund, A. M., & Tobler, P. N. (2021). Effort Mobilization and Healthy Aging. *The Journals of Gerontology: Series B*, *76*(Supplement_2), S135–S144. https://doi.org/10.1093/geronb/gbab030

Hess, T. M., Smith, B. T., & Sharifian, N. (2016). Aging and effort expenditure: The impact of subjective perceptions of task demands. *Psychology and Aging*, *31*(7), 653–660. https://doi.org/10.1037/pag0000127

Houx, L., Pons, C., Saudreau, H., Dubois, A., Creusat, M., Le Moine, P., Rémy-Néris, O., Ropars, J., LeReste, J.-Y., & Brochard, S. (2021). No pain, no gain? Children with cerebral palsy and their experience with physiotherapy. *Annals of Physical and Rehabilitation Medicine*, *64*(3), 101448. https://doi.org/10.1016/j.rehab.2020.10.002

Howard, I. M., & Kaufman, M. S. (2018). Telehealth applications for outpatients with neuromuscular or musculoskeletal disorders: Telehealth Applications for Outpatients. *Muscle & Nerve*, *58*(4), 475–485. https://doi.org/10.1002/mus.26115

Hurvitz, E. A., Whitney, D. G., Waldron-Perrine, B., Ryan, D., Haapala, H. J., Schmidt, M., Gray, C., & Peterson, M. D. (2021). Navigating the Pathway to Care in Adults With Cerebral Palsy. *Frontiers in Neurology*, *12*, 734139. https://doi.org/10.3389/fneur.2021.734139

Jahnsen, R., Aamodt, G., & Rosenbaum, P. (2007). Gross Motor Function Classification System used in adults with cerebral palsy: Agreement of self-reported versus professional rating.

Developmental Medicine & Child Neurology, *48*(9), 734–738. https://doi.org/10.1111/j.1469-8749.2006.tb01358.x

Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J., & Holm, I. (2004). Musculoskeletal pain in adults with cerebral palsy compared with the general population. *Journal of Rehabilitation Medicine*, *36*(2), 78–84. https://doi.org/10.1080/16501970310018305

Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J. K., & Holm, I. (2003). Physiotherapy and Physical Activity – Experiences of Adults with Cerebral Palsy, with Implications for Children. *Advances in Physiotherapy*, *5*(1), 21–32. https://doi.org/10.1080/14038190310005779

Jahnsen, R., Villien, L., Egeland, T., & Stanghelle, J. K. (2004). Locomotion skills in adults with cerebral palsy. *Clinical Rehabilitation*, *18*(3), 309–316. https://doi.org/10.1191/0269215504cr735oa

Jahnsen, R., Villien, L., Stanghelle, J. K., & Holm, I. (2007). Fatigue in adults with cerebral palsy in Norway compared with the general population. *Developmental Medicine & Child Neurology*, *45*(5), 296–303. https://doi.org/10.1111/j.1469-8749.2003.tb00399.x

Jersak, T., & Noritz, G. (2021). Evaluation of Pain in Adults With Childhood-Onset Disabilities and Communication Difficulties. *Frontiers in Neurology*, *12*, 722971. https://doi.org/10.3389/fneur.2021.722971

Jiang, B., Walstab, J., Reid, S. M., Davis, E., & Reddihough, D. (2016). Quality of life in young adults with cerebral palsy. *Disability and Health Journal*, *9*(4), 673–681. https://doi.org/10.1016/j.dhjo.2016.04.006

Johnson, S. P. (2010). How Infants Learn About the Visual World. *Cognitive Science*, *34*(7), 1158–1184. https://doi.org/10.1111/j.1551-6709.2010.01127.x

Kanemaru, N., Watanabe, H., Kihara, H., Nakano, H., Nakamura, T., Nakano, J., Taga, G., & Konishi, Y. (2014). Jerky spontaneous movements at term age in preterm infants who later developed cerebral palsy. *Early Human Development*, *90*(8), 387–392. https://doi.org/10.1016/j.earlhumdev.2014.05.004

Kantarcigil, C., Sheppard, J. J., Gordon, A. M., Friel, K. M., & Malandraki, G. A. (2016). A telehealth approach to conducting clinical swallowing evaluations in children with cerebral palsy. *Research in Developmental Disabilities*, *55*, 207–217. https://doi.org/10.1016/j.ridd.2016.04.008

Kelley, K., & Preacher, K. J. (2012). On effect size. *Psychological Methods*, *17*(2), 137–152. https://doi.org/10.1037/a0028086

Kerns, R. D., Turk, D. C., & Rudy, T. E. (1986). The West Haven- Yale Multidimensional Pain Inventory. *Pain*, *23*, 345–356.

Kim, Y., & Welk, G. J. (2017). The accuracy of the 24-h activity recall method for assessing sedentary behaviour: The physical activity measurement survey (PAMS) project. *Journal of Sports Sciences*, *35*(3), 255–261. https://doi.org/10.1080/02640414.2016.1161218

Koo, T. K., & Li, M. Y. (2016). A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research. *Journal of Chiropractic Medicine*, *15*(2), 155–163. https://doi.org/10.1016/j.jcm.2016.02.012

Krigger, K. W. (2006). Cerebral Palsy: An Overview. *Cerebral Palsy*, *73*(1), 10.

Kwong, A. K. L., Fitzgerald, T. L., Doyle, L. W., Cheong, J. L. Y., & Spittle, A. J. (2018). Predictive validity of spontaneous early infant movement for later cerebral palsy: A systematic review. *Developmental Medicine & Child Neurology*, *60*(5), 480–489. https://doi.org/10.1111/dmcn.13697

Lai, B., Lee, E., Kim, Y., Matthews, C., Swanson-Kimani, E., Davis, D., Vogtle, L., & Rimmer, J. H. (2021). Leisure-time physical activity interventions for children and adults with cerebral palsy: A scoping review. *Developmental Medicine & Child Neurology*, *63*(2), 162–171. https://doi.org/10.1111/dmcn.14751

Lai, C.-J., Liu, W.-Y., Yang, T.-F., Chen, C.-L., Wu, C.-Y., & Chan, R.-C. (2015). Pediatric Aquatic Therapy on Motor Function and Enjoyment in Children Diagnosed With Cerebral Palsy of Various Motor Severities. *Journal of Child Neurology*, *30*(2), 200–208. https://doi.org/10.1177/0883073814535491

Langan, J., Kern, K. L., Hurvitz, E. A., & Brown, S. H. (2014). Upper-Limb Position Sense Deficits in Adults with Cerebral Palsy: *American Journal of Physical Medicine & Rehabilitation*, *93*(9), 774–781. https://doi.org/10.1097/PHM.0000000000000100

Lauruschkus, K., Nordmark, E., & Hallström, I. (2015). “It’s fun, but …” Children with cerebral palsy and their experiences of participation in physical activities. *Disability and Rehabilitation*, *37*(4), 283–289. https://doi.org/10.3109/09638288.2014.915348

Lauzé, M., Martel, D. D., & Aubertin-Leheudre, M. (2017). Feasibility and Effects of a Physical Activity Program Using Gerontechnology in Assisted Living Communities for Older Adults. *Journal of the American Medical Directors Association*, *18*(12), 1069–1075. https://doi.org/10.1016/j.jamda.2017.06.030

Lawrence, H., Hills, S., Kline, N., Weems, K., & Doty, A. (2016). Effectiveness of Exercise on Functional Mobility in Adults with Cerebral Palsy: A Systematic Review. *Physiotherapy Canada*, *68*(4), 398–407. https://doi.org/10.3138/ptc.2015-38LHC

Lee, I.-M., Shiroma, E. J., Lobelo, F., Puska, P., Blair, S. N., & Katzmarzyk, P. T. (2012). Effect of physical inactivity on major non-communicable diseases worldwide: An analysis of burden of disease and life expectancy. *The Lancet*, *380*(9838), 219–229. https://doi.org/10.1016/S0140-6736(12)61031-9

Lennon, N., Church, C., & Miller, F. (2018). Patient-reported mobility function and engagement in young adults with cerebral palsy: A cross-sectional sample. *Journal of Children's Orthopaedics*, *12*(2), 197–203. https://doi.org/10.1302/1863-2548.12.170127

Leo, J. A., Faulkner, G., Volfson, Z., Bassett-Gunter, R., & Arbour-Nicitopoulos, K. (2018). Physical Activity Preferences, Attitudes, and Behaviour of Children and Youth With Physical Disabilities. *Therapeutic Recreation Journal*, *52*(2), 140–153. https://doi.org/10.18666/TRJ-2018-V52-I2-8443

Li, C., & Chen, S. (2012). Exploring experiences of physical activity in special school students with cerebral palsy: A qualitative perspective. *European Journal of Adapted Physical Activity*, *5*(1), 7–17. https://doi.org/10.5507/euj.2012.001

Lindsay, S., & McPherson, A. C. (2012). Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. *Disability and Rehabilitation*, *34*(2), 101–109. https://doi.org/10.3109/09638288.2011.587086

Lineweaver, T. T., Kugler, J., Rabellino, A., & Stephan, Y. (2018). Beliefs about age-related changes in physical functioning across the adult life span and their relationship with physical activity levels of older adults. *Aging, Neuropsychology, and Cognition*, *25*(4), 613–631. https://doi.org/10.1080/13825585.2017.1356903

Liptak, G. S. (2008). Health and well being of adults with cerebral palsy: *Current Opinion in Neurology*, *21*(2), 136–142. https://doi.org/10.1097/WCO.0b013e3282f6a499

Lorentzen, J., Greve, L. Z., Kliim-Due, M., Rasmussen, B., Bilde, P. E., & Nielsen, J. B. (2015). Twenty weeks of home-based interactive training of children with cerebral palsy improves functional abilities. *BMC Neurology*, *15*(1), 75. https://doi.org/10.1186/s12883-015-0334-0

Lundh, S., Nasic, S., & Riad, J. (2018). Fatigue, quality of life and walking ability in adults with cerebral palsy. *Gait & Posture*, *61*, 1–6. https://doi.org/10.1016/j.gaitpost.2017.12.017

Maitre, N. L., Benninger, K. L., Neel, M. L., Haase, J. A., Pietruszewski, L., Levengood, K., Adderley, K., Batterson, N., Hague, K., Lightfoot, M., Weiss, S., Lewandowski, D. J., & Larson, H. (2021). Standardized Neurodevelopmental Surveillance of High-risk Infants Using Telehealth: Implementation Study during COVID-19. *Pediatric Quality & Safety*, *6*(4), e439. https://doi.org/10.1097/pq9.0000000000000439

Marcroft, C., Khan, A., Embleton, N. D., Trenell, M., & PlÃ¶tz, T. (2015). Movement Recognition Technology as a Method of Assessing Spontaneous General Movements in High Risk Infants. *Frontiers in Neurology*, *5*. https://doi.org/10.3389/fneur.2014.00284

Marini, S., Leoni, E., Raggi, A., Sanna, T., Malavolta, N., Angela, B., Maietta Latessa, P., & Dallolio, L. (2019). Proposal of an Adapted Physical Activity Exercise Protocol for Women with Osteoporosis-Related Vertebral Fractures: A Pilot Study to Evaluate Feasibility, Safety, and Effectiveness. *International Journal of Environmental Research and Public Health*, *16*(14), 2562. https://doi.org/10.3390/ijerph16142562

Martin Ginis, K. A., & Latimer-Cheung, A. E. (2005). *Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-Sci), Administration and Scoring Manual*. https://sciactioncanada.ok.ubc.ca/resources/para-sci-manual/

Martin Ginis, K. A., Papathomas, A., Perrier, M.-J., Smith, B., & SHAPE-SCI Research Group. (2017). Psychosocial factors associated with physical activity in ambulatory and manual wheelchair users with spinal cord injury: A mixed-methods study. *Disability and Rehabilitation*, *39*(2), 187–192. https://doi.org/10.3109/09638288.2015.1045991

Mauldin, K., Gieng, J., Saarony, D., & Hu, C. (2021). Performing nutrition assessment remotely via telehealth. *Nutrition in Clinical Practice*, *36*(4), 751–768. https://doi.org/10.1002/ncp.10682

McCormick, A., Brien, M., Plourde, J., Wood, E., Rosenbaum, P., & McLean, J. (2007). Stability of the Gross Motor Function Classification System in adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *49*(4), 265–269. https://doi.org/10.1111/j.1469-8749.2007.00265.x

McHugh, M. L. (2013). The Chi-square test of independence. *Biochemia Medica*, 143–149. https://doi.org/10.11613/BM.2013.018

McNamee, M., Parnell, R., & Vanlandewijck, Y. (2021). Fairness, technology and the ethics of Paralympic sport classification. *European Journal of Sport Science*, *21*(11), 1510–1517. https://doi.org/10.1080/17461391.2021.1961022

Messer, B., & Harter, S. (2012). *The Self-Perception Profile for Adults: Manual and Questionnaires* (pp. 1–41). Department of Psychology.

Mezaal, M. A., Nouri, K. A., Abdool, S., Al Safar, K., & Nadeem, A. S. M. (2009). Cerebral Palsy In Adults Consequences of Non Progressive Pathology. *The Open Neurology Journal*, *3*(1), 24–26. https://doi.org/10.2174/1874205X00903010024

Miller, M. J., Pak, S. S., Keller, D. R., & Barnes, D. E. (2021). Evaluation of Pragmatic Telehealth Physical Therapy Implementation During the COVID-19 Pandemic. *Physical Therapy*, *101*(1), pzaa193. https://doi.org/10.1093/ptj/pzaa193

Miller, S. M., & Siegel, J. T. (2017). Youth sports and physical activity: The relationship between perceptions of childhood sport experience and adult exercise behavior. *Psychology of Sport and Exercise*, *33*, 85–92. https://doi.org/10.1016/j.psychsport.2017.08.009

Miller, T. W., Elliott, B., Long, K., Mazenac, C., & Moder, M. (2006). Telehealth Home Health Applications for Adults with Developmental Disabilities. *Telemedicine and E-Health*, *12*(2), 137–145. https://doi.org/10.1089/tmj.2006.12.137

Mitchell, L. E., Ziviani, J., & Boyd, R. N. (2016). A randomized controlled trial of web-based training to increase activity in children with cerebral palsy. *Developmental Medicine & Child Neurology*, *58*(7), 767–773. https://doi.org/10.1111/dmcn.13065

Moll, L. R., & Cott, C. A. (2013). The paradox of normalization through rehabilitation: Growing up and growing older with cerebral palsy. *Disability and Rehabilitation*, *35*(15), 1276–1283. https://doi.org/10.3109/09638288.2012.726689

Moreau, N. G., Bodkin, A. W., Bjornson, K., Hobbs, A., Soileau, M., & Lahasky, K. (2016). Effectiveness of Rehabilitation Interventions to Improve Gait Speed in Children With Cerebral Palsy: Systematic Review and Meta-analysis. *Physical Therapy*, *96*(12), 1938–1954. https://doi.org/10.2522/ptj.20150401

Morgan, P. E., & McGinley, J. L. (2013). Falls, fear of falling and falls risk in adults with cerebral palsy: A pilot observational study. *European Journal of Physiotherapy*, *15*(2), 93–100. https://doi.org/10.3109/21679169.2013.795241

Morgan, P., & McGinley, J. (2013). Performance of adults with cerebral palsy related to falls, balance and function: A preliminary report. *Developmental Neurorehabilitation*, *16*(2), 113–120. https://doi.org/10.3109/17518423.2012.725107

Morgan, P., & McGinley, J. (2014). Gait function and decline in adults with cerebral palsy: A systematic review. *Disability and Rehabilitation*, *36*(1), 1–9. https://doi.org/10.3109/09638288.2013.775359

Morgan, P., Murphy, A., Opheim, A., & McGinley, J. (2016). Gait characteristics, balance performance and falls in ambulant adults with cerebral palsy: An observational study. *Gait & Posture*, *48*, 243–248. https://doi.org/10.1016/j.gaitpost.2016.06.015

Morris, J. H., Oliver, Tracy, Kroll, Thilo, Joice, Sara, & Williams, Brian. (2017). Physical activity participation in community dwelling stroke survivors: Synergy and dissonance between motivation and capability. A qualitative study. *Physiotherapy*, *103*, 311–321. http://dx.doi.org/10.1016/j.physio.2016.05.001

Mudge, S., Rosie, J., Stott, S., Taylor, D., Signal, N., & McPherson, K. (2016). Ageing with cerebral palsy; what are the health experiences of adults with cerebral palsy? A qualitative study: Table 1. *BMJ Open*, *6*(10), e012551. https://doi.org/10.1136/bmjopen-2016-012551

Nagata, J. M., Vittinghoff, E., Pettee Gabriel, K., Garber, A. K., Moran, A. E., Sidney, S., Rana, J. S., Reis, J. P., & Bibbins-Domingo, K. (2021). Physical Activity and Hypertension From Young Adulthood to Middle Age. *American Journal of Preventive Medicine*, *60*(6), 757–765. https://doi.org/10.1016/j.amepre.2020.12.018

Nieuwenhuijsen, C., Donkervoort, M., Nieuwstraten, W., Stam, H. J., & Roebroeck, M. E. (2009). Experienced Problems of Young Adults With Cerebral Palsy: Targets for Rehabilitation Care. *Archives of Physical Medicine and Rehabilitation*, *90*(11), 1891–1897. https://doi.org/10.1016/j.apmr.2009.06.014

Nyquist, A., Jahnsen, R. B., Moser, T., & Ullenhag, A. (2019). The coolest I know – a qualitative study exploring the participation experiences of children with disabilities in an adapted physical activities program. *Disability and Rehabilitation*, 1–9. https://doi.org/10.1080/09638288.2019.1573937

O'Connell, N. E., Smith, K. J., Peterson, M. D., Ryan, N., Liverani, S., Anokye, N., Victor, C., & Ryan, J. M. (2019). Incidence of osteoarthritis, osteoporosis and inflammatory musculoskeletal diseases in adults with cerebral palsy: A population-based cohort study. *Bone*, *125*, 30–35. https://doi.org/10.1016/j.bone.2019.05.007

O'Donovan, M., Buckley, C., Benson, J., Roche, S., McGowan, M., Parkinson, L., Byrne, P., Rooney, G., Bergin, C., Walsh, D., Bird, R., McGroarty, F., Fogarty, H., Smyth, E., Ahmed, S., O'Donnell, J. S., Ryan, K., O'Mahony, B., Dougall, A., & O'Connell, N. M. (2020). Telehealth for delivery of haemophilia comprehensive care during the COVID-19 pandemic. *Haemophilia*, *26*(6), 984–990. https://doi.org/10.1111/hae.14156

Olshansky, S. J., Layden, J., & Butler, R. N. (2005). A Potential Decline in Life Expectancy in the United States in the 21st Century. *The New England Journal of Medicine*, 8.

Opheim, A., Jahnsen, R., Olsson, E., & Stanghelle, J. K. (2009). Walking function, pain, and fatigue in adults with cerebral palsy: A 7-year follow-up study: Walking Function, Pain, and Fatigue in Adults with CP. *Developmental Medicine & Child Neurology*, *51*(5), 381–388. https://doi.org/10.1111/j.1469-8749.2008.03250.x

Oppenheim, W. L. (2009). Complementary and alternative methods in cerebral palsy. *Developmental Medicine & Child Neurology*, *51*, 122–129. https://doi.org/10.1111/j.1469-8749.2009.03424.x

Ortega-Pérez de Villar, L., Martínez-Olmos, F. J., Junqué-Jiménez, A., Amer-Cuenca, J. J., Martínez-Gramage, J., Mercer, T., & Segura-Ortí, E. (2018). Test-retest reliability and minimal detectable change scores for the short physical performance battery, one-legged standing test and timed up and go test in patients undergoing hemodialysis. *PLOS ONE*, *13*(8), e0201035. https://doi.org/10.1371/journal.pone.0201035

Oskoui, M., Coutinho, F., Dykeman, J., Jetté, N., & Pringsheim, T. (2013). An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, *55*(6), 509–519. https://doi.org/10.1111/dmcn.12080

Palisano, R. J., Hanna, S. E., Rosenbaum, P. L., Russell, D. J., Walter, S. D., Wood, E. P., Raina, P. S., & Galuppi, B. E. (2000). Validation of a Model of Gross Motor Function for Children With Cerebral Palsy. *Physical Therapy*, *80*(10), 974–985. https://doi.org/10.1093/ptj/80.10.974

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (2008). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine & Child Neurology*, *39*(4), 214–223. https://doi.org/10.1111/j.1469-8749.1997.tb07414.x

Paneth, N., Hong, T., & Korzeniewski, S. (2006). The Descriptive Epidemiology of Cerebral Palsy. *Clinics in Perinatology*, *33*(2), 251–267. https://doi.org/10.1016/j.clp.2006.03.011

Park, E. S., Rha, D.-W., Shin, J. S., Kim, S., & Jung, S. (2014). Effects of Hippotherapy on Gross Motor Function and Functional Performance of Children with Cerebral Palsy. *Yonsei Medical Journal*, *55*(6), 1736. https://doi.org/10.3349/ymj.2014.55.6.1736

Pavasini, R., Guralnik, J., Brown, J. C., di Bari, M., Cesari, M., Landi, F., Vaes, B., Legrand, D., Verghese, J., Wang, C., Stenholm, S., Ferrucci, L., Lai, J. C., Bartes, A. A., Espaulella, J., Ferrer, M., Lim, J.-Y., Ensrud, K. E., Cawthon, P., … Campo, G. (2016). Short Physical Performance Battery and all-cause mortality: Systematic review and meta-analysis. *BMC Medicine*, *14*(1), 215. https://doi.org/10.1186/s12916-016-0763-7

Peterson, M. D., Haapala, H., Kamdar, N., Lin, P., & Hurvitz, E. A. (2021). Pain phenotypes among adults living with cerebral palsy and spina bifida. *Pain*, *Publish Ahead of Print*. https://doi.org/10.1097/j.pain.0000000000002240

Peterson, M. D., Kamdar, N., & Hurvitz, E. A. (2019). Age-related trends in cardiometabolic disease among adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *61*(4), 484–489. https://doi.org/10.1111/dmcn.13777

Peterson, M. D., Lin, P., Kamdar, N., Hurvitz, E. A., & Mahmoudi, E. (2021). Psychological, Cardiometabolic, and Musculoskeletal Morbidity and Multimorbidity Among Adults With Cerebral Palsy and Spina Bifida: A Retrospective Cross-sectional Study. *American Journal of Physical Medicine & Rehabilitation*, *100*(10), 940–945. https://doi.org/10.1097/PHM.0000000000001787

Peterson, M. D., Lin, P., Kamdar, N., Mahmoudi, E., Marsack-Topolewski, C. N., Haapala, H., Muraszko, K., & Hurvitz, E. A. (2021). Psychological morbidity among adults with cerebral palsy and spina bifida. *Psychological Medicine*, *51*(4), 694–701. https://doi.org/10.1017/S0033291720001981

Peterson, M. D., Lin, P., Kamdar, N., Mahmoudi, E., Schmidt, M. M., Haapala, H. J., & Hurvitz, E. A. (2020). Cardiometabolic Morbidity in Adults With Cerebral Palsy and Spina Bifida. *The American Journal of Medicine*, *133*(12), e695–e705. https://doi.org/10.1016/j.amjmed.2020.05.032

Peterson, M. D., Ryan, Jennifer, Hurvitz, Edward, & Mahmoudi, Elham. (2015). Chronic Conditions in Adults With Cerebral Palsy. *JAMA*, *314*(21), 2303–2305.

Piek, J. P., & Carman, R. (1994). Developmental profiles of spontaneous movements in infants. *Early Human Development*, *39*(2), 109–126. https://doi.org/10.1016/0378-3782(94)90160-0

Piercy, K. L., Troiano, R. P., Ballard, R. M., Carlson, S. A., Fulton, J. E., Galuska, D. A., George, S. M., & Olson, R. D. (2018). The Physical Activity Guidelines for Americans. *JAMA*, *320*(19), 2020. https://doi.org/10.1001/jama.2018.14854

Pietruszewski, L., Burkhardt, S., Yoder, P. J., Heathcock, J., Lewandowski, D. J., & Maitre, N. L. (2020). Protocol and Feasibility-Randomized Trial of Telehealth Delivery for a Multicomponent Upper Extremity Intervention in Infants With Asymmetric Cerebral Palsy. *Child Neurology Open*, *7*, 2329048X2094621. https://doi.org/10.1177/2329048X20946214

Portney, LG. (2020). *Foundations of Clinical Research: Applications to Evidence-Based Practice* (4th ed). McGraw-Hill Education LLC.

Posłuszny, A., Myśliwiec, A., Saulicz, E., Doroniewicz, I., Linek, P., & Wolny, T. (2017). Current understanding of the factors influencing the functional independence of people with cerebral palsy: A review of the literature. *International Journal of Developmental Disabilities*, *63*(2), 77–90. https://doi.org/10.1080/20473869.2016.1145396

Preston, E., Dean, C. M., Ada, L., Stanton, R., Brauer, S., Kuys, S., & Waddington, G. (2017). Promoting physical activity after stroke via self-management: A feasibility study. *Topics in Stroke Rehabilitation*, *24*(5), 353–360. https://doi.org/10.1080/10749357.2017.1304876

Raichle, K. A., Hanley, M., Jensen, M. P., & Cardenas, D. D. (2007). Cognitions, Coping, and Social Environment Predict Adjustment to Pain in Spinal Cord Injury. *The Journal of Pain*, *8*(9), 718–729. https://doi.org/10.1016/j.jpain.2007.05.006

Reddihough, D. S., & Collins, K. J. (2003). The epidemiology and causes of cerebral palsy. *Australian Journal of Physiotherapy*, *49*, 6.

Redmond, R., & Parrish, M. (2008). Variables Influencing Physiotherapy Adherence Among Young Adults With Cerebral Palsy. *Qualitative Health Research*, *18*(11), 1501–1510. https://doi.org/10.1177/1049732308325538

Reitan, R. M. (1958). Validity of the Trail Making Test as an Indicator of Organic Brain Damage. *Perceptual and Motor Skills*, *8*, 271–276.

Richardson, B. R., Truter, P., Blumke, R., & Russell, T. G. (2017). Physiotherapy assessment and diagnosis of musculoskeletal disorders of the knee via telerehabilitation. *Journal of Telemedicine and Telecare*, *23*(1), 88–95. https://doi.org/10.1177/1357633X15627237

Rimmer, J. H., Riley, B. B., & Rubin, S. S. (2001). A New Measure for Assessing the Physical Activity Behaviors of Persons with Disabilities and Chronic Health Conditions: The Physical Activity and Disability Survey. *American Journal of Health Promotion*, *16*(1), 34–45. https://doi.org/10.4278/0890-1171-16.1.34

Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., & Jurkowski, J. (2004). Physical activity participation among persons with disabilities. *American Journal of Preventive Medicine*, *26*(5), 419–425. https://doi.org/10.1016/j.amepre.2004.02.002

Rimmer, J. H., Wang, E., Pellegrini, C. A., Lullo, C., & Gerber, B. S. (2013). Telehealth Weight Management Intervention for Adults with Physical Disabilities: A Randomized

Controlled Trial. *American Journal of Physical Medicine & Rehabilitation*, *92*(12), 1084–1094. https://doi.org/10.1097/PHM.0b013e31829e780e

Riquelme, I., Cifre, I., & Montoya, P. (2011). Age-Related Changes of Pain Experience in Cerebral Palsy and Healthy Individuals. *Pain Medicine, 12*(4), 535–545. https://doi.org/10.1111/j.1526-4637.2011.01094.x

Robinson, J. D., Prochaska, J. D., & Yngve, D. A. (2017). Pre-surgery evaluations by telephone decrease travel and cost for families of children with cerebral palsy. *SAGE Open Medicine*, *5*, 205031211772004. https://doi.org/10.1177/2050312117720046

Robinson, L. E., Stodden, D. F., Barnett, L. M., Lopes, V. P., Logan, S. W., Rodrigues, L. P., & D'Hondt, E. (2015). Motor Competence and its Effect on Positive Developmental Trajectories of Health. *Sports Medicine, 45*(9), 1273–1284. https://doi.org/10.1007/s40279-015-0351-6

Roebroeck, M. E., Jahnsen, R., Carona, C., Kent, R. M., & Chamberlain, M. A. (2009). Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Developmental Medicine & Child Neurology*, *51*(8), 670–678. https://doi.org/10.1111/j.1469-8749.2009.03322.x

Rogers, L., & Wong, E. (2018). *Cerebral Palsy* [Review of Pathophysiology of Disease]. McMaster Pathophysiology Review. http://www.pathophys.org/cerebralpalsy/

Rosenbaum, P., & Gorter, J. W. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, *38*(4), 457–463. https://doi.org/10.1111/j.1365-2214.2011.01338.x

Rosenbaum, P. L., Walter, S. D., Hanna, S. E., Palisano, R. J., Russell, D. J., Raina, P., Wood, E., Bartlett, D. J., & Galuppi, B. E. (2003). Prognosis for Gross Motor Function in

Cerebral Palsy: Creation of Motor Development Curves: *Obstetrical & Gynecological Survey*, *58*(3), 166–168. https://doi.org/10.1097/01.OGX.0000055751.17527.56

Ross, S. M., MacDonald, M., & Bigouette, J. P. (2016). Effects of strength training on mobility in adults with cerebral palsy: A systematic review. *Disability and Health Journal*, *9*(3), 375–384. https://doi.org/10.1016/j.dhjo.2016.04.005

Ryan, J. M., Crowley, V. E., Hensey, O., Broderick, J. M., McGahey, A., & Gormley, J. (2014). Habitual physical activity and cardiometabolic risk factors in adults with cerebral palsy. *Research in Developmental Disabilities*, *35*(9), 1995–2002. https://doi.org/10.1016/j.ridd.2014.03.051

Ryan, J. M., Crowley, V. E., Hensey, O., McGahey, A., & Gormley, J. (2014). Waist Circumference Provides an Indication of Numerous Cardiometabolic Risk Factors in Adults With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, *95*(8), 1540–1546. https://doi.org/10.1016/j.apmr.2014.03.029

Sainsbury, A., Seebass, G., Bansal, A., & Young, J. B. (2005). Reliability of the Barthel Index when used with older people. *Age and Ageing*, *34*(3), 228–232. https://doi.org/10.1093/ageing/afi063

Salem, Y., & Godwin, E. M. (2009). Effects of task-oriented training on mobility function in children with cerebral palsy. *NeuroRehabilitation*, *24*, 8. https://doi.org/10.3233/NRE-2009-0483

Sallis, J. F., Floyd, M. F., Rodrıguez, D. A., & Saelens, B. E. (2012). Role of Built Environments in Physical Activity, Obesity, and Cardiovascular Disease. *Recent Advances in Preventive Cardiology and Lifestyle Medicine*, *125*, 729–737. https://doi.org/10.1161/CIRCULATIONAHA.110.969022

Sandström, K. (2007). The lived body—Experiences from adults with cerebral palsy. *Clinical Rehabilitation*, *21*(5), 432–441. https://doi.org/10.1177/0269215507073489

Sandström, K., Alinder, J., & Öberg, B. (2004). Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disability and Rehabilitation*, *26*(17), 1023–1031. https://doi.org/10.1080/09638280410001703503

Schiff, M., Helton, J., & Fu, J. (2021). Adverse childhood experiences and obesity over time. *Public Health Nutrition*, *24*(11), 3205–3209. https://doi.org/10.1017/S1368980021001804

Schlichting, T., Martins da Silva, K., Silva Moreira, R., Marques de Moraes, M. V., Cicuto Ferreira Rocha, N. A., Boyd, R. N., & Neves dos Santos, A. (2022). Telehealth Program for Infants at Risk of Cerebral Palsy during the Covid-19 Pandemic: A Pre-post Feasibility Experimental Study. *Physical & Occupational Therapy In Pediatrics*, 1–20. https://doi.org/10.1080/01942638.2022.2057209

Schwartz, L., Engel, J. M., & Jensen, M. P. (1999). Pain in persons with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, *80*(10), 1243–1246. https://doi.org/10.1016/S0003-9993(99)90023-0

Shields, N., Loy, Y., Murdoch, A., Taylor, N. F., & Dodd, K. J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology*, *49*(5), 350–354. https://doi.org/10.1111/j.1469-8749.2007.00350.x

Shields, N., & Synnot, A. (2016). Perceived barriers and facilitators to participation in physical activity for children with disability: A qualitative study. *BMC Pediatrics*, *16*(1), 9. https://doi.org/10.1186/s12887-016-0544-7

Shields, N., Synnot, A. J., & Barr, M. (2012). Perceived barriers and facilitators to physical activity for children with disability: A systematic review. *British Journal of Sports Medicine*, *46*(14), 989–997. https://doi.org/10.1136/bjsports-2011-090236

Shore, B. J., Allar, B. G., Miller, P. E., Matheney, T. H., Snyder, B. D., & Fragala-Pinkham, M. (2019). Measuring the Reliability and Construct Validity of the Pediatric Evaluation of Disability Inventory–Computer Adaptive Test (PEDI-CAT) in Children With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, *100*(1), 45–51. https://doi.org/10.1016/j.apmr.2018.07.427

Sienko, S. (2019). Understanding the factors that impact the participation in physical activity and recreation in young adults with cerebral palsy (CP). *Disability and Health Journal*, *12*(3), 467–472. https://doi.org/10.1016/j.dhjo.2019.02.008

Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A Report from the WHOQOL Group. *Quality of Life Research*, *13*(2), 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00

Slaman, J., Bussmann, J., van der Slot, W. M., Stam, H. J., Roebroeck, M. E., & van den Berg-Emons, R. J. (2013). Physical Strain of Walking Relates to Activity Level in Adults With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, *94*(5), 896–901. https://doi.org/10.1016/j.apmr.2012.11.005

Smith, J. P. (2009). *Reconstructing childhood health histories*. *46*(2), 17.

Smith, K. J., Peterson, M. D., O'Connell, N. E., Victor, C., Liverani, S., Anokye, N., & Ryan, J. M. (2019). Risk of Depression and Anxiety in Adults With Cerebral Palsy. *JAMA Neurology*, *76*(3), 294. https://doi.org/10.1001/jamaneurol.2018.4147

Smith, S. E., Gannotti, M., Hurvitz, E. A., Jensen, F. E., Krach, L. E., Kruer, M. C., Msall, M. E., Noritz, G., Rajan, D. S., & Aravamuthan, B. R. (2021). Adults with Cerebral Palsy Require Ongoing Neurologic Care: A Systematic Review. *Annals of Neurology*, *89*(5), 860–871. https://doi.org/10.1002/ana.26040

Stewart, A. L., & King, A. C. (1991). Evaluating the efficacy of physical activity for influencing quality-of-life outcomes in older adults. *Exercise and Aging*, *13*(3), 108–116.

Stodden, D. F., Gao, Z., Goodway, J. D., & Langendorfer, S. J. (2014). Dynamic Relationships Between Motor Skill Competence and Health-related Fitness in Youth. *Pediatric Exercise Science*, *26*(3), 231–241. https://doi.org/10.1123/pes.2013-0027

Stodden, D. F., Goodway, J. D., Langendorfer, S. J., Roberton, M. A., Rudisill, M. E., Garcia, C., & Garcia, L. E. (2008). A Developmental Perspective on the Role of Motor Skill Competence in Physical Activity: An Emergent Relationship. *Quest*, *60*(2), 290–306. https://doi.org/10.1080/00336297.2008.10483582

Strauss, D., Ojdana, K., Shavelle, R., & Rosenbloom, L. (2004). Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation*, *19*(1), 69–78. https://doi.org/10.3233/NRE-2004-19108

Strauss, D., Shavelle, R., Reynolds, R., Rosenbloom, L., & Day, S. (2007). Survival in cerebral palsy in the last 20 years: Signs of improvement? *Developmental Medicine & Child Neurology*, *49*(2), 86–92. https://doi.org/10.1111/j.1469-8749.2007.00086.x

Sutter, E. N., Francis, L. S., Francis, S. M., Lench, D. H., Nemanich, S. T., Krach, L. E., Sukal-Moulton, T., & Gillick, B. T. (2021). Disrupted Access to Therapies and Impact on Well-Being During the COVID-19 Pandemic for Children With Motor Impairment and Their

Caregivers. *American Journal of Physical Medicine & Rehabilitation*, *100*(9), 821–830. https://doi.org/10.1097/PHM.0000000000001818

Tenforde, A. S., Hefner, J. E., Kodish-Wachs, J. E., Iaccarino, M. A., & Paganoni, S. (2017). Telehealth in Physical Medicine and Rehabilitation: A Narrative Review. *PM&R*, *9*, S51–S58. https://doi.org/10.1016/j.pmrj.2017.02.013

Teulier, C., Lee, D. K., & Ulrich, B. D. (2015). Early gait development in human infants: Plasticity and clinical applications: Early Gait Development. *Developmental Psychobiology*, *57*(4), 447–458. https://doi.org/10.1002/dev.21291

The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. (1995). *Social Science & Medicine*, *41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

Thelen, E., Ulrich, B. D., & Wolff, P. H. (1991). Hidden Skills: A Dynamic Systems Analysis of Treadmill Stepping during the First Year. *Monographs of the Society for Research in Child Development*, *56*(1), i. https://doi.org/10.2307/1166099

Thorpe, D. (2009). The role of fitness in health and disease: Status of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *51*, 52–58. https://doi.org/10.1111/j.1469-8749.2009.03433.x

Thorpe, D., Gannotti, M., Peterson, M. D., Wang, C.-H., & Freburger, J. (2021). Musculoskeletal diagnoses, comorbidities, and physical and occupational therapy use among older adults with and without cerebral palsy. *Disability and Health Journal*, *14*(4), 101109. https://doi.org/10.1016/j.dhjo.2021.101109

Treacy, D., & Hassett, L. (2018). The Short Physical Performance Battery. *Journal of Physiotherapy*, *64*, 61. https://doi.org/10.1016/j.jphys.2017.04.002

Turk, M. A. (2009). Health, mortality, and wellness issues in adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *51*, 24–29. https://doi.org/10.1111/j.1469-8749.2009.03429.x

Turk, M. A., & Fortuna, R. J. (2019). Health Status of Adults with Cerebral Palsy. In V. P. Prasher & M. P. Janicki (Eds.), *Physical Health of Adults with Intellectual and Developmental Disabilities* (pp. 87–120). Springer International Publishing. https://doi.org/10.1007/978-3-319-90083-4_6

Ulrich, B. D. (2010). Opportunities for Early Intervention Based on Theory, Basic Neuroscience, and Clinical Science. *Physical Therapy*, *90*(12), 1868–1880. https://doi.org/10.2522/ptj.20100040

Usuba, K. (2013). *Leisure Time Physical Activities and Quality of Life in Adults with Cerebral Palsy*.

Usuba, K., Oddson, B., Gauthier, A., & Young, N. L. (2014). Changes in Gross Motor Function and Health-Related Quality of Life in Adults With Cerebral Palsy: An 8-Year Follow-Up Study. *Archives of Physical Medicine and Rehabilitation*, *95*(11), 2071-2077.e1. https://doi.org/10.1016/j.apmr.2014.05.018

van der Dussen, L., Nieuwstraten, W., Roebroeck, M., & Stam, H. J. (2001). Functional level of young adults with cerebral palsy. *Clinical Rehabilitation*, *15*(1), 84–91. https://doi.org/10.1191/026921501670159475

van der Slot, W. M. A., Benner, J. L., Brunton, L., Engel, J. M., Gallien, P., Hilberink, S. R., Månum, G., Morgan, P., Opheim, A., Riquelme, I., Rodby-Bousquet, E., Şimşek, T. T., Thorpe, D. E., van den Berg-Emons, R. J. G., Vogtle, L. K., Papageorgiou, G., & Roebroeck, M. E. (2020). Pain in adults with cerebral palsy: A systematic review and meta-analysis of individual participant data. *Annals of Physical and Rehabilitation Medicine*, S1877065720300348. https://doi.org/10.1016/j.rehab.2019.12.011

van der Slot, W. M. A., Benner, J. L., Brunton, L., Engel, J. M., Gallien, P., Hilberink, S. R., Månum, G., Morgan, P., Opheim, A., Riquelme, I., Rodby-Bousquet, E., Şimşek, T. T., Thorpe, D. E., van den Berg-Emons, R. J. G., Vogtle, L. K., Papageorgiou, G., & Roebroeck, M. E. (2021). Pain in adults with cerebral palsy: A systematic review and meta-analysis of individual participant data. *Annals of Physical and Rehabilitation Medicine*, *64*(3), 101359. https://doi.org/10.1016/j.rehab.2019.12.011

Van Naarden Braun, K., Doernberg, N., Schieve, L., Christensen, D., Goodman, A., & Yeargin-Allsopp, M. (2016). Birth Prevalence of Cerebral Palsy: A Population-Based Study. *Pediatrics*, *137*(1), e20152872. https://doi.org/10.1542/peds.2015-2872

Vandervelde, L., Van den Bergh, P. Y. K., Penta, M., & Thonnard, J. L. (2010). Validation of the ABILHAND questionnaire to measure manual ability in children and adults with neuromuscular disorders. *Journal of Neurology, Neurosurgery & Psychiatry*, *81*(5), 506–512. https://doi.org/10.1136/jnnp.2009.177055

Vanhees, L., Lefevre, J., Philippaerts, R., Martens, M., Huygens, W., Troosters, T., & Beunen, G. (2005). How to assess physical activity? How to assess physical fitness? *European Journal of Cardiovascular Prevention & Rehabilitation*, *12*(2), 102–114. https://doi.org/10.1097/01.hjr.0000161551.73095.9c

Vasudevan, V., Rimmer, J. H., & Kviz, F. (2015). Development of the Barriers to Physical Activity Questionnaire for People with Mobility Impairments. *Disability and Health Journal*, *8*(4), 547–556. https://doi.org/10.1016/j.dhjo.2015.04.007

Vasunilashorn, S., Coppin, A. K., Patel, K. V., Lauretani, F., Ferrucci, L., Bandinelli, S., & Guralnik, J. M. (2009). Use of the Short Physical Performance Battery Score to Predict Loss of Ability to Walk 400 Meters: Analysis From the InCHIANTI Study. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *64A*(2), 223–229. https://doi.org/10.1093/gerona/gln022

Verbunt, J. (2008). Reliability and validity of the PAD questionnaire: A measure to assess pain-related decline in physical activity. *Journal of Rehabilitation Medicine*, *40*(1), 9–14. https://doi.org/10.2340/16501977-0126

Verbunt, J. A., Huijnen, I. P. J., & Köke, A. (2009). Assessment of physical activity in daily life in patients with musculoskeletal pain. *European Journal of Pain*, *13*(3), 231–242. https://doi.org/10.1016/j.ejpain.2008.04.006

Verschuren, O., Peterson, M. D., Balemans, A. C. J., & Hurvitz, E. A. (2016). Exercise and physical activity recommendations for people with cerebral palsy. *Developmental Medicine & Child Neurology*, *58*(8), 798–808. https://doi.org/10.1111/dmcn.13053

Verschuren, O., Smorenburg, A. R. P., Luiking, Y., Bell, K., Barber, L., & Peterson, M. D. (2018). Determinants of muscle preservation in individuals with cerebral palsy across the lifespan: A narrative review of the literature: Muscle preservation in individuals with cerebral palsy. *Journal of Cachexia, Sarcopenia and Muscle*, *9*(3), 453–464. https://doi.org/10.1002/jcsm.12287

Vogtle, L. K. (2009). Pain in adults with cerebral palsy: Impact and solutions. *Developmental Medicine & Child Neurology*, *51*(s4), 113–121. https://doi.org/10.1111/j.1469-8749.2009.03423.x

Vogtle, L. K., Malone, L. A., & Azuero, A. (2014). Outcomes of an exercise program for pain and fatigue management in adults with cerebral palsy. *Disability and Rehabilitation*, *36*(10), 818–825. https://doi.org/10.3109/09638288.2013.821181

Washburn, R. A., Zhu, W., McAuley, E., Frogley, M., & Figoni, S. F. (2002). The physical activity scale for individuals with physical disabilities: Development and evaluation. *Archives of Physical Medicine and Rehabilitation*, *83*(2), 193–200. https://doi.org/10.1053/apmr.2002.27467

Wheeler, S. M., & Bryant, A. S. (2017). Racial and Ethnic Disparities in Health and Health Care. *Obstetrics and Gynecology Clinics of North America*, *44*(1), 1–11. https://doi.org/10.1016/j.ogc.2016.10.001

Whitney, D. G., Bell, S., Whibley, D., Slot, W. M. A. V. der, Hurvitz, E. A., Haapala, H. J., Peterson, M. D., & Warschausky, S. A. (2020). Effect of pain on mood affective disorders in adults with cerebral palsy. *Developmental Medicine & Child Neurology*, *n/a*(n/a), 7. https://doi.org/10.1111/dmcn.14559

Whitney, D. G., Hurvitz, E. A., Devlin, M. J., Caird, M. S., French, Z. P., Ellenberg, E. C., & Peterson, M. D. (2018b). Age trajectories of musculoskeletal morbidities in adults with cerebral palsy. *Bone*, *114*, 285–291. https://doi.org/10.1016/j.bone.2018.07.002

Whitney, D. G., Hurvitz, E. A., & Peterson, M. D. (2020). Cardiometabolic disease, depressive symptoms, and sleep disorders in middle-aged adults with functional disabilities: NHANES 2007–2014. *Disability and Rehabilitation*, *42*(15), 2186–2191. https://doi.org/10.1080/09638288.2018.1555720

Whitney, D. G., Warschausky, S. A., Ng, S., Hurvitz, E. A., Kamdar, N. S., & Peterson, M. D. (2019). Prevalence of Mental Health Disorders Among Adults With Cerebral Palsy: A

Cross-sectional Analysis. *Annals of Internal Medicine*, *171*(5), 328. https://doi.org/10.7326/M18-3420

Whitney, D., Hurvitz, E., Ryan, J., Devlin, M., Caird, M., French, Z., Ellenberg, E., & Peterson, M. (2018a). Noncommunicable disease and multimorbidity in young adults with cerebral palsy. *Clinical Epidemiology*, *Volume 10*, 511–519. https://doi.org/10.2147/CLEP.S159405

Winnick. (2011). *Adapted Physical Education and Sport* (5th ed.). Human Kinetics.

Wolf, S. L., Catlin, P. A., Ellis, M., Archer, A. L., Morgan, B., & Piacentino, A. (2001). Assessing Wolf Motor Function Test as Outcome Measure for Research in Patients After Stroke. *Stroke*, *32*(7), 1635–1639. https://doi.org/10.1161/01.STR.32.7.1635

Wright, A., Roberts, R., Bowman, G., & Crettenden, A. (2019). Barriers and facilitators to physical activity participation for children with physical disability: Comparing and contrasting the views of children, young people, and their clinicians. *Disability and Rehabilitation*, *41*(13), 1499–1507. https://doi.org/10.1080/09638288.2018.1432702

Wu, C., Fu, T., Lin, K., Feng, C., Hsieh, K., Yu, H., Lin, C., Hsieh, C., & Ota, H. (2011). Assessing the Streamlined Wolf Motor Function Test as an Outcome Measure for Stroke Rehabilitation. *Neurorehabilitation and Neural Repair*, *25*(2), 194–199. https://doi.org/10.1177/1545968310381249

Yeroushalmi, S., Maloni, H., Costello, K., & Wallin, M. T. (2020). Telemedicine and multiple sclerosis: A comprehensive literature review. *Journal of Telemedicine and Telecare*, *26*(7–8), 400–413. https://doi.org/10.1177/1357633X19840097

Yi, Y. G., Jung, S. H., & Bang, M. S. (2019). Emerging Issues in Cerebral Palsy Associated With Aging: A Physiatrist Perspective. *Annals of Rehabilitation Medicine*, *43*(3), 241–249. https://doi.org/10.5535/arm.2019.43.3.241

Young, N. L., Steele, C., Fehlings, D., Jutai, J., Olmsted, N., & Williams, I. J. (2005). Use of health care among adults with chronic and complex physical disabilities of childhood. *Disability and Rehabilitation*, *27*(23), 1455–1460. https://doi.org/10.1080/00222930500218946

Zaffuto-Sforza, C. D. (2005). Aging with cerebral palsy. *Physical Medicine and Rehabilitation Clinics of North America*, *16*(1), 235–249. https://doi.org/10.1016/j.pmr.2004.06.014

Ziebell, M., Imms, C., Froude, E. H., McCoy, A., & Galea, M. (2009). The relationship between physical performance and self-perception in children with and without cerebral palsy. *Australian Occupational Therapy Journal*, *56*(1), 24–32. https://doi.org/10.1111/j.1440-1630.2008.00775.x

Zischke, C., Simas, V., Hing, W., Milne, N., Spittle, A., & Pope, R. (2021). The utility of physiotherapy assessments delivered by telehealth: A systematic review. *Journal of Global Health*, *11*, 04072. https://doi.org/10.7189/jogh.11.04072