AN EXPLORATORY EXAMINATION OF THE ROLE THAT LIFESTYLE ACTIVITY AND EXTENT OF DISABILITY HAS ON COGNITIVE FUNCTION AND QUALITY OF LIFE IN ADULTS WITH CEREBRAL PALSY

By

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PUBLIC ABSTRACT

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Cerebral palsy is a physiological disability that affects 3-3.5:1,000 live births in the US and is caused by malformation or damage to the brain during the early stages of development and results in spastic paresis, constant movement of the affected area. Cerebral palsy can cause deficits in muscle-control, -coordination, or -tone; and issues/difficulties with balance, reflexes, posture, and/or fine, gross, and oral motor skills. Cognitive performance, extent of disability and quality of life data was collected and tested to observe the nature of their relationships with demographic characteristics, exercise, general physical activity, and sedentary behaviors. Recruitment and data collection were completed online and a sample of 148 (34 female) adults with cerebral palsy participated in the study. Results showed that general physical activity was strongly associated with self-report extent of disability as well as emotional health-related quality of life. Both sedentary behavior and demographic characteristics (age, sex, education, etc.) were not observed to be significantly related. Cognitive performance was observed to be negatively related with exercise, however, due to testing limitations analyses of cognitive function were statistically underpowered. The findings from this exploratory research provide insight into the future of research on adults living with cerebral palsy.

ABSTRACT

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Cerebral palsy is a physiological disability that affects 3-3.5:1,000 live births in the US and is caused by malformation or damage to the brain during the early stages of development and while not the cause, prematurity and low birth weight are considered the primary risk-factors associated with a future diagnosis of cerebral palsy (by 2 years of age). According to the CDC, more than half of the individuals with cerebral palsy can walk independently or with the use of a walker. Roughly 40% or fewer with cerebral palsy have some form of intellectual or other co-occurring mental disability such as autism. A breadth of research has been conducted observing various non-physical benefits of regular exercise/physical activity as well as the negative impacts of a sedentary lifestyle. To better understand and serve those with cerebral palsy; study was interested in observing exercise/general physical activity/sedentary behavior. To determine if they relate to cognitive performance, extent of symptomology, and quality of life exist; and if so, to what extent. Adults with cerebral palsy (total n=148, 34 female) were recruited and completed all data collection online. General physical activity was observed to be significantly related to extent of disability and quality of life, exercise was observed to be negatively related to cognition, and both demographics and sedentary behavior were not significantly related to any of the test variables.

I dedicate this project to my wife, without her support over the last decade and a half of college across three states this would never have been possible. And to Piotr, not only for his invaluable help in developing this project and its methods. But also, for opening my eyes.

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KEY TO ABBREVIATIONS

GMFCS	Gross Motor Function Classification System
MACS	Manual Ability Classification System
CFCS	Communication Function Classification System
ITT	Inspection Time Task
PADS-R	Physical Activity and Disability Survey-Revised
SBQ	Sedentary Behavior Questionnaire
QoL	Quality of Life
RAND	Research and Development (Corporation, Santa Monica, California)
BMI	Body Mass Index (weight in pounds x 703 ÷ height in inches^2)
CDC	Centers for Disease Control and Prevention
WHO	World Health Organization
U.S.	United States of America

Introduction

Cerebral palsy is a permanent, non-progressive physical disability in which damage to the brain results in a wide range of motor control deficits that affect movement and posture. According to the CDC (Centers for Disease Control & Prevention), more than half of the individuals with cerebral palsy can walk independently or with the use of a walker. Roughly 40% or fewer with cerebral palsy have some form of intellectual or other co-occurring mental disability such as autism, and 35% have some form of epilepsy (Christensen, et. al., 2014). There are many causes of cerebral palsy, and every case of cerebral palsy is unique to the individual. As such, the term *cerebral palsy* identifies a range of symptoms and severities, all which are the result of damage or malformation during the early development of the brain. The primary window of risk for developing cerebral palsy is during the perinatal period of development which lasts from the twentieth week of gestation to the twenty-eighth day of life (Paneth, et. al., 2006). However, there are incidence of cerebral palsy resulting from injury, or neural damage from other sources occurring within a few months following birth to as late in development as age 2 (Paneth, et. al., 2006). Although pre-mature birth is the primary risk-factor associated with a future diagnosis of cerebral palsy, researchers have determined that the development of cerebral palsy is likely not caused by a single event or symptom (Perlman, 2006); in roughly 10-20% of cases, miscellaneous intrapartum complications involving the mother and/or child including major trauma, injury, and/or complications are involved in the etiology and future diagnosis of cerebral palsy. Combining multiple methods of identifying the prevalence of cerebral palsy, researchers have determined that roughly 3-3.5: 1,000 livebirths result in a cerebral palsy diagnosis (Kirby, et. al., 2011). Regardless of the cause(s), cerebral palsy cannot be accurately diagnosed until the child is two years old (Paneth, et. al., 2006, Rosenbaum, et. al., 2007); the type, timing, and extent of injury to the brain (neurological damage or malformation) all affect the physical effects that a person diagnosed with cerebral palsy experiences.

Those with cerebral palsy may exhibit such issues as muscle-control, -coordination, or -tone; and issues/difficulties with balance, reflexes, posture, and/or fine, gross, and oral motor skills. Anecdotally, the experience has been described as having a charley horse, or muscle spasm that never (or rarely) goes away. Additionally, instead of being in a single muscle group (as commonly experienced in able-bodied individuals) for those with cerebral palsy, the spasms and associated pain and discomfort is simultaneously occurring in each body part impacted by spastic paresis. As such, there are myriad barriers to physical activity present for individuals with cerebral palsy, given that the modes of physical activity available are dependent on the extent to which the disability impacts their motor and other functions. However, innumerable adapted physical activities and exercises are available to provide activity fitting the individual's abilities, such as arm/leg exercises, assisted walking, aquatic aerobics, in addition to rehabilitative therapies/stretches/exercise.

The national physical activity and health behavior data shows an increase in the percentage of the population that does not meet the recommended regular physical activity levels, as well as a steady increase in those that are overweight/obese in the U.S. (Matthews, et. al., 2008). It is important to differentiate exercise and physical activity as well as sedentary behavior. Physical activities are any action resulting in movement of the body or a limb. Examples of physical activities include, but are not limited to; walking, doing housework, grocery shopping, gardening, etc. While exercise is a form of physical activity, exercise requires intentional, repetitive action for the purpose of improving or maintaining fitness, exercises include things like walking, jogging, running, swimming, sports participation/practice, weightlifting, yoga, and many others. While the difference between physical activity and exercise is often easily discernable in able-bodied individuals, certain daily activities might feel more like exercise to someone with spastic paresis. One of the main methods of determining if an activity is exercise vs. physical activity is in the precise reading of the definition of exercise use; requiring intentional repetitive movements that serve the purpose of maintaining fitness. While general physical activity applies to anytime spent in motion or participating in a movement-based activity. Exercise is physical activity engaged in that has a specific fitness-based purpose/goal. For example, an individual could walk as a part of their daily commute to school/work, which would be physical activity and for exercise they could go to a track or on a nature path and walk a specific distance every evening as part of an effort to make their daily commuting less taxing.

Sedentary behaviors may appear visually and even feel experientially as just not being active. But being sedentary is not the absence of behavior, but rather a set of behaviors identified by a continued and conscious lack of movement like sitting a desk job without standing or moving for hours at a time or spending a few hours sitting and watching television. A lack of regular physical activity and/or a sedentary lifestyle has been associated with various negative health outcomes including high blood pressure, diabetes, and weight gain (Hales, et. al., 2017). The effects of sedentary behaviors are even more harmful for populations with physical disabilities because negative health outcomes, such as obesity, have a greater effect on individuals with physical disabilities compared to their able-bodied peers; by increasing the severity of the health risks and exacerbating existing difficulties with motor function (Dunlop, et. al., 2015). Further research is needed to develop an understanding of the long-term and varied implications that sedentary behaviors can have on people with disabilities such as cerebral palsy (worsening symptoms, reduced independence, quality of life, etc.).

Unlike physical disabilities of differing etiologies, such as spinal cord damage or physical birth defects (i.e. malformation of a limb), cerebral palsy is caused by *neurological* damage or malformation which then manifests physically in the body. Other physical disabilities usually result from trauma to a specific part of the body other than the brain. In these cases, where there is little-to-no brain damage, it would be likely that the cognitive benefits associated with physical activity behaviors would reflect those observed in their able-bodied peers. Although the physical presentation of cerebral palsy might appear like the physical presentation of other physical disabilities, its origin is vastly different. For example, an individual who suffered an injury to his/her spinal cord resulting in paraplegia might use the same modified exercises as an individual with diplegic cerebral palsy of the legs. There are, however, two key differences. First, is the location on the body where the damage exists causing the disability (the brain versus spinal cord). Second, damage to the spinal cord results in flaccid paralysis (little-to-no movement or feeling) while cerebral palsy results in spastic paresis (uncontrolled or difficult to control, often continuous movement commonly causing pain/discomfort). While both individuals are exercising, their neural responses to the physical activity may not be the same. It is possible that the neurological damage that led to the individual with cerebral palsy's motor disability may also impede the cognitive benefits of physical activity. Based on existent literature this relationship, in persons with cerebral palsy, is currently unknown.

A growing body of research has focused on physical activity in the population with cerebral palsy, with an emphasis on the physical fitness benefits of exercise, physical therapy methods, and the general physical activity/exercise behaviors of those with cerebral palsy (Dodd, et. al., 2002, Damiano, 2006). Utilizing adapted activity methodologies, researchers have provided insight into the physical activity/exercise behaviors and capacities of individuals with cerebral palsy, in addition to implementing a variety of adapted physical activity intervention programs with the goal of improving physical fitness (Fowler, et. al., 2007, Butler, et. al., 2010). However, within these studies there is little-to-no emphasis on the cognitive or quality of life implications of acute physical activity or an active lifestyle (Groff, et. al., 2009, Maher, et. al., 2016). There may be wide-reaching implications on patient care and the overall understanding of cerebral palsy if physical activity has a similar effect on cognition in those with cerebral palsy as their able-bodied peers.

In able-bodied populations limiting sedentary behavior and increasing physical activity/exercise has been associated with positive changes in cognitive function, mood, and quality of life (Etnier, et. al., 1997, Colcombe & Kramer, 2003, Etnier, et. al., 2006). In addition, studies like these demonstrate more substantial positive changes in cognition in individuals with deficits to cognition, such as seniors, sedentary individuals, or individuals with mental, emotional, or physical maladies (Hillman, et. al., 2006, Etnier, et. al., 2014, Cockshell & Mathias, 2013). These activity/cognitive results imply that benefits from activity go beyond the physical and those benefits tend to be more robust in those with the most to gain. One aspect that may be critical in this relationship is the concept of quality of life. Cerebral palsy is a lifetime diagnosis with non-progressive symptoms, meaning that the portions of the body and the extent impacted is mostly stable for life. The extent of symptoms and adaptability of the individual (and their environment) has a direct impact on an individual's quality of life (Eiser & Morse, 2001) Quality of life (QoL) is defined by the World Health Organization as, "The individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and subjective perspectives in each of those domains." (Eiser & Morse, 2001, pg. 249). QoL is a concept that often attempts to see the whole picture to understand the individual/group. Therefore, the method used for determining QoL in adults with cerebral palsy, should inquire about as many factors of their cerebral palsy that might have an influence on QoL as possible. Or, as is the case for this study, ask questions regarding a specific aspect of their quality of life (health); with questions related to the role the individual's disability has on their life (Hays, et. al., 1993). For this aspect of quality of life eight subcategories are integrated into the overall measure including: physical and emotional limitations and abilities/well-being, social life, energy/fatigue level, pain, and general healthiness. For adults with cerebral palsy, examining the results of the sub-scales is crucial, considering that cerebral palsy can have both broad and specific impacts on the individual's quality of life. Given the definition of quality of life, results from previous behavioral research, and the variability of cerebral palsy symptoms; it is expected that there would be a significant relationship associated between exercise/physical activity/sedentary behavior and quality of life.

Cerebral palsy is identified by the associated spastic paresis the extent of which is based on what parts of the body present symptoms and the extent those symptoms impact function (Paneth, et. al., 2006). Frequently, in the research community, cerebral palsy severity in determined by a single measure, one that is based on the researcher's direct observation of the individual and is recorded on a scale of 1-5 (1 = least effected by cerebral palsy). Additionally, this measure is specific only to overall motor skills. The gross motor classification system (GMFCS) is the standard, however there are similar measures (1-5 observation-based scales) that examine effects of cerebral palsy on fine motor skills as well as, communication skills; each of which could be different from gross motor skills. For example, individuals with diplegia in the legs and is wheelchair (or powerchair) bound could have an upper body that is mostly unaffected. In that case, they would be a 4 or 5 on the GMFCS, but a 1 or 2 for communication and fine motor skills. While other individuals reported at a GMFCS level of 5 may be affected head-to-toe, would be reported as being just as disabled as the former example. This possibility for discrepancy is accounted for through an examination of the results in association with each of the measures for extent of disability.

With empirical evidence supporting the potent effects of physical activity on cognition in individuals with cognitive function deficits, these effects could be greater in the cerebral palsy population as well. Because, this population is more deficient in these areas than their able-bodied peers. It is possible that reductions in sedentary behavior and increased physical activity (or exercise) could have more robust benefits for those with cerebral palsy; including the cognitive and emotional benefits observed in their able-bodied peers. For example, executive tasks such as attention and language related functions; recent research has observed correlations between cognitive function relative to communication function and gross motor skills (Ballester-Plané, et. al., 2017). Both gross motor skills, and communication ability are primary deficits within the cerebral palsy population (Christensen, et. al., 2014). If physical activity is associated with cognitive benefits in individuals with cerebral palsy, there may also be direct, measurable, positive changes in quality of life and even a possible reduction in symptomology over time (Langlois, et. al., 2013).

This exploratory study researched the intersection of two fields of study which have remained primarily separate in examining the population with cerebral palsy: cognitive function and sedentary/physical activity behaviors. If the positive relationship between physical activity and cognitive function and the inverse relationship of sedentary behaviors and cognitive function that have been observed in able-bodied participants are mirrored for adults with cerebral palsy; then adults with cerebral palsy would likely experience similar cognitive benefits from regularly participating in physical activities compared to their more sedentary peers. While the results of this research contribute to the overall understanding of the relationship between cognition and activity level, they also have a potential impact on the population of adults with cerebral palsy. Observing the relationship between cognitive performance and exercise/physical activity/sedentary behavior levels, in addition with severity of disability and quality of life; the results could lead to paradigm shifts in promoting physical activity for caretakers and individuals with cerebral palsy. The findings also provide support for additional research into the neurocognitive benefits of physical activity to better serve individuals living with cerebral palsy; while expanding the scientific understanding of the relationship between physical activity, sedentary behavior, and cognitive function.

Research Aims & Hypotheses

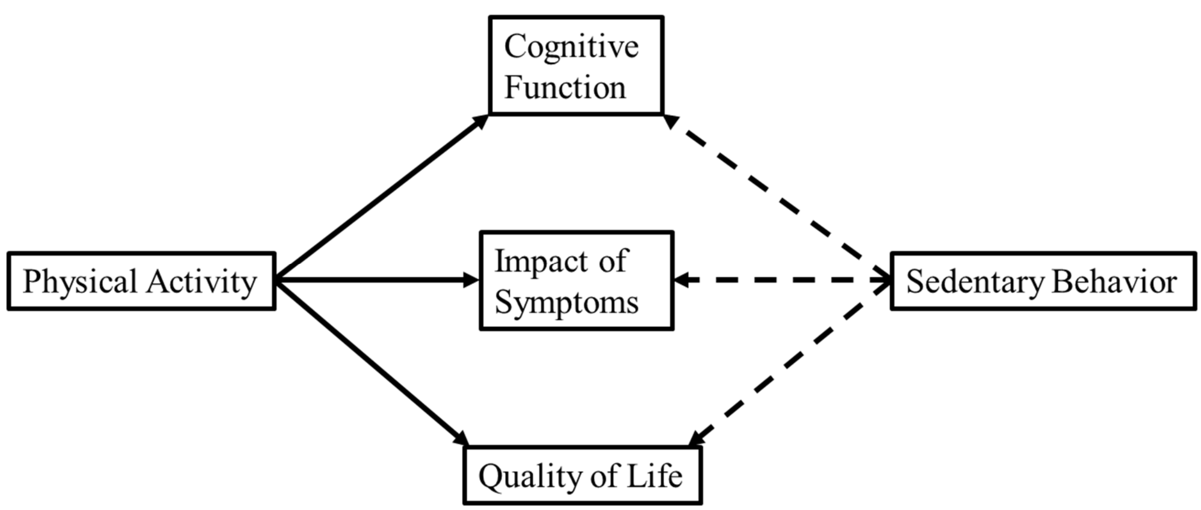
It is hypothesized that the relationship(s) between physical activity, sedentary behavior, quality of life, and extent of disability will reflect those known and proposed across neurocognitive behavioral research of cerebral palsy and able-bodied sample populations. The hypothesized interconnected associations are visually laid out in the concept map (Figure 1.) illustrating the hypothesized positive influence of physical activity on cognitive function, self-reported extetn of disability, and quality of life. As well as, the hypothesized negative impact of sedentary behavior on cognitive function, self-report of extetn of disability, and decreased quality of life. Physical activity may be associated with fewer symptoms associcated with cerebral palsy, which in-turn may enable greater physical activity; the opposite may be the case for sedentary behaviors which may be associated with more sever symptoms, and increased sedentary behavior.

Aim 1: Examine the relationship between physical activity/sedentary behavior and cognition, controlling for confounding variables.

Aim 2: Examine the relationship between physical activity/sedentary behavior and extent of disability, controlling for confounding variables.

Aim 3: Examine the relationship between physical activity/sedentary behavior and quality of life (both mental health related and physical health related), controlling for confounding variables.

Figure 1. Concept Map of Test Hypotheses



Solid arrows indicate a positive (helpful) effect.
Dashed arrows indicate a negative (hindering) effect.

Literature Review

Exercise Science, Cognitive Psychology, & Cerebral palsy

This study exclusively examined adult (18+) participants with a cerebral palsy diagnosis, thus, much of the literature review focuses on studies involving the effects of physical activity and exercise in cerebral palsy populations. Although the existent literature on this population in this field is limited in scope as well as depth, the hypothetical framework has been established in able-bodied populations. As a result, this literature review begins with an examination of the relevant portion of the research that has set precedent in the field for the benefits of physical activity and exercise beyond fitness, such as neuro-cognitive and quality of life. Focusing specifically on the methods, concepts, and results that apply. This will be followed by a review of the literature on studies conducted where participants had a cerebral palsy diagnosis.

Meta-analyses provide a comprehensive view on a specific topic, one such meta-analysis was conducted to observe the relationships fitness training and cognition (Colcombe & Kramer, 2003) across 18 experimental studies including 98 participants. Although this review was focused on older participants (55-80 years of age), the authors could state that, fitness training increased performance, regardless of the type of task used to measure cognition, the fitness training method/modality, or the participants' demographic characteristics beyond age (Colcombe & Kramer, 2003); this conclusion precedes a guiding statement support further research into the positive relationship between exercise (planned, repetitive physical activity to improve or maintain fitness) and cognition (executive control function). This study could make these observations by comparing the cognitive test results of participants who partook in fitness training to those who did not. This means that by being active for a time of at least 1 month, to over 6 months with an exercise duration of at-least 30 minutes, individuals could either improve or maintain a higher level of cognitive function compared to those who were/are sedentary (Colcombe & Kramer, 2003).

Following the 2003 report by Colcombe & Kramer, in 2006 Etnier, and colleagues conducted a meta-analysis that sought to examine whether the positive influence of exercise/physical activity on cognitive function was the result of changes in fitness. More specifically, cardio-respiratory fitness from 37 studies including 1,306 participants, aged 5-60+. Through the process of statistical analysis across multiple study designs, the researchers determined that differences in cardio-respiratory fitness were not driving differences in cognitive outcomes (Etnier, et., al., 2003). Instead, recognizing that, in many cases, cognition benefits were observed in pre-post exercise treatment studies, regardless of pre-post fitness scores. The researchers provided a variety of possible explanations for the changes in cognition being observed independently from changes in fitness; one of which was that engaging in regular physical activity may play a role in cognition. The authors admitted that focusing on fitness gains as the moderator of the observed cognitive benefits was misguided and urged future researchers to broaden their view of the possible mediators/moderators indicated in the relationship between physical activity and cognition.

The results of these two analyses support the hypotheses which suppose that physical activity/exercise has positive benefits extending beyond physical fitness, including cognitive function. Utilizing the concept that regular physical activity, regardless of modality, has a beneficial impact on cognitive function, on a variety of measures, across the lifespan. The specific cognitive functions and related benefits include, but are not limited to attention (Pontifex, et. al., 2015), short-term and long-term memory (Etnier, et. al., 2014), sleep quality (Fox, 1999), and a decline in experienced symptoms of depression and other emotional disturbances such as anxiety (Fox, 1999). A variety of experimental and meta-analytic research methodologies have been used across the lifespan in a wide range of sample populations (Colcombe & Kramer, 2003, Etnier, et. al., 2006, Hillman, et. al., 2006, Hayes, et. al., 2015). Research has provided evidence and direct observations supporting the positive relationship between physical activity and performance on cognitive function tasks (Hillman, et. al., 2006, Hayes, et. al., 2015). The existent evidence drives the hypotheses of this dissertation: that independent of modality, the difference in cognitive function and other non-physical benefits observed in physically active versus sedentary able-bodied individuals will also be observable in individuals with cerebral palsy.

Effects of Activity Level Beyond the Physical

Although the existent literature in cerebral palsy populations is limited in scope as well as depth, the conceptual framework for this project has been well established in able-bodied populations. As a result, this portion of the literature review will begin with an examination of the research that has set precedent in the field for the neurocognitive benefits of physical activity. This relationship has been observed in able-bodied participants using cognitive function measures related to the measure utilized in this project. The results of the inspection time task correspond to the information processing speed and short-term memory aspects of cognitive ability (Johnson & Deary, 2011). The following section will first cover general concepts, followed by experimental designs, to relate the results and concepts to this study.

Cognition is an often-used umbrella term that covers a variety of mental/brain processes. However, cognition should be recognized as a group of functions that relate specifically to conscious thoughts and actions. In other words, cognition can be understood as the neural processes that individuals are aware of and consciously experience. Cognition is measured through the testing of functions associated with conscious thought such as: memory, attention, planning, and problem solving. Testing these functions is critical to observing the relationships among physical activity, sedentary behaviors, and cognition. The inspection time task used in this study measures memory and information processing speed, both of which are aspects of cognition.

Traditional cognitive testing used with able-bodied participants assesses specific aspects of cognition (i.e. attention) by measuring reaction time and/or accuracy of responses to a stimulus, typically requiring response times measured in milliseconds. Motor control, specifically spastic paresis is the most common physical symptom associated with cerebral palsy and individuals are uniquely affected. Therefore, a reaction time/accuracy task would be heavily susceptible to bias based on participant limitations, to the point of being entirely impractical. A preferable approach in this population is a test that does not rely on a timed physical response, one such method is the inspection time task (Deary, et. al., 1991). The inspection time task presents a simple stimulus image for a variable time-period (ex:10ms-200ms), the stimulus is covered after the amount of time expires and the participants then respond based on the stimulus originally presented. This process is repeated multiple times across randomized presentation durations. Results are recorded based on the accuracy of the responses and the duration before the stimulus was covered. The results of the task provide a measure associated with information processing speed and memory, which relate to measures of general intelligence and skills associated with speech, comprehension, and planning (Johnson & Deary, 2011). The inspection time task allows for observation of the speed at which the individual can observe and remember a quickly presented stimulus, without requiring a timed response.

Lifestyle physical activity/sedentary behavior and cognitive function appear to be inter-locked; each potentially has a positive/negative feedback effect on the other, with cognitive function aiding in the formation and accessibility of skill-based memory and action. This observation and acknowledgment of a correlation between cognitive skills and physical activity provides a keen opportunity to further examine the nature of the relationship. Cockshell & Mathias (2013) observed the effect of chronic fatigue syndrome on a variety of cognitive measures, one being information processing speed. For this study, traditional response time/accuracy methods were used. The study utilized a cross-sectional design comparing a sample with chronic fatigue syndrome to a healthy control group. Of the various aspects of cognition measured (attention, visual/verbal learning, verbal fluency, and visuospatial ability), chronic fatigue syndrome had a significant negative relationship with performance on the tasks associated with information processing speed. However, chronic fatigue was not associated with diminished attention or memory, compared to healthy peers. These findings provide evidence that factors such as health and lifestyle can have both selective and global impacts on cognition. Physical activity level was not assessed by the researchers; however, the results provide support for the exploration of the information processing aspect of cognition, particularly within a clinical sample population.

Comparatively, a study conducted by Hillman, et. al., (2006) observed whether physical activity was positively related to cognition. The results were compared between younger (mean age 25.5 years old) and older (mean age 49.6 years old) community dwelling adults. The cognitive task provided an assessment of executive control and processing speed using the Eriksen flanker test (Eriksen & Eriksen, 1974), which is a reaction time/accuracy test. For this computerized task, participants are first shown a small plus in the center of the screen (to focus the eyes to the center of the screen), then shown a row of 5 arrows in one of four combinations for 100ms: <<<<<, >>>>>, <<><<, >><>>. The first two being congruent trials with all arrows going in the same direction and latter being incongruent trials with the center arrow pointing the opposite direction of the flanking arrows. The participants respond based on the direction the center arrow is pointing using a hand-held controller: a left thumb response if it is pointing left and right thumb if pointing right. Reaction time and accuracy are determined globally and for congruent/incongruent trials, which tests the interference control aspect of cognition (Hillman, et. al., 2006). A questionnaire was used to measure physical activity and mental health. Level of physical activity was rated 0-4, on a categorical 'sweat index' stating the average number of days in a week the participant was active to the extent of sweating (0 days to more than 4 days). It was observed that two variables had a significant impact on performance on the cognitive task: age and physical activity. Age was negatively associated with both reaction time and accuracy for both congruent and incongruent trials. Physical activity was negatively associated with reaction time (i.e. faster reaction time) and positively associated with accuracy in the older sample, for both congruent and incongruent trials, with a greater relationship between physical activity and performance on the incongruent trials (Hillman, et. al., 2006). Physical activity was not observed to have a significant relationship on cognitive task performance in the younger sample. The researchers discuss that the lack of observable differences in the younger sample may be due to physical activity benefitting aspects of cognition that require a greater amount of executive control. This would explain the sample specific relationship of physical activity on cognition, especially with the strongest relationship being between physical activity and performance on incongruent trials by the older sample. The evidence provided by Cockshell & Mathias (2013) and Hillman, et. al. (2006) support the use of a cross-sectional design to observe the differences in performance on an information processing speed-based cognitive task within a clinical sample population, based on group differences in lifestyle physical activity/sedentary behaviors.

Although the relationship between physical activity and cognition has been well-established, the mechanism(s) through which this relationship operates is not yet fully understood. Etnier and colleagues (2006) conducted a meta-analysis that sought to examine whether the positive influence of exercise/physical activity on cognitive function was the result of changes in fitness. Cardio-respiratory fitness and cognition was analyzed from 37 studies that utilized a variety of testing methods, and included 1,306 participants, ranging in age from 5 years old to over 60. In a majority of cases, cognition benefits were observed in pre-post exercise treatment studies regardless of the presence of changes in fitness scores (Etnier, et. al., 2006). The authors suggest that focusing on fitness gains as the moderator of the observed cognitive benefits was misguided. Instead, the authors urged future researchers to broaden their view of the possible mediators/moderators indicated in the relationship between physical activity and cognition. This analysis provides support for the use of regular physical activity and sedentary behaviors, instead of physical fitness, as observable mechanisms that effect cognition.

When discussing and comparing regular physical activity and sedentary behaviors, it is critical to understand that although being sedentary experientially may be the opposite of being active. Functionally, being sedentary is not the opposite of being physically active. Rather, they are two separate behaviors: each with their own impact on physical and cognitive health (Etnier, et. al., 2006, Dunlop, et. al., 2015). On the surface being sedentary (primarily stationary/expending minimal energy) appears to be the opposite of active (an active lifestyle/regular exercise). The differentiation rests on the way that the body naturally responds to being sedentary or active. The differences in cognitive responses can be observed both in lifestyle (Hillman, et. al., 2006) and laboratory controlled acute bouts of being sedentary/active (Pontifex, et. al., 2015). There is substantial evidence that regular physical activity can maintain and/or improve cognitive health (Etnier, et. al., 2006, Pontifex, et. al., 2015). Sedentary behaviors/lifestyle have been observed to lead to both physical and cognitive detriments. To understand the deleterious effects of sedentary behavior, researchers gathered behavioral data and conducted cognitive testing on a sample population of healthy seniors (Kesse-Guyot, et. al., 2012). A battery of cognitive tests was used to assess memory (lexical-semantic, episodic, and working) and mental flexibility. Cognitive tests included: naming words that start with the letter 'P' and listing animals, forward and backward computerized digit-span testing, and a trail-making task to measure various aspects of memory and mental flexibility, respectively. Researchers made observations of sedentary behaviors on cognition utilizing cross-sectional data collected as part of a concurrent longitudinal study. Researchers observed that time spent watching TV and using a computer were associated with lower scores on the each of the memory tasks. Results showed that sedentary behavior was the only factor that had a distinct negative relationship with cognitive functions associated with memory (Kesse-Guyot, et. al., 2012). It was observed that TV watching had a stronger negative relationship with cognition, compared to computer use. The proposed study aims to replicate this finding in sedentary individuals with cerebral palsy, the inspection time task tests both information processing speed and memory. In addition, Kesse-Guyot and colleagues provide insightful considerations regarding the limitations of their study. Namely, sedentary behaviors were assessed based on self-report which are subject to miscalculation and/or misrepresentation. Researchers also attest that a reverse causality effect may be present; with cognitive decline reducing the ability to partake in previously utilized physical activities. These limitations have been accounted for by testing age, other demographic data, and utilizing specialized questionnaires developed to assess both physical activity and sedentary behaviors within the cerebral palsy population (Heller, et. al., 2002, Kayes, 2014, Vasudevan, et. al., 2015,). Regardless of the limitations, the findings support the hypothesis that sedentary behaviors, particularly mentally passive sedentary behaviors have a unique negative relationship with cognitive function (Kesse-Guyot, et. al., 2012). The results also provide evidence that there are differences in cognitive function associated with passive and interactive sedentary behaviors. Researchers speculate that time spent on the computer is a cognitively active, physically sedentary behavior; and as such was not related to declines in the verbal memory and executive function aspects of the results.

As discussed, researchers have struggled in the development of testing methodologies to observe adults with cerebral palsy, more specifically, in testing hypothesized relationships. One technique is to utilize the results of general measures to observe/infer related associations. One measure that provides such insight for adults with cerebral palsy is quality of life which can provide insight into previously un-observed outcomes. The development, and success in the use of disability-specific measures for aspects of life such as, quality of life and physical activity (Hays, et. al., 1993, Kayes, et. al., 2007) have provided researchers with the tools necessary to examine, or begin to, the complex impact that cerebral palsy has. Not to imply that QoL is a gold-standard measurement, QoL may, however, be associated with lifestyle/behaviors like the non-physical benefits of a more active, less sedentary lifestyle observed across the able-bodied population. Like cognition, quality of life is an umbrella term that combines many aspects of life into a single concept. Mental/emotional well-being is a fundamental aspect of quality of life and although being physically active has been observed to be associated positively with QoL. This may be an indirect result of improved subjective well-being and considered to delay/prevent certain negative health outcomes (Fox, 1999). A study examined the associations between physical activity and mental/emotional well-being (Fox, 1999) by observing a variety of mental-health disparities and how they were associated with physical and mental health outcomes, such as sleep, and quality of life. Stating that quality of life is a major implication associated with not only mental and physical health/well-being but more specifically impacted by issues that are not often diagnosed such as general malaise, sense of helplessness, poor body image, chronic stress, and family/social stress (Fox, 1999). A recent study (Jarl, et. al., 2019) directly observed the associations between disability level and health-related quality of life by examining disability using the three standardized methods designed to discern extent of motor, manual, and communication function. The results showed a trend toward more problems being associated with a higher gross motor disability. However, the results also showed that manual ability and communication function also trend toward more issues, they were more incremental with those at a rating one (1) reporting higher quality of life than rating one in gross motor ability. However, the declines in quality of life became more similar for the higher disability ratings (Jarl, et. al., 2019). The authors of these studies provide valuable insight into considerations future researchers should take. Such as taking into consideration and statistically controlling for any variables that may be an aspect of the observed behavior/relationship. It is also paramount that researchers be cautious in the examination of the role that being physically active has on emotional well-being and consider that the directionality of this association is still being understood. In other words, it is still unknown if those with comparatively better cognition seek out, and participate in activity/exercise more easily and with greater efficacy than those with cognitive decrements; or that cognitive efficacy is a direct result of the degree to which someone participates an regular exercise/physical activity.

Cerebral palsy

Cerebral palsy diagnoses are determined once the child is at least twenty-four months-old and presents motor impairments and non-progressive neural damage that is second to lesions or anomalies (Rosenbaum, et. al., 2007). More specifically, cerebral palsy is a combination of permanent neurological disorders that affect the development of movement and posture (Rosenbaum, et. al., 2007). Changes in sensation and perception, as well as communication, cognition, and behavior are common troubles and can be associated with co-morbid epilepsy and secondary musculoskeletal complications. (Rosenbaum, et. al., 2007). The specific nature (physical and neurological) of the disability is dependent on the location of the damage/malformation, severity, and the stage of development during which it occurs. There is a wide range of symptoms possible for those diagnosed with cerebral palsy which presents a challenge for researchers in the form of the difficulty in identifying grouping norms. The most prevalent method is by determining the degree to which the symptoms of cerebral palsy impact independent mobility. The gross motor function classification system (GMFCS, McCormick, et. al., 2007) provides a one to five scale each level being associated with a different statement identifying the participants mobility status. This measure is often viewed by researchers as being an adequate measure of overall cerebral palsy severity. But given the range of symptomologies the GMFCS is capable of miss-identifying participants. There are two other measures that operate in the same way (statements valued 1-5) but are focused on aspects beyond mobility. The communication function classification system (CFCS, Hidecker, et. al., 2011) is used to determine the extent that cerebral palsy interferes with the individual's ability to both send and receive information. The CFCS provides insight into not only motor function/control of the neck and face, but also dependence on caretakers to serve as a relay to communicate to and for the individual. A third measure for identifying extent of disability is the manual ability classification system (MACS, Eliasson et. al., 2006) which is used to determine the extent to which the individual can interact with objects using their hands. Each of these measures identifies an aspect of motor control/difficulty that is a result of cerebral palsy. To be thorough, the researchers decided to record and test individually relationships associated with each of the measure for extent of disability, rather than rely solely on mobility status. Minor modifications were made to each of the measures so that extent could be determined by the individual, rather than by observations and determinations made by the researcher (Appendix E).

Cerebral palsy affects approximately 3-3.5:1,000 live births in the United States (Paneth, et. al., 2006). Of those with cerebral palsy, 58.2% walk independently, and 11.2% walk with hand-held devices, such as a walker; and 30.6% have limited, or no walking function (Christensen, et. al., 2014). Researchers also observed that around 40% had some form of intellectual disability (autism spectrum disorder, ADHD, intellectual development disorder, etc.), and approximately 60% had a co-occurring physical disability, and 35% had epilepsy. The strongest associated risk factors for cerebral palsy are low birth weight and prematurity (Odding, et. al., 2006); however, these are often symptoms of other disturbances (cause/s of low birth weight or premature birth) that may result in the child developing cerebral palsy (Perlman, 2006). Improvements to medical technology and care have been associated with an increase in the incidence of cerebral palsy. This is due to improved fetal observation, neonatal care, and particularly improvements to the survival-rate of very pre-term infants (Paneth, et. al., 2006). The life expectancy for infants with cerebral palsy is associated with socio-economic status, gestational age at birth and birth weight (Holmes, et. al., 2013). For adults with cerebral palsy, average life expectancy ranges between thirty and seventy years with severity of disability (motor and intellectual) as a primary factor; with mild cases of cerebral palsy typically having a longer life expectancy than more severe cases (Hutton & Pharoah, 2006). It is difficult to determine the effects of physical therapy on survival considering that the severity of cerebral palsy symptoms impact access and ability to perform physical tasks. Individuals with mild cerebral palsy can more easily participate in therapies which may further improve life expectancy, so that severity of symptoms would still be the determining factor (albeit indirect) attributed with mortality rate (Holmes, et. al., 2013).

Physical Activity Benefits for Individuals with Cerebral palsy

The following studies examine the benefits of physical activity and exercise and include participants with cerebral palsy. Researchers have examined various factors associated with physical activity in individuals with cerebral palsy with the intention of improving activity level, fitness, and overall health. Individuals with cerebral palsy tend to spend more time being sedentary, and take fewer breaks for activity, compared to their able-bodied peers (Obeid, et. al., 2014). To better understand the physical activity and sedentary behaviors in people with cerebral palsy, researchers have developed information regarding fitness changes, determinates of physical activity, and general observations of the health of individuals with cerebral palsy. These studies provide caretakers and physicians of and individuals with cerebral palsy information and guidance to reduce sedentary time and introduce/increase/improve physical activity.

A sedentary lifestyle can lead to chronic illness and diseases such as obesity, high blood-pressure, and type-II diabetes. Individuals with cerebral palsy and those who are able-bodied are at risk of the same lifestyle related health effects. For individuals with cerebral palsy, such issues associated with sedentary behaviors are considered secondary health conditions but can have a much greater impact through the exacerbation of cerebral palsy symptoms like chronic pain, mobility, and independence compared to able-bodied individuals (Jahnsen, et. al., 2003, Obeid, et. al., 2014). The authors provided advice to parents/caregivers to reduce the risk of secondary health risks noting that children with cerebral palsy should be more active while also being less sedentary by reducing the duration of their sedentary behaviors (Obeid, et. al., 2014). When collecting sedentary behavior (or physical activity) clarity is a critical factor. For adults with cerebral palsy, this is especially true. Being confined to a wheel/power chair may lead an individual to think that they are always sedentary, or nearly incapable of exercise/physical activities. To be specific about sedentary behaviors, the sedentary behavior questionnaire (SBQ, Rosenberg, et. al., 2010) queries about sedentary behaviors and how much time during an average day (weekday and weekends separately) is spent in that behavior. Providing researchers with a weekly and average daily account of hours spent engaged in sedentary behaviors (Appendix C). Reporting physical activity level for adults living with cerebral palsy presents similar difficulties, such as determining the role different behaviors/activities have on the individual's overall level of exercise/general activity. The physical activity and disability survey-revised (PADS-R) is unique in that it was designed/revised specifically to record exercise/general physical activity in adults with cerebral palsy, multiple sclerosis, and/or other extreme mobility-effecting disabilities (Kayes, et. al., 2009). This measure utilizes not only in-depth questioning to gather as much meaningful data as possible, but also extensive developmental and mathematical research to provide methodology for compiling and translating complex behavior into simple quantitative results (Appendix D).

Considering the limitations of previous research, a study (Verschuren, et. al., 2007) was an 8-month long aerobic/anaerobic fitness training program was conducted in youths aged 7-18 with cerebral palsy (n=86) with secondary measures of self-competence and health-related quality of life. Researchers provided a controlled fitness training program and collected data across multiple factors (health, fitness, social, autonomy, and cognition) associated with quality of life at four time-points pre, during, post, and after a 4-month follow-up (a total of one calendar year). The results of the study demonstrated that by the mid-point of the intervention (4 months), participants showed positive changes in fitness, social domains, autonomy, and cognition (Verschuren, et. al., 2007). By the end of the program, aerobic and anaerobic capacities showed significant improvement from baseline. The quality of life and social/autonomy results are based on a parent-completed questionnaire, rather than based on participant responses. The cognitive aspects covered in the questionnaire were: concentration, verbal expression, learning, reading, writing, arithmetic, understanding of school subjects, and understanding other people (Vogels, et. al., 1998). There are two methodological factors limiting the results for observing cognition in this study. First, the results were based on parent responses to a questionnaire, which limits the accuracy of the results, which were to understand the youth's experience. Second, cognitive function was also reported based on parent questionnaire responses related to aspects of cognition. These limitations were accounted for by obtaining data directly from the adult participants, including performance on a cognitive function task the results of which specifically relate to information processing and memory aspects of cognition. Based on the parent responses, children in the intervention group maintained the positive changes in their reported cognitive aspects at the 4-month follow-up. Fitness gains were the only variable to show a decline at the 4-month follow-up. (Verschuren, et. al., 2007). This study presents evidence for the various benefits of physical activity and/or exercise beyond fitness in adolescents with cerebral palsy.

Within an adult sample of individuals with cerebral palsy, researchers studied the specific determinants of physical activity and sedentary behaviors (Heller, et. al., 2002). Data in this study was collected from the caregivers too, rather than the individuals with cerebral palsy. The sample consisted of 83 individuals with cerebral palsy (female = 44), whose ages ranged from 30-79 years old, with 18% living at home, and the rest living in either a nursing/group home or assisted living (Heller, et. al., 2002). Of the 83 individuals with cerebral palsy, half had participated in some form of regular physical activity (mean frequency of 1.6 days/week). The majority of these activities were arm/leg exercises, walking, and aerobics with the remaining being rehabilitative or therapeutic stretching/exercises (Heller, et. al., 2002). Caregivers also responded to the perceived barriers to physical activity/exercise, which included: cost, time, and lack of knowledge of where/how to pursue activities or exercise opportunities. It was observed that fewer than 20% of the adults with cerebral palsy had some form of exercise equipment where they lived. Perhaps most striking, is that only 50% of caregivers believed that exercise would be helpful to the person with cerebral palsy, with the other 50% believing that exercise would either not be helpful, or even be harmful to the person with cerebral palsy. Hierarchical regression analysis determined that caregiver attitude toward physical activity/exercise accounted for the greatest amount of variance (approximately 20%) of exercise/physical activity frequency. Individual variables were not significant predictors of exercise, including age, sex, health status, mobility, arm/hand limitations, or level of intellectual disability. The authors stated, "When caregivers perceived *more* benefits of exercise, adults with cerebral palsy were *more* likely to exercise." (Heller, et. al., 2002, p. 228). This in an important finding. Understanding the benefits associated with physical activity could be part of a paradigm shift in the care of individuals with cerebral palsy. Caregivers in nursing homes reported significantly more negative attitudes toward physical activity/exercise than caregivers in other environments. Perhaps future studies will be able to influence caregiver attitudes toward promoting safe and effective physical activity.

A unique data element in the study of physical activity behaviors of adults with cerebral palsy is the concept of responsibility. As discussed by Jahnsen, et. al. (2003), many adults with cerebral palsy learned a variety of physical activities throughout a lifetime (in many cases) of therapy experiences, without learning techniques of personal accountability for their own long-term fitness/health. Most of the participants reported enjoying physical therapy as children, but many reported that as adults they had been going through the motions of therapy without learning skills to maintain life-long, independent health. The results of multiple regression analyses conveyed that above all other variables, skills learning was most significantly predictive of regular physical activity before other variables such as sex, age, and severity of cerebral palsy (Jahnsen, et. al., 2003). It is unclear exactly what facilitated the skills learning that occurred during childhood as reported by the participants, but it was most likely a variety of factors associated with the individual, their doctor(s)/therapist(s), family, etc. An important factor is the nature of the physical therapy used to treat cerebral palsy. To treat spasticity and improve range of motion and mobility, children with cerebral palsy often receive passive physical therapy in addition to active physical therapy and by using a variety of mechanical devices used as a part of therapy. Active physical therapy exercises require the individual to move his/her body, often against some form of resistance (weights, elastic bands, hand-crank, pedals, etc.); while passive physical therapy involves an external force moving a relaxed joint through its range of motion or to stimulate movement in certain muscle groups, typically done manually by a therapist or the individual or therapist using an external device (Pin, et. al., 2006). If therapy relied too heavily on passive physical therapy, or the use of expensive devices, the patient was not taught how to complete alternative exercises themselves, and little learning was likely. In addition, the preventative health benefits of the physical therapy, like dimensions of fitness, may be lost through neglect.

Summary

Assembling these results leads toward a central theme when the related findings are compared. Evidence supports that group characteristics such as advanced age (65+), health-status, and sedentary behaviors have been shown to have deleterious effects on a variety of cognitive functions including information processing speed, executive control, and various aspects of memory. However, regardless of the decrements to cognition associated with these characteristics, physical activity has been observed to have an inverse effect, either maintaining or improving cognition/cognitive function. Whether participants were seniors, almost entirely sedentary, or had clinical diagnoses (such as cerebral palsy or chronic fatigue), increases in physical activity have been positively associated with an array of cognitive functions (Vogels, et. al., 1998, Hillman, et. al., 2006, Verschuren, et. al., 2007, Kesse-Guyot, et. al., 2012, Cockshell & Mathias, 2013, Hayes, et. al., 2015). If the proposed relationship is responsible for the results observed in the older sample population and in the sample of individuals with chronic fatigue syndrome, this supports the concept that physical activity benefits are greater in groups with existent greater deficits, or when under high levels of cognitive demand (Hillman, et. al., 2006, Cockshell & Mathias, 2013). In addition, the beneficial impact of regular physical activity on cognitive functions are observable across various age groups and in those with a variety of clinical disorders (ADHD, Alzheimer's disease, anxiety, and many and many others).

The results outlined in this literature review supported conducting this exploratory research, which supposes that lifestyle (chronic) physical activity and/or regular exercise have positive benefits which include cognitive function, quality of life, and impact of symptoms, with the inverse being observable in relation with lifestyle sedentary behaviors. Additionally, that extent of disability will correspond with cognitive performance (reduced performance expected for more extreme symptoms) and that more positive quality of life will be related to greater amount of exercise/physical activity.

Methods

Participants

An initial sample of 220 individuals with self-reported cerebral palsy were recruited to participate through email, social media, and a podcast about life for adults with cerebral palsy. Of those initially expressing interest, 157 individuals provided written informed consent in accordance with the Institutional Review Board policies: with 148 individuals engaging with the online survey. Analysis were conducted on a final maximum sample of between 37 and 130 participants (34 female; 39.0 ± 12.6 years of age) who completed at least two portions of the online survey a summary of participation by section can be seen in table 1. Demographic characteristics and symptom severity are characterized in table 4.

Early recruiting relied on making and utilizing professional connections; these included known academic researchers and physical therapists, as well as local and state disability resource organizations. Direct contact (in-person and/or by phone) was made/attempted with these were intermediaries requesting if they could inform their patients, clients, or past participants of this study. This method resulted in fewer than five participants. Next, contact was attempted with dozens of state and city organizations, as well as recreation programs (across the United States) specializing in providing resources to individuals with cerebral palsy and/or their caretakers. The organizations, etc. were sent an e-mail introducing the researcher and the study, including all information requite for participation. Only one of the organizations responded, and informed that they would not be able to share the study providing no explanation for the decision and so, no participants were reached through these groups. Simple word-of-mouth (friends, family, personal social-media connections) was another method used but recruited fewer than ten participants. The recruiting focus then shifted towards social-media groups, rather than official organization pages. There are several social-media groups specifically for those living with cerebral palsy. These were closed groups, explicitly for those with the disability to be able to connect and discuss their shared disability. Contact was made with group administrators, using the same descriptions of the study that was used for the organizations. Unlike the organizations run by able-bodied advocates, the cerebral palsy diagnosed administrators responded with excitement. Some of these administrators took it upon themselves to introduce the researcher and the study to the group. Once the study was posted to the group pages responses began coming in. Additionally, the author was invited to be a guest on a podcast called *The Real Life of Adults with Cerebral Palsy* (Granucci, et. al., 2019) run by one of the social media group administrators.

Procedure

Study design was cross-sectional, and all assessments were completed using an online format. After following a general participation link, interested participants were provided with a description of the study and informed consent documentation including an explanation of their rights as participants. Following consenting to participate, participants were asked to complete a basic demographic questionnaire. Followed by the Sedentary Behavior Questionnaire (SBQ, Rosenberg, et. al., 2010) to assess lifestyle sedentary behavior. Then, participants were asked to complete the RAND 36-item health-related quality of life survey (RAND corporation "Research ANd Development", Hays, et. al., 1993) to assess mental and physical health related quality of life. After which they completed the Physical Activity and Disability Survey-Revised (PADS-R, Heller, et. al., 2002, Kayes, et. al., 2009) assessing lifestyle physical activity to assess exercise related and general physical activity levels. Finally, to self-report their cerebral palsy symptoms using the gross motor function classification system, the manual ability classification system, and the communication function classification system (GMFCS, Rosenbaum, et. al., 2002, MACS, McCormick, et. al., 2007, CFCS, Eliasson, et. al., 2006). Attention was taken in the presentation and order of each testing measure, to retain constancy as well as to avoid participant expectation bias. Following completion of all questionnaires, participants were directed to complete an online inspection time task (ITT, Deary, et. al., 1991) administered using PsychoJS to assess cognitive processing speed. Participation in this investigation was entirely voluntary, a majority were able to finish in under an hour, and no compensation was provided for participants' engagement with this study, averages and ranges of time to complete each measure can be found on table 2.

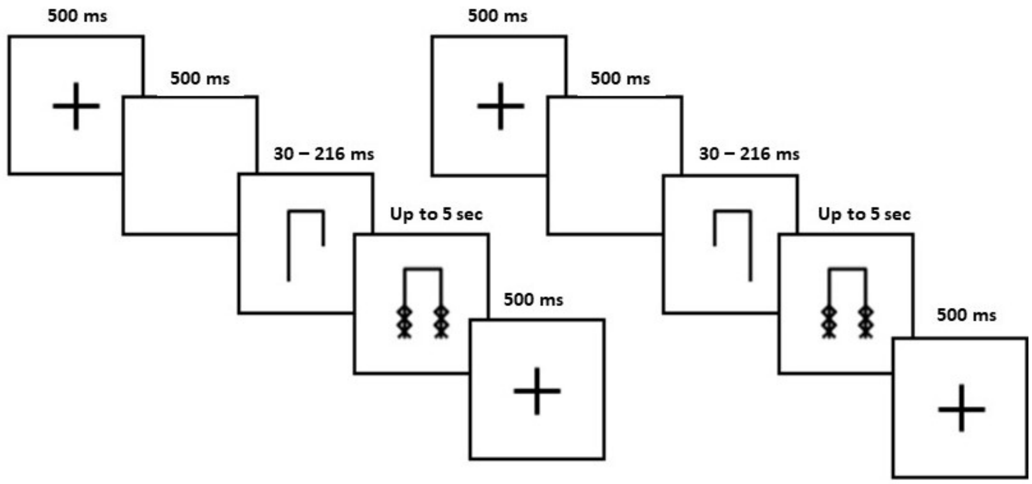
Exercise, General Physical Activity, & Sedentary Behavior

Physical activity was measured by participant responses on the PADS-R, (Heller, et. al., 2002, Kayes, et. al., 2009); with physical activity/exercise being reported across a variety of situations and accounting for intensity and type, with a test-retest reliability of 0.87 (Heller, et. al., 2002, Kayes, et. al., 2009). This included exercise and leisure time activities, general activity, daily function, and mobility. Sedentary behavior was assessed using the SBQ which asks participants to recall typical hours/day spent engaged in 9 various sedentary behaviors (TV watching, lounging, computer use, etc.) reliability for weekdays across all items has a range of 0.64-0.90, weekends 0.51-0.93 (Rosenberg, et. al., 2010). Both the PADS-R and SBQ collect data specific to weekdays and weekend days and for each item participants were asked to recall their behavior during the previous week. For the PADS-R if a participant skipped a question or otherwise did not answer, that variable was omitted from the equation, therefore allowing for an activity score to still be calculated, for the SBQ a non-response was dealt with in the same manner. These surveys have been tested for reliability and validity and used in multiple studies to observe behaviors in similar clinical samples (Heller, et. al., 2002, Helmerhorst, et. al., 2011, Kayes, 2014, Vasudevan, et. al., 2015).

Cognitive Function Assessment

Cognitive function was assessed using an inspection time task, which provides a measure of early information processing speed free of bias toward individuals with decrements in manual motor control (Nathan & Stough, 2001). Participants were asked to attend to a centrally presented focal cue (small '+'), and were then shown an inverted U shape with asymmetrical parallel vertical lines (see Figure 2). The stimulus was presented for a duration of either 30, 50, 66, 83, 100, 116, 133, 150, 183, or 216 milliseconds (ms) before being masked by a pair of bold 'zig-zag' lines. The mask then remained on the screen until a response was provided or a 5 second period without response elapsed to ensure participants had sufficient time to respond to the direction corresponding to the longer vertical line. By varying the duration which the asymmetrical vertical lines are shown before being masked, information processing speed can be quantified as the minimum exposure time necessary for the participant to reliably perceive and utilize information (Vickers & Smith, 1986). A total of 110 trials were presented with equiprobable responses and stimulus durations. Inspection time criterion performance was quantified as the stimulus duration at which response accuracy decreases below a threshold of 85%; which has previously been used to characterize information processing speed in pre-senile seniors (Deary, et. al., 1996).

Figure 2. Inspection Time Task



Cue presented for 500ms, blank screen presented for 500ms, stimulus presented for 30-216ms, mask presented until participant responds (up to 5 seconds).

Extent of Disability

This study used three measurements to assess the extent of the participants' disability. The first, was the gross motor function classification system (GMFCS) which is a standardized classification system developed to quantify mobility-based gross motor functions in children and adolescents (Rosenbaum, et. al., 2002) and has been established as a classification tool for adult samples as well (McCormick, et. al., 2007). Participants responded to the GMFCS by self-reporting their mobility into one of five levels, the GMFCS results are coded as 1-5; with level 5 requiring the most assistance and level 1 being the most independent in the participant's ability to move, reliability 0.97 (McCormick, et. al., 2007). Due to the exploratory nature of the study, and diversity of possible symptoms, it was determined that it would be prudent to have participants report extent of disability on more than one aspect. This will allow for an in-depth analysis as to the extent that expression of an individual's cerebral palsy is related to behavior. The second measurement used was the manual ability classification system (MACS) which rates the participant's ability to use his/her upper extremities, particularly with daily tasks and object manipulation. Like the GMFCS, the MACS ranks ability 1-5 with level 1 having the greatest amount of control, and level 5 requiring most assistance, and reports a reliability range between 0.91 and 0.97, with variations in population such as age and region (Eliasson, et. al., 2006). The third measurement that was used to establish the extent to which the individual's disability impacts daily life was the communication function classification system (CFCS). The CFCS has a reliability of 0.82 and describes an individual's ability to communicate with others (Hidecker, et. al., 2011). CFCS is also scored level 1 to 5 with level 1 relating to most ease and comfort in communication situations, and level 5 corresponding to little-to-no communication either sending or receiving, especially with strangers. The GMFCS, MACS, and CFCS provided a comprehensive analysis of the extent to which an individual's disability impacts their daily functions of mobility, object manipulation, and ability to communicate with others. Each of the disability classifications were self-determined with participants selecting a description of ability that most related to them.

Quality of Life

Quality of life was assessed using the RAND-36 (Hays, et. al., 1993). The RAND-36 has been previously used to assess quality of life for adults with disabilities and has been specifically used in adults with cerebral palsy (Gaskin & Morris, 2008). Quality of life (QoL) is measured as a combination of eight sub-scales: physical functioning, role limitations due to physical health, role limitations due to emotional health, energy/fatigue, emotional well-being, social functioning, pain, and general health. The responses in each of the sub-scales is given a value with each totaling 100 (e.g. 0, 20, 40, etc. or 0, 25, 50, etc.), the mean score is collected for each sub-scale out of 100. If a participant skipped a question the authors of the measure simply omitted that item from their analysis (total out of 35 items instead of 36), either way, the total QoL is recorded out of 100. Reliability for the subscales range from 0.78-0.93 and when compared to more extensive measures of QoL the correlation was 0.99 mean difference of -1.37 ±0.98 (Hays, et. al., 1993). The present investigation specifically focused upon the mental health related quality of life and physical health related quality of life subscales given prior research in typical adult populations exhibiting positive relations between these aspects of quality of life and physical activity/sedentary behavior. The questionnaire as presented to participants can be found in the appendices.

Statistical Analysis

A priori power analysis determined that, given the number of possible predictors included, that a sample size of roughly 100 participants would be necessary for full statistical power (power (1-β err prob): 0.80, medium effect size ($f^2 = 0.15$). Prior to analysis, all variables were individually screened for homoscedasticity and normality. Separate Hierarchical linear regression analyses were then performed to determine the independent contributions of exercise related, general physical activity, and sedentary behavior for explaining variance in cognition (as assessed using inspection time criterion performance). Extent of disability (assessed separately using the gross motor function classification system, manual ability classification system, and communication function classification system) were each also tested for their relationship(s) with exercise related, general physical activity, and sedentary behavior. Both mental and physical health related quality of life were analyzed using the same methods. Each of the hierarchical linear regressions were preformed after accounting for the influence of demographic factors (i.e., Age, Biological Sex [0 = Female, 1 = Male], Race [0 = White, 1 = Nonwhite], and BMI) (Pontifex et al., 2014, 2016). Preliminary analyses were conducted examining the correlations between exercise related physical activity and general physical activity assessed using the

PADS-R survey as well as results from the sedentary behavior questionnaire. All data analyses were performed in R version 3.6 (R Core Team, 2013) utilizing a familywise alpha level of $p = .05$. Effect sizes were reported as Cohen's f^2.

Results

Demographics & Compliance

Although the individual reasons are not known, errors in filling-out the questionnaire and accessing the cognitive task remained an issue. As a result, the total number of participants who reached the end of a given portion of the questionnaire, did not ensure the same number answered all the questions for the measure. In some cases, participant's that missed responses may have had their responses for that measure omitted from analysis (Table 1). But their other, completed, responses were included. This accounts for the difference in sample sizes across the various test measures (see Tables 1 and 4). For example: In the extent of disability portion, a participant may have only provided a response for two of the three measures; they would be included in the count in the flow chart and their other two responses to extent of disability would be included in the analysis. Mean values (± SD) for demographic characteristics and variables for testing the aims are provided in Table 3.

Table 1. Participation by measure in the order they were presented
Followed Link n = 220
Consented to participate n = 157
Completed Demographics n = 148
Completed SBQ n = 136
Completed RAND-36 n = 128
Completed PADS-R n = 121
Completed Extent of Disability n = 121
Completed ITT n = 38

An important aspect of the entire data collection process was to reduce participant demand in-order to allow as many individuals to participate as possible. Solutions included:

limiting the questionnaire to only the most important variables, no time limit, minor adjustments to wording of questions (such as changing tense to first-person) and method of response, with no changes or impacts on the calculation of results, running pilot testing to ensure that participation could be completed in less than one hour, with duration of participation dependent on the individual (see Table 2).

Table 2. Time to Complete Each Test Section

Test section	Mean (±SD) (minutes)	Range (minutes)
Demographics	2.1 ± 1.3	0.6-7.0
SBQ	2.1 ± 0.9	0.9-5.5
RAND-36	4.9 ± 2.5	1.1-14.5
PADS-R	4.9 ± 2.5	0.1-14.3

Aims Results

Aim 1: Examine the relationship between physical activity/sedentary behavior and cognition

Performance data on the Inspection Time Task was only available for 38 participants. Hierarchical regression analysis indicated that exercise related physical activity explained a statistically significant (Fchange(5, 31) = 7.0, p = 0.013, f^2 = 0.18 [95% CI: 0.0 to 0.61]) change in variance in inspection time criterion performance such that greater exercise related physical activity was associated with a longer stimulus presentation time necessary to achieve the criterion of 85% accuracy (R^2change = 0.12, see Table 4 & Figure 3). Whereas, neither general physical activity nor lifestyle sedentary behavior explained a statistically significant (Fchange(5, 31)'s ≤ 0.6, p's ≥ 0.4, f^2's ≤ 0.02 [95% CI: 0.0 to 0.15]) change in variance in inspection time criterion performance (R^2change's ≤ 0.01).

Aim 2: Examine the relationship between physical activity/sedentary behavior and extent of disability

Gross Motor Function Classification System: Hierarchical regression analysis indicated that general physical activity explained a statistically significant change in variance in gross motor function classification (Fchange(5, 114) = 16.8, $p < 0.001$, $f^2 = 0.13$ [95% CI: 0.02 to 0.25]) such that greater general physical activity was associated with less severe impairments in gross motor function (R^2change = 0.12; see Table 4 & Figure 4). Whereas, neither exercise related physical activity or lifestyle sedentary behavior explained a statistically significant (Fchange(5, 114)'s ≤ 2.5, p's ≥ 0.12, f^2's ≤ 0.02 [95% CI: 0.0 to 0.08]) change in variance in gross motor function classification (R^2change's ≤ 0.02).

Manual Ability Classification System: Hierarchical regression analysis indicated that general physical activity explained a statistically significant (Fchange(5, 112) = 27.0, $p < 0.001$, $f^2 = 0.19$ [95% CI: 0.07 to 0.34]), change in variance in manual ability classification such that greater general physical activity was associated with less severe impairments in manual ability (R^2change = 0.19; see Table 4 & Figure 4). Whereas, neither exercise related physical activity or lifestyle sedentary behavior explained a statistically significant (Fchange(5, 112)'s ≤ 2.2, p's ≥ 0.14, f^2's ≤ 0.02 [95% CI: 0.0 to 0.07]), change in variance in manual ability classification (R^2change's ≤ 0.01).

Communication Function Classification System: Hierarchical regression analysis indicated that general physical activity explained a statistically significant (Fchange(5, 113) = 6.0, $p = 0.016$, $f^2 = 0.05$ [95% CI: 0.0 to 0.13]) change in variance in communication function classification such that greater general physical activity was associated with less severe impairments in communication function (R^2change = 0.05; see Table 4 & Figure 4). Whereas, neither exercise related physical activity or lifestyle sedentary behavior explained a statistically significant ($F_{change}(5, 113)$'s ≤ 2.4, p's ≥ 0.12, f^2's ≤ 0.02 [95% CI: 0.0 to 0.08]) change in variance in communication function classification (R^2change's ≤ 0.02).

Aim 3: Examine the relationship between physical activity/sedentary behavior and quality of life

Mental Health Related Quality of Life: Hierarchical regression analysis indicated that general physical activity explained a statistically significant ($F_{change}(5, 113) = 6.7$, $p = 0.011$, $f^2 = 0.06$ [95% CI: 0.0 to 0.15]) change in variance in mental health related quality of life such that greater general physical activity was associated with superior mental health related quality of life (R^2change = 0.05; see Table 4 & Figure 5). Whereas, neither exercise related physical activity or lifestyle sedentary behavior explained a statistically significant ($F_{change}(5, 118)$'s ≤ 0.7, p's ≥ 0.4, f^2's ≤ 0.01 [95% CI: 0.0 to 0.04]) change in variance in mental health related quality of life (R^2change's ≤ 0.01).

Physical Health Related Quality of Life: Hierarchical regression analysis indicated that neither exercise related physical activity, general physical activity, nor lifestyle sedentary behavior explained a statistically significant ($F_{change}(5, 118)$'s ≤ 2.6, p's ≥ 0.1, f^2's ≤ 0.02 [95% CI: 0.0 to 0.08]) change in variance in physical health related quality of life (R^2change's ≤ 0.02; see Table 4 & Figure 5).

Table 3. Mean (± SD) values for demographic attributes, physical activity, sedentary behavior, cognition, symptoms, and quality of life variables for the complete sample of participants.

Measure	Mean (± SD)
N	130 (34 female)
Race	10% nonwhite
Age (years)	39.0 ± 12.6
Body Mass Index	27.3 ± 7.6
Exercise Related Physical Activity (z score)	-0.3 ± 0.7
General Physical Activity (z score)	-1.2 ± 0.9
Lifestyle Sedentary Behavior (hours per week)	67.9 ± 29.4
Inspection Time Criterion Performance (ms)	86.7 ± 35.0
Gross Motor Function Classification System Rating (1–5)	2.4 ± 1.2
Manual Ability Classification System Rating (1–5)	1.9 ± 0.8
Communication Function Classification System Rating (1–5)	1.3 ± 0.7
Mental Health Related Quality of Life (t score)	50.0 ± 8.1
Physical Health Related Quality of Life (t score)	50.0 ± 7.5

Table 4. Summary of Hierarchical Regression Analysis

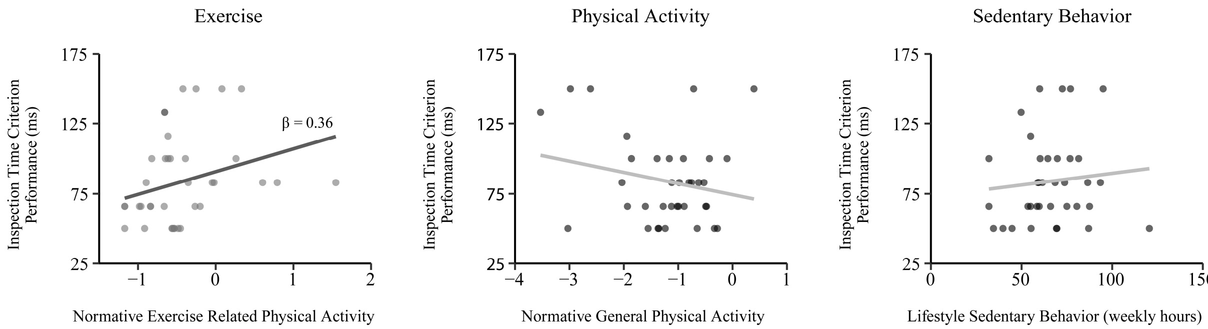
	R^2	R^2change	B [95% CI]	SE B	β	t
Inspection Time Criterion Performance						
Exercise Related Physical Activity (n = 38)						
	0.45	0.12	21.42 [4.85 to 37.98]	8.12	0.36	2.4*
General Physical Activity (n = 38)						
	0.33	0.0	0.88 [-12.66 to 14.43]	6.64	0.02	0.1
Lifestyle Sedentary Behavior (n = 38)						
	0.34	0.01	-0.25 [-0.88 to 0.39]	0.31	-0.14	0.8
Gross Motor Function Classification System Rating						
Exercise Related Physical Activity (n = 120)						
	0.07	0.02	-0.25 [-0.57 to 0.07]	0.16	-0.15	1.6
General Physical Activity (n = 120)						
	0.17	0.12	-0.46 [-0.69 to -0.24]	0.11	-0.36	4.1*
Lifestyle Sedentary Behavior (n = 116)						
	0.08	0.0	0.00 [-0.01 to 0.01]	0.0	0.05	0.5
Manual Ability Classification System						
Exercise Related Physical Activity (n = 118)						
	0.04	0.01	0.10 [-0.12 to 0.31]	0.11	0.09	0.9
General Physical Activity (n = 118)						
	0.22	0.19	-0.38 [-0.52 to -0.23]	0.07	-0.45	5.2*
Lifestyle Sedentary Behavior (n = 114)						
	0.05	0.02	0.00 [0.00 to 0.01]	0.0	0.15	1.5

Table 4 (cont'd)

Communication Function Classification System						
Exercise Related Physical Activity (n = 119)						
	0.04	0.01	0.07 [-0.12 to 0.27]	0.10	0.07	0.7
General Physical Activity (n = 119)						
	0.09	0.05	-0.18 [-0.32 to -0.03]	0.07	-0.23	2.4*
Lifestyle Sedentary Behavior (n = 115)						
	0.06	0.02	0.00 [-0.01 to 0.00]	0.0	-0.15	1.6
Mental Health Related Quality of Life						
Exercise Related Physical Activity (n = 119)						
	0.06	0.0	0.35 [-1.86 to 2.56]	1.11	0.03	0.3
General Physical Activity (n = 119)						
	0.11	0.05	2.07 [0.49 to 3.66]	0.80	0.24	2.6*
Lifestyle Sedentary Behavior (n = 124)						
	0.05	0.01	-0.02 [-0.07 to 0.03]	0.03	-0.08	0.9
Physical Health Related Quality of Life						
Exercise Related Physical Activity (n = 119)						
	0.06	0.0	0.25 [-1.72 to 2.23]	1.00	0.02	0.3
General Physical Activity (n = 119)						
	0.08	0.02	1.17 [-0.27 to 2.61]	0.73	0.15	1.6
Lifestyle Sedentary Behavior (n = 124)						
	0.07	0.0	0.00 [-0.05 to 0.05]	0.02	0.00	< 0.1

Note: * = $p \leq 0.05$. Models were assessed in addition to an initial model characterizing the predictive capacity of Sex, Race, Age, and BMI.

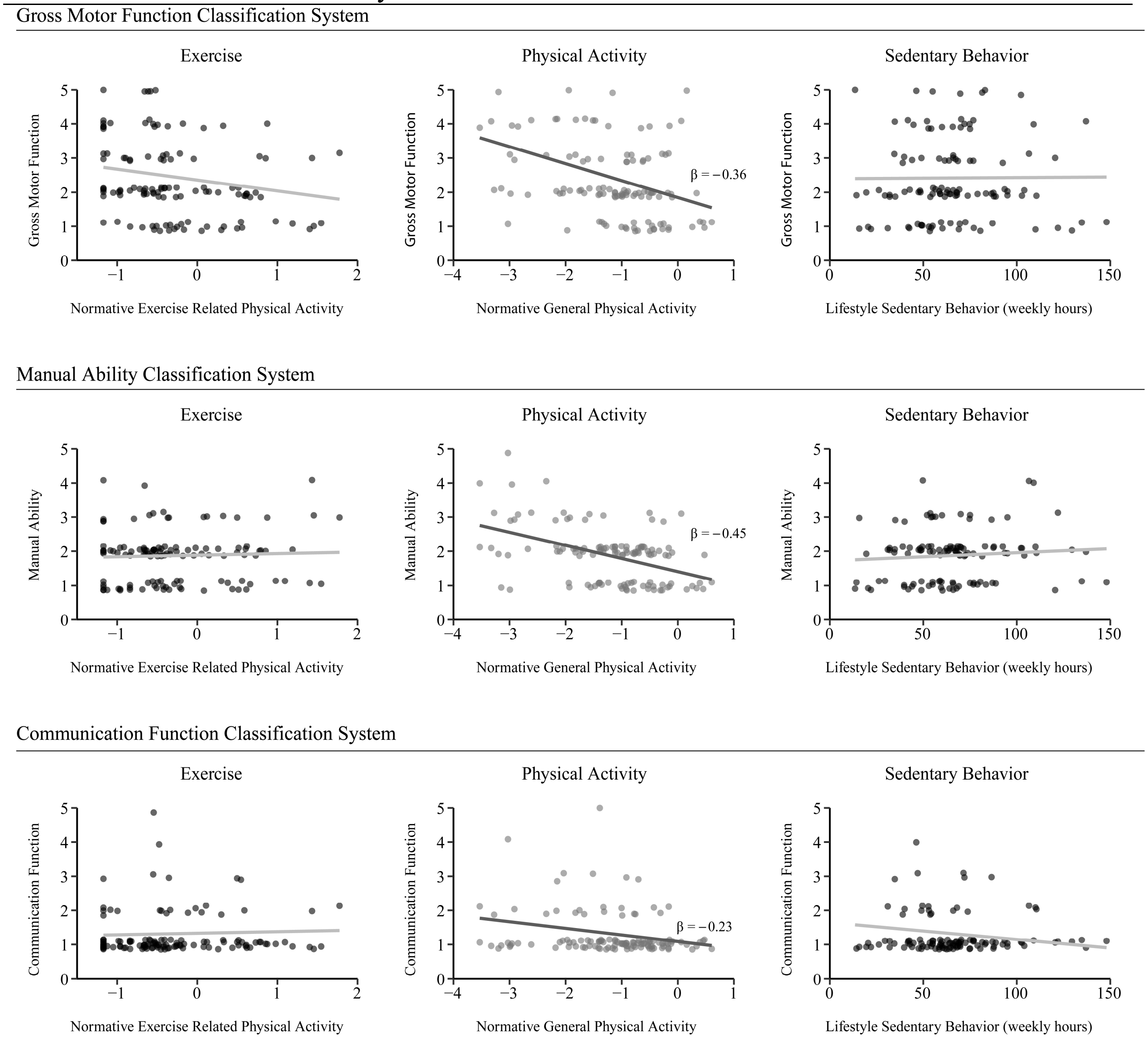
Figure 3. Scatterplots for the relationship between exercise, physical activity, and sedentary behavior and cognition.



Greater inspection time criterion performance is indicative of poorer stimulus processing speed as it reflects a slower stimulus presentation speed necessary to achieve the criterion of 85% accuracy. * Significance ($p \leq 0.05$). Models were assessed in addition to an initial model characterizing the predictive capacity of Sex, Race, Age, and BMI. * Significance ($p \leq 0.05$).

*

Figure 4. Scatterplots for the relationship between exercise, physical activity, and sedentary behavior and extent of disability.

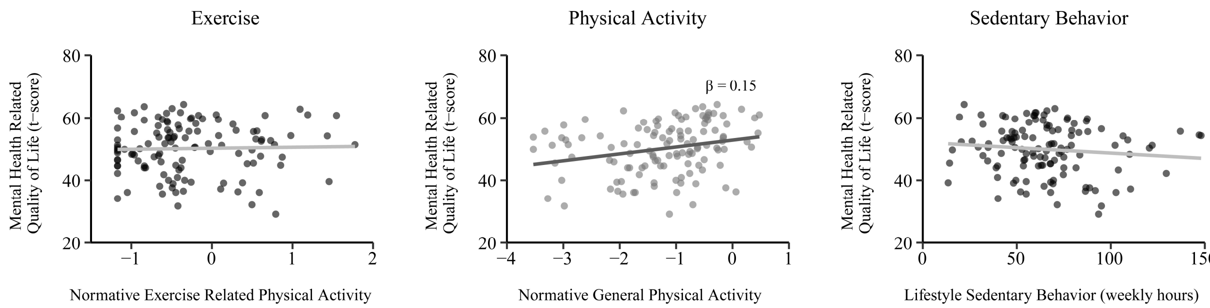


To prevent overplotting of categorical responses for graphing purposes, a small amount of random jitter was introduced along the y-axis (vertically) for extent of disability classification data. * Significance ($p \leq 0.05$). Models were assessed in addition to an initial model characterizing the predictive capacity of Sex, Race, Age, and BMI. * Significance ($p \leq 0.05$).

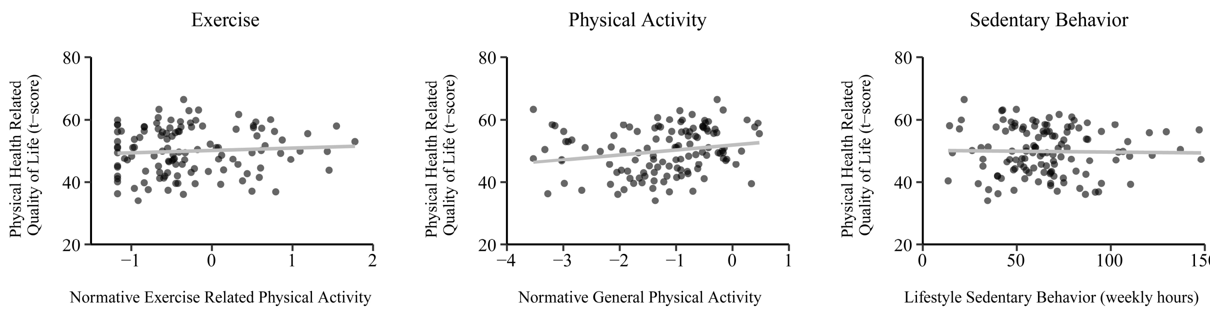
*

Figure 5. Scatterplots for the relationship between exercise, physical activity, and sedentary behavior and quality of life.

Mental Health Related Quality of Life



Physical Health Related Quality of Life



Models were assessed in addition to an initial model characterizing the predictive capacity of Sex, Race, Age, and BMI. * Significance ($p \leq 0.05$).

*

Discussion

This exploratory study successfully demonstrated a testing method that was able to collect cognitive (n=38) and behavioral (n=121-148) data online from adults with cerebral palsy. Approaching the process of collecting data from this population, there was always a possibility of not being able to get the required participants for statistical power, even just getting enough (100) adults with cerebral palsy to follow the link for participation was considered a longshot. Attempts were made to recruit participants across a variety means, including in-person networking, contacting professionals working with adults with cerebral palsy, and sending test information to cerebral palsy/disability support groups and organizations nation-wide. However, social-media platforms were the best out-reach tool. The online testing method allowed for data to be collected nation-wide and even internationally, rather than regionally restricted within reasonable driving distance from the university.

Cognition and exercise/general activity/sedentary behavior

Contrary to the hypothesized relationship, greater exercise related physical activity was associated with a slower stimulus presentation speed necessary to achieve criterion level performance, with exercise related physical activity accounting for approximately 12% of the variance in cognitive performance. Neither general physical activity nor lifestyle sedentary behaviors were observed to have significant linear relationships, positive or negative, with performance on the inspection time task ($p > 0.05$). Therefore, greater amounts of exercise were significantly related to poorer performance on the ITT, with other factors such as age, race, sex, and BMI not contributing positively or negatively significant variance in cognitive function. The difference between the expected and observed relationship between activity type/level and cognition may be the result of living with the spastic paresis effect of cerebral palsy. Depending on the intensity/regularity of spastic paresis, every moment of life could, essentially be a physical activity. Considering that multiple major muscle groups may be in a daily, constant state of excitation, which could put the individual in a state of near exhaustion, not only physically but mentally/emotionally. The additional mental and physical effort required for intentional exercise may result in exhausting available neural resources. which could result in later difficulty in managing symptoms. This is, however, just speculation until future research is conducted to thoroughly investigate the nature of these relationships. Particularly when considering the conflicting results between exercise and general physical activity and their relationship with cognition. These observation could also allude to differences in attitudes toward testing and/or performance expectations based on an individual's reported behaviors (i.e. participants that report more exercise may try to perform 'better' or 'faster' on the ITT, resulting in a higher error rate). Simultaneously, the relationships could be the result of the insufficient sample size. The diversity in respondents paired with small sample of cognitive data suggests that significant relationships do exist between these variables in this population. However, the extent and true nature of the negative relationship between exercise and cognition in adults with cerebral palsy is still uncertain. Future research could be conducted to observe short-term (acute) and long-term effects of basic physical activity and/or exercise in adults with cerebral palsy to better understand this relationship.

Self-reported extent of disability and exercise/general activity/sedentary behavior

Self-reported extent of disability, across all three measures, was observed to have statistically significant, negative, linear relationship with amount of general physical activity; after controlling for demographic factors of which none were observed to be significantly related to the outcome variables of extent of disability or exercise/activity/sedentary level. Given the physical impairments present in individuals with cerebral palsy it is unsurprising that lower levels of general physical activity were observed in individuals with the most severe impairments in gross motor skills, with general physical activity predicting 12% of the variance in impairment. Further, the strongest relationship between general physical activity and the extent of disability was observed for manual ability, with greater general physical activity relating to less severe symptomology in manual ability (accounting for almost 20% of the variance). Less severe impairments in communication skills (accounting for 5% of the variance) were also related to those with greater amounts general physical activity. Accordingly, although it is important to note the cross-sectional nature of the present investigation, the nature of the findings is suggestive that general physical activity might have a role in reducing symptomology. Specifically, one might expect individuals with the most severe impairments in gross motor skills to be less able to participate in general physical activities, however, of note is that several individuals with the most severe impairment in gross motor skills exhibited quite high levels of general physical activity suggesting that there remain opportunities for general physical activity engagement regardless of the severity of impairments. When comparing these results to those from the RAND-36, it is possible that individual's impairment could be reflected in the way the read and answer questions regarding their capacity for and engagement in exercise/physical activity. Future research could be conducted to begin to unravel the inter-connectedness of emotional health, extent of disability, and physical activity level. Further, there is a less-clear path by which impairments in manual skills and communication would reduce the extent to which an individual might engage in general physical activity. Thus speculatively, these findings provide initial evidence that future research conducting longitudinal randomized controlled trials can build from to better determine the extent to which greater general physical activity might serve to reduce the manifestation of impairments associated with cerebral palsy.

However, within the present investigation, no relationships were observed relative to the extent of disability for either exercise related physical activity or sedentary behavior ($p > 0.05$). The cause-effect direction between extent of disability and activity/sedentary level is unknown. Life with cerebral palsy can be not only difficult but also complicated. On top of the normal societal/occupational expectations, adults with cerebral palsy must overcome their physical limitations to pursue a healthy lifestyle (Alves-Nogueira, et. al., 2020). However, the affected neural tissue resulting in symptoms of cerebral palsy could be the primary factor in this case with sedentary behaviors and exercise-specific behaviors not resulting in neural changes. This could be causally related to the damaged tissue being unable to effectively communicate with the rest of the brain nullifying the expected relationship, but the design of this study precludes ability to elucidate that. Researchers could examine acute bouts of activity and/or sedentary behavior with pre-post responses to a neuro-cognitive test. Again, utilizing modified versions of existing research in the able-bodied population (Pontifex, et. al., 2015). Seeking to be generally more active could be producing the positive relationship due to the lower cognitive demand while being active. Congruently, due to the presence of spastic paresis, being entirely sedentary is not possible. As such, a revised method for determining sedentary behavior in adults with cerebral palsy should be utilized in future studies, perhaps with a method of measuring volume of daily spastic activity. Further research is thus necessary to better examine these relationships and determine the mechanisms by which exercise related physical activity and sedentary behavior may be less relevant to symptomology than general physical activity in this population.

Quality of Life and exercise/general activity/sedentary behavior

Consistent with prior research in able-bodied adults, general physical activity engagement was positively associated with mental health related quality of life. Such findings contribute to the extant literature in this area suggesting that emotional stability and well-being are positively related to general physical activity engagement (Fox, 1999, Etnier, et. al., 2006, Cockshell & Mathias, 2013) expanding these findings to now include adults with cerebral palsy. However, given the cross-sectional research design employed within the present investigation, it is important to acknowledge that individuals with greater emotional stability and well-being may also have been able to engage in greater levels of general physical activity engagement. Thus, further research is necessary to better understand the directionality of these relationships and the extent to which they may exist within a positive-feedback loop. Novel to the present investigation was the extension of this literature base to begin assessing exercise related physical activity behaviors and sedentary behavior as they related to quality of life. However, no relationships were observed for either of these behaviors relative to either mental health or physical health related quality of life ($p > 0.05$). One possible explanation for why physical health-related quality of life was not observed to be significantly related with activity level is that activity capacity and participation could be an insignificant aspect of life and self-concept for many adults with cerebral palsy. Given that the associated physical limitations are for the most part stable in this population, individuals are likely to be content and/or accepting of their specific physical boundaries. Thus, making space for individuals to pursue alternative sources of satisfaction associated with feelings toward their quality of life as well as those activities having an impact on emotional rather than physical quality of life. It is possible that the specific impacts of the individual's cerebral palsy symptoms do not register as significantly on quality of life as was hypothesized. However, a visual examination of the relationships that were observed demonstrate a trend suggesting the possibility that the hypothesized relationships exists, but currently lacks statistical significance to make any substantial, generalizable statements one-way or the other. Future studies could focus specifically on observing factors associated with differences in sub-categories of quality of life in adults with cerebral palsy including examination of their general physical activities. Out of the three measures used to identify activity level one was observed to lack statistical significance across all analyses, sedentary behavior. It was assumed that there would be observable negative outcomes for those with more time spent sedentary (Kesse-Guyot, et. al., 2012). One possible explanation could be, again, the spasticity associated with the individual's cerebral palsy. This observation could imply that even while sedentary, the continual spastic movements expend an amount of energy that the brain/body react as if even sitting is a physical activity. It may be that, with spastic paresis, it is rare/difficult to be truly sedentary. This could account for the lack of observable effects of being sedentary on the test measures. The negative relationship observed associated with exercise could be a result of this relationship too, in that exercise may risk neurological exhaustion. Although either of these relationships is purely speculative with the existing research into adults with cerebral palsy.

Strengths & Limitations

A strength associated with this study was the design which allowed the large sample of behavioral data to be collected entirely online. A recent meta-analysis review of research into adults with cerebral palsy identified five considerations researchers of adults with cerebral palsy (especially when recording QoL) should be aware of. These are, using standardized methods for measuring and defining both cerebral palsy and QoL, collect data from the individual and a proxy if/when possible, include age as a variable in statistical analysis, and to strive to improve scope and depth of methodologies used to research adults with cerebral palsy (Alves-Nogueira, et. al., 2020). This study, which completed data collection before the publication of these guidelines, addresses four of the five recommendations by using the standardized and expanded method of measuring extent of disability, measuring quality of life with the more comprehensive RAND-36, age was included in all statistical analyses, and existing techniques were used in a novel fashion to collect data. An additional strength is the sample size collected for the behavioral data ($n = 121$-148), which, according to the review is considered a large sample size ($n \geq 100$) and is in the top 20% for sample size of all existing research on adults with cerebral palsy (Alves-Nogueira, et. al., 2020). Additionally, the review identifies a medium/moderate sample size in this population as any sample with between 30 and 100 participants (roughly 50% of all adult cerebral palsy studies); with a sample of 38 individuals completing the ITT, the cognitive result sample is large for the field, while still being under powered for full statistical power.

The most obvious limitation present in this study is the small sample size for the cognitive test, with only thirty-eight individuals completing the cognitive assessment. That said, obtaining cognitive data from nearly forty adults with cerebral palsy is a step forward in the field of research on this clinical population. Many studies that are not longitudinal and/or conducted through hospitals often have sample sizes of less than forty, some with samples in the single digits. Such low levels of representation thus greatly hinder the ability to make strong claims regarding the observed findings, particularly given the constraints inherent in online-based research investigations. Accordingly, given that the findings of the present investigation are in opposition to the extant literature in able-bodied populations; it is essential that further research be conducted to determine if the observed findings are an artifact of a severely underpowered sample; are related in some way to the way in which the cognitive assessment was delivered in an online medium; or if exercise related physical activity is indeed negatively associated with cognition in this population. One of the largest barriers in conducting the study was recruiting participants. Following approval to join, various online communities of adults with cerebral palsy, was a month's long process of posting the recruitment information and responding to innumerable questions, which provided a wealth of anecdotal information. The recruitment posts often became conversation threads that covered topics ranging from the inspiration and goals of the study to the goals and inspirations of the members with cerebral palsy. Members were forthcoming in describing, often in-detail, aspects of their disability and/or their experience. This included what it was like 'aging-out' of care around the time they turned eighteen and the difficulties with present access to care and information. Early in process of connecting over social media, it became clear that, not only are there dozens of online communities, representing thousands of adults living with cerebral palsy around the globe; but that adults with cerebral palsy are, for the most part, highly motivated to participate in research. Although interested individuals were able to ask questions about participating in the study, confusion and misunderstanding of the directions did occur; in response to online comments, the directions were slightly altered and/or made more explicit as an attempt to reduce confusion.

It was observed that population is highly motivated and interested in participating in research. Participants voiced appreciation that the research was interested in the adult experience of living with cerebral palsy and that *they* were asked the survey questions directly. The opportunity to represent themselves and their community was another positive aspect of the participant experience. This follows the difficulty in receiving responses when first attempting to recruit participants. Responses from able-bodied operators of organizations that provide aid and resources to people and caretakers of people with cerebral palsy, were non-existent or underwhelming; none of which provided any level of assistance nor did any agree to send recruitment information to their members. However, when reaching out directly, adults with cerebral palsy responded with excitement, interest, and lots of questions. Anecdotally, researchers were told many stories about being an adult living with cerebral palsy; many of which, shared a theme about how rewarding their childhoods were, working with doctors, nurses, physical therapists, researchers, etc. Many the participants also reported that they had lost much (if not, all) of that support after, or around the time they turned eighteen. In other words, individuals in this population have first-hand understanding of the value that advances in scientific knowledge around cerebral palsy can have on the quality of life and overall experience of people with cerebral palsy, starting in early childhood development. In addition, many have first-hand experience of the negative realities of losing or not having access to quality-professional support systems. This is a possible contributing factor for the higher than expected response rate coming directly from the sample population.

A primary limiting factor that had impacted every aspect of the study was funding and general resources. As a doctoral dissertation, this study received no funding and was completed using open-access software and data collection methods along with other pre-existing/owned technologies. As this study is novel and exploratory in nature it was advisable to use familiar data collection techniques modified to fit the study, rather than risk wasting resources on programming that may, or may not, have suited the study's needs. Additionally, without funding there was not an opportunity to offer any incentive or reward for participation or to advertise the study beyond social media posts and word-of-mouth. From the outset, it was known that collecting cognitive data and/or physical activity data from an adult sample of the cerebral palsy population was going to be a difficult task. Most of the organizations that offer support for adults with, and caregivers of those with cerebral palsy did not respond to e-mails. While all online social network groups created by and/or for adults with cerebral palsy welcomed the opportunity to participate in research.

The online method of collecting data was novel, and therefore presented researchers with un-foreseen limitations. The first testing issue was that participation was required a monitor and a keyboard, and so, had to be done at a laptop or personal computer. Many participants connected over mobile devices and it was reported by a few participants (and likely experienced by others) that although filling out the survey on a mobile device worked seamlessly; the cognitive test did not operate properly on a mobile format. Also, due to system requirements, the study operated best when completed on either the Chrome or Explorer web browsers. Even still, some participants commented that the cognitive test would not complete loading, and therefore not run (or even start). This could have been because they were using a different browser, had internet connectivity/speed issues, or the presentation of the test was being modified by browser accessibility features, causing the test to crash. Beyond the cognitive task, participants were able to skip responses, which resulted in participants accidentally not submitting answers (a missed click, for example). This had a direct impact on the process of data reduction and analysis. Fortunately, the test measures had pre-existing methodologies to compensate for missing data points. While completing the test, there was no method for participants to ask questions of the researchers and/or stop and return to an in-progress survey. If a participant stopped (or the browser/tab closed), they would have to start-over, which would result in one individual submitting more than one response. This was the case for multiple participants. Unfortunately, there is no way for the researchers to know the exact cause(s) of the low compliance in completing the cognitive test, or for the missing questionnaire responses. Future research using an online testing format should resolve these issues within the test design.

Recommendations/Implications

Based on direct responses, anecdotal observation, and conversations utilizing direct online participant contact and data collection appears to be an advisable means of collecting data from adults with cerebral palsy. This was of particular benefit for several reasons beyond recruitment. The benefits were largely in-favor of the participants; one of the largest was the elimination of time demand on the participants. Although the study was designed to be completed in less than one hour to reduce demand, the study too had no timing requirements. This allowed participants to take as many breaks as needed to comfortably complete their participation. Although the methods were unable to collected data related to this effect beyond raw time to complete (Table 2). It is likely that this population benefits from the removal of time/speed-related stress. Future research designs may benefit from regularly including time-to-complete as a variable to better serve and understand this population on a research level. Although exercise and general physical activity were both observed to have significant relationships, sedentary behavior was not observed to have significant relationships with the target variables of cognition, extent of disability, and quality of life. The steady excitation of muscles and uncontrolled movement of the joints and limbs, observable in many individual's with cerebral palsy, even while at rest must expend more energy than someone without spastic paresis at rest. Future research into the impact of a sedentary lifestyle, may be interested in directly measuring energy output of spastic paresis at rest compared to measurable output during a variety of activities to observe physiological responses, of the paresis, while sedentary vs.

during exercise. Additionally, future researchers may find that, with spastic paresis the body is rarely, truly sedentary. This could account for the lack of findings for sedentary behavior. In addition, this could also cause early exhaustion both physically and mentally. Perhaps the SBQ was unable to record an accurate measure of sedentary behavior. Future researchers may have to develop a more refined method for reporting sedentary lifestyle patterns for adults with cerebral palsy.

To reach the goal of understanding cerebral palsy, it is imperative that researchers understand the population affected. An important step in reaching that understanding is connection and communication. This population is unique in that essentially all adults with cerebral palsy had childhood's that were improved by doctors and researchers. It is through these past experiences that this population has first-hand understanding of the direct role that developing research has on people with cerebral palsy. Additionally, many individuals lack knowledge about the exact nature of their disability and struggle with knowing whether their daily activities are helping or not. These adults desire understanding and representation, almost to a point of desperation. This desperation reveals itself in the many conversation topics and responses that the researchers engaged in as part of the process of recruiting participants from various social media groups. The individuals wanted as much information and advice as was possible; in addition, the members were incredibly forth-coming about living with cerebral palsy and the innumerable associated personal/shared struggles therein. Although this study achieved a large response rate for demographics, there was also a significant drop-out rate. Regardless of the reason/s (presently unknown), future applications of this testing method should consider the possibility of either dividing the questionnaire into a multi-session process or conduct more focused research, with fewer variables in-order to retain as many participants as possible. Put differently, future studies may benefit from using; shorter, more specific questionnaires; questionnaires that can be completed across multiple sessions; having an open line of communication with the researcher even when using online data collection methods, in addition to providing the opportunity for the participant to set the pace of participation.

Conclusion

A fundamental aspect of this study was to observe and assess adults with cerebral palsy as similarly to an able-bodied sample as possible. This was done to provide a better understanding of whether it is physical activity, sedentary behavior, or extent of disability driving the hypothesized/observed relationship(s); with the goal of observing if the known associations physical activity, exercise, and sedentary lifestyle have on cognitive function, extent of symptoms, and quality of life in able-bodied adults. Relationships that have been observed across the lifespan and with various health disparities (obesity, autism, diabetes, etc.) were expected to be observable in adults with cerebral palsy. This study demonstrates one way to collect quality demographic, behavioral, and cognitive, data from a diverse sample of the adult population with a cerebral palsy diagnosis. In doing so, it was observed that increased levels of exercise were negatively associated with cognition; self-report of extent of disability was negatively associated with general physical activity, and that greater amounts general physical activity were associated with a higher reporting of mental health and physical health related quality of life.

The results give insight into the role of general activity in adults with cerebral palsy. This is a first look into how the lifestyle behavior choices relate to extent of disability, quality of life, and cognitive function. For adults with cerebral palsy general physical activity was observed to be positively related with extent of disability and with emotional health related quality of life.

Although future research is needed to confirm these results and to enhance testing methods to observe/report the behaviors of adults with cerebral palsy more accurately. Adults with cerebral palsy and/or their families/caretakers should be aware that increases in regular daily activity regardless of how minimal (walking, doing chores, completing errands, self-care, etc.) they may seem from the outside, can benefit the individual in their emotional health and possibly their perception of the extent of their disability. This line of research has the capacity to inform and possibly modify the treatment that individuals with cerebral palsy receive. This includes educating youths with cerebral palsy about their disability and their responsibilities to their own health. Additionally, further discoveries may help to tailor care and activity prescription. With the objective of improving overall quality of life through the reduction of sedentary behavior-related health outcomes which is expected to improve longevity but also by caring for the individual's neuro-cognitive and emotional health. Essentially, this study opens a door to a wide variety of broad and specific project which have the potential to impact both the scientific understanding of cerebral palsy and the treatment/lifelong care for those that live with cerebral palsy. The results also provide a framework for continued safe and reliable examination of this population; rather than relegating the adult population with cerebral palsy as a sample that is too diverse, difficult to collect data on, or otherwise excused as an under-represented group in the literature. There is evidence to support future projects interested in online data collection, especially online cognitive testing for special populations. The results of this project open new doors into expanding the understanding of adult life with cerebral palsy, while doing the same for the evidence of the cognitive associations with physical activity, exercise, and sedentary behaviors.

Summary

In consideration of current events, there will likely be an expansion in online testing methods. Offsite, digital data collection was utilized this study to decrease participant demand. Study designs like this one will be part of adapting to, a global pandemic affecting all aspects of daily life and putting those with compromised immune systems, or access to healthcare at increased risk of illness. Contemporary studies, especially those with the goal of collection behavioral or cognitive data, could benefit in a way. That is, while a large portion of the population is becoming more adept at using their home computers to complete their day jobs, they would likely be better candidates then they were before the outbreak. This situation does away with the go-to ‘convenience’ samples for data collection, college students. This study demonstrated that with online testing, participant samples can be recruited from a broader source population. While contacting students via their university e-mails is still on option for convenience sampling, there is a huge sample of individuals that are looking for things to do. Especially if there is any compensation available for participation. Although the nation is facing a second great depression, if researchers are still able to conduct projects, researchers could be entering a new era. One in which there is a new standard for recruitment and data collection, direct contact digital assessment. Secure video conferencing could even be implemented when using a metric that is usually considered to be in person; such as the Wechsler abbreviated scale of intelligence (WASI-II, Wechsler, D., 2011) which had to be removed from the testing procedure in the case of this dissertation. In retrospect, if it were critical to the analysis, methods could be put in-place for reporting results of measures that are traditionally considered to require face-to-face interaction between the participant and researcher. As described, such methods would provide accommodation for participants with a disability, the comfort of being in their own living environment, and the ability to ask questions, covering many of the observed limitations of this study.

The motivation for this study was to be a source of change and to challenge the stigmas and pitfalls surrounding the conduction of research on adults with cerebral palsy. The first step taken, was to focus on the disability only regarding methods used to collect data. Otherwise their disability was considered a secondary factor and not as the primary test variable. Our primary interest was in the lives of individuals with this diagnosis, not in the disability itself. This objective was communicated to the social media groups and was met with positive feedback from the members. There is a shared narrative among most of the adults encountered. That of a childhood enriched by doctors, researchers, physical therapists, and the various groups/organizations involved. Until they reached adulthood (reported around age 17-20) when their health insurance status changes and they are no longer eligible for the same degree of care or coverage. Suddenly, and often without preparation or guidance they find themselves on their own and many reported struggling or relying heavily on others in their 20's. They felt abandoned and forgotten many say they felt 'written-off' as just having a non-progressive physical disability. This leads to a feeling of literal helplessness and is disheartening because they know their population isn't being studied, the advancement of knowledge in youths with cerebral palsy continues to expand in breadth and width, while the understanding of aging and cerebral palsy advances at a snail's-pace by comparison. So much so, that the average life expectancy, and which factors beyond their disability play a role in life-expectancy/aging are widely unknown. The most recent study reporting life expectancy in cerebral palsy, published six years ago, only reported for those with the most severe symptoms (GMFCS, MACS, CFCS > 3, poor vision, IQ<50), providing percentages that survive up to certain ages, 72% lived to 10 years, 44% to 20 years, 34% to 30 years, and 27% to 40 (Colver, et. al., 2014). Given this lack of scientific knowledge, adults living with cerebral palsy often want little more than to better understand their disability and ideas on how to live without making their situations more difficult than necessary or worse.

This group of exceptional humans fight everyday of their lives, a never-ending daily fight against their own bodies. They struggle against misinformation and societal stigma; many are assumed to be intellectually challenged by individuals in their community. They wake-up every morning with a full day of struggle ahead of them, and yet, based on contacts made during the testing process, they face the world with optimism and enviable tenacity. To overcome so much, for some just to get dressed or put-in an 8-hour workday and then to retain a sense of humor, joy, and ability to see the beauty in life is inspiring. Life is tougher for them than most, but this is a group of fighters and they deserve the attention of the scientific community, regardless of the perceived difficulty or barriers to conducting research. If they fight, so must we.

APPENDICIES

Appendix A. Informed Consent Participant Demographics Questionnaire

Thank you for your interest in our study! Are you:

- An adult 18 years of age or older.
- Diagnosed with Cerebral Palsy.
- Using a laptop or computer.

Yes

No

Participant Information and Consent Form

"Physical Activity, Sedentary Behaviors, and Cognitive Function in Adults with Cerebral Palsy."

Investigators Directing Research:

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You are being asked to participate in a research study. If you agree to participate in this study, you will be asked to indicate your agreement within this informed consent document. This informative document will tell you about the purpose, risks, and benefits of this research study. You should consent only after you have been given all the necessary information and have decided that you wish to participate.

Purpose of the Research

The main goal of this research study is to understand the associations between physical activity, sedentary behaviors, and cognition function in adults with cerebral palsy. By participating in this research, you will be helping to increase our understanding of the potential cognitive benefits of an active lifestyle.

What You Will Do

If you should agree to participate, you will be asked to complete the following tests and procedures which should take less than 30 minutes to complete:

- **Questionnaires** – After completing this informed consent, you will be asked to complete a series of questionnaires. These questionnaires will assess the extent of your disability, your quality of life, activity preferences, and demographic characteristics.
- **Computerized Brain Games** – You will be asked to complete a visual computer-based brain game. This game should take less than 10 minutes to complete.

Privacy and Confidentiality
Confidentiality is assured for all participants with regard to any responses and information you provide. All data collected will be numerically coded and grouped with data from other participants. Access to this information will be limited to only members of the research team and no individual data will be identifiable once the study is complete. All records will be kept for a minimum of three (3) years after the close of the study in a locked secure location and your confidentiality will be protected to the maximum extent of the law. However, government representatives, when required by law, and the Michigan State University Human Research Protection Program may deem it necessary to look at and/or copy your information. Your personal information will not be used if the results of this study are published or presented at scientific meetings.

Your Rights to Participate, Say No, or Withdraw
Participation in this project is entirely voluntary. You may at any time: 1) refuse to participate, 2) withdraw your participation, and/or 3) skip a question or activity should you feel uncomfortable, wish not to answer, or wish not to engage in the activity.

Costs and Compensation for Participation
Participation in this research study is free. No additional compensation is being provided for your participation in this research study.

Potential Benefits
If you agree to take part in this study, there may not be any direct benefit. We hope that the information learned from this study will contribute to gaining further insight into the relationship between health-behaviors and cognition. These findings may also have implications for lifestyle factors that relate to improved cognitive health across the lifespan, and may provide a rationale for you to be active.

Potential Risks

All procedures, techniques, equipment, and measures to be used in the study are routinely used in educational and research settings involving humans. No individual methodological element is new, untested, or of questionable safety for the health and general well being of humans. It is possible that some of that questions may make you feel slightly uncomfortable or embarrassed. However, as a reminder you may at any time: 1) refuse to participate, 2) withdraw your participation, and/or 3) skip a question or activity should you feel uncomfortable or wish not to answer.

Your Rights to Get Help if Injured

If you are injured as a result of your participation in this research project, Michigan State University will assist you in obtaining emergency care, if necessary, for the research related injuries. If you have insurance for medical care, your insurance carrier will be billed in the ordinary manner. As with any medical insurance, any costs that are not covered or in excess of what are paid by your insurance, including deductibles, will be your responsibility. The University's policy is not to provide financial compensation for lost wages, disability, pain or discomfort, unless required by law to do so. This does not mean that you are giving up any legal rights you may have. If at any time, day or night, you experience adverse physical symptoms, you should immediately contact your personal physician or emergency personnel (i.e., dial 911).

Contact Information

If at any time, either now or later, you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the researcher, Dr. Matthew B. Pontifex (517-432-5105, pontifex@msu.edu), who is responsible for this study. If you have questions or concerns about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail: irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

Documentation of Informed Consent

Before you agree to participate, please ensure that you:

- Are aware of what you will be asked to do.
- Give your consent voluntarily.
- Know that you can withdraw your consent at any time.

Please save a copy of this consent form for your records. To download this consent form click here.

Click the box below to indicate that you voluntarily agree to participate in this research study which will have you complete:

- **Questionnaires** – Assessing the extent of your disability, your quality of life, activity preferences, and demographic characteristics.
- **Computerized Brain Game** – After the questionnaires, you will be asked to complete a visual computer-based brain game.

I consent to participate in this study.

Appendix B. Participant Demographics Questionnaire

All data collected will be numerically coded and grouped with data from other participants. So that we can match up your data with the computerized brain game data, please enter the information below:

Please enter the first three (3) letters of your first name below:

Please enter the last four (4) numbers of your phone number below:

What is your date of birth? (MM/DD/YYYY)

Race/Ethnicity

- Asian / Pacific Islander
- Black / African American
- Hispanic / Latino
- Native American
- White / Caucasian
- Other

What is your biological sex?

- Female
- Male

What is your height (Feet, inches)

What is your weight (Pounds)

What is your highest level of education?

- Some High-School, no diploma
- High-School graduate, or equivalent (example: GED)
- Some college, no degree
- Associate's degree/Trade/Technical/Vocational training
- Bachelor's degree
- Advanced or Professional degree

Do you use any of the following for mobility assistance (select all that apply).

- Manual wheelchair
- Power chair
- Walker/cane
- Arm/elbow crutches
- Leg braces
- Other
- None

Who do you live with? Spouse, etc.

- I live alone
- Spouse/Significant other
- Child(ren)/dependents
- Sibling or other family
- Friend/Room-mate
- I live in a group residence
- Other

Aside from cerebral palsy, do you have any other medical diagnoses that you are being treated for?

- No
- Yes

Appendix C. Sedentary Behavior Questionnaire (SBQ)

On a typical weekday, how much time do you spend (from when you wake up until you go to bed) doing the following?

	None	15 minutes or less	30 minutes	1 hour	2 hours	3 hours	4 hours	5 hours	6 hours
Watching television	○	○	○	○	○	○	○	○	○
Playing computer/videogames	○	○	○	○	○	○	○	○	○
Sitting while listening to music	○	○	○	○	○	○	○	○	○
Sitting and talking on the phone	○	○	○	○	○	○	○	○	○
Doing paperwork or office work	○	○	○	○	○	○	○	○	○
Sitting and reading	○	○	○	○	○	○	○	○	○
Playing a musical instrument	○	○	○	○	○	○	○	○	○
Doing arts and crafts	○	○	○	○	○	○	○	○	○
Sitting and driving/riding in a car, bus, or train	○	○	○	○	○	○	○	○	○
Taking a nap	○	○	○	○	○	○	○	○	○

On a typical weekend day, how much time do you spend (from when you wake up until you go to bed) doing the following?

	None	15 minutes or less	30 minutes	1 hour	2 hours	3 hours	4 hours	5 hours	6 hours
Watching television	○	○	○	○	○	○	○	○	○
Playing computer/videogames	○	○	○	○	○	○	○	○	○
Sitting while listening to music	○	○	○	○	○	○	○	○	○
Sitting and talking on the phone	○	○	○	○	○	○	○	○	○
Doing paperwork or office work	○	○	○	○	○	○	○	○	○
Sitting and reading	○	○	○	○	○	○	○	○	○
Playing a musical instrument	○	○	○	○	○	○	○	○	○
Doing arts and crafts	○	○	○	○	○	○	○	○	○
Sitting and driving/riding in a car, bus, or train	○	○	○	○	○	○	○	○	○
Taking a nap	○	○	○	○	○	○	○	○	○

Appendix D. Health-Related Quality of Life (RAND-36)

In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

Compared to one year ago, how would you rate your health in general now?

- Much better now than one year ago
- Somewhat better now than one year ago
- About the same
- Somewhat worse now than one year ago
- Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
Lifting or carrying groceries	○	○	○
Climbing several flights of stairs	○	○	○
Climbing one flight of stairs	○	○	○
Bending, kneeling, or stooping	○	○	○
Walking more than a mile	○	○	○
Walking several blocks	○	○	○
Walking one block	○	○	○
Bathing or dressing yourself	○	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No
Cut down the amount of time you spent on work or other activities	○	○
Accomplished less than you would like	○	○
Were limited in the kind of work or other activities	○	○
Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No
Cut down the amount of time you spent on work or other activities	○	○
Accomplished less than you would like	○	○
Didn't do work or other activities as carefully as usual	○	○

During the past 4 weeks. to what extent has your physical health or emotional problems interfered with your normal social activities with family. friends. neighbors. or groups?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

How much bodily pain have you had during the past 4 weeks?

- None
- Very Mild
- Mild
- Severe
- Very severe

During the past 4 weeks. how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

How much of the time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of pep?	○	○	○	○	○	○
Have you been a very nervous person?	○	○	○	○	○	○
Have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○	○
Have you felt calm and peaceful?	○	○	○	○	○	○
Did you have a lot of energy?	○	○	○	○	○	○
Have you felt downhearted and blue?	○	○	○	○	○	○
Did you feel worn out?	○	○	○	○	○	○
Have you been a happy person?	○	○	○	○	○	○
Did you feel tired?	○	○	○	○	○	○

During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

How TRUE or FALSE is each of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick easier than other people	○	○	○	○	○
I am as healthy as anybody I know	○	○	○	○	○
I expect my health to get worse	○	○	○	○	○
My health is excellent	○	○	○	○	○

Appendix E. Physical Activity and Disability Survey-Revised (PADS-R)

Over the week, how many hours did you spend participating in aerobic exercise activities for the primary purpose of maintaining or improving your health and fitness.

Aerobic activities are those exercises done for a sustained period of time which result in an increase in your heart rate and breathing rate (e.g. walking, jogging, attending an aerobics class, bicycling)

Please indicate the total number of hours spent in each intensity of activity over the past week.

Number of hours spent active

-2 0 2 4 6 8 10 12 14 16

Light intensity activities (don't sweat or breathe heavily)

Moderate intensity activities (sweat a little or breathe heavier)

Vigorous intensity activities (sweat and breathe hard)

Over the week, how many hours did you spend participating in strength exercise activities (e.g. lifting weights or using elastic bands or weight training machines, pilates, core body strengthening & stability, tai chi) for the primary purpose of maintaining or improving your health and fitness.

Please indicate the total number of hours spent in each intensity of activity over the past week.

Number of hours spent active

-2 0 2 4 6 8 10 12 14 16

Light intensity activities (don't sweat or breathe heavily)

Moderate intensity activities (sweat a little or breathe heavier)

Vigorous intensity activities (sweat and breathe hard)

Over the week, how many hours did you spend participating in flexibility exercise activities (e.g. yoga) for the primary purpose of maintaining or improving your health and fitness.

Please indicate the total number of hours spent in each intensity of activity over the past week.

Number of hours spent active

-2 0 2 4 6 8 10 12 14 16

Light intensity activities (don't sweat or breathe heavily)

Moderate intensity activities (sweat a little or breathe heavier)

Vigorous intensity activities (sweat and breathe hard)

Over the week, how many hours did you spend participating in any sports, recreational, or leisure time activities that you might do in shorter bouts of activity and/or do not cause you to sweat and breathe a little harder e.g. boating, fishing by the jetty, bowling, etc)?

Please indicate the total number of hours spent in each intensity of activity over the past week.

Number of hours spent active

-2 0 2 4 6 8 10 12 14 16

Light intensity activities (don't sweat or breathe heavily)

Moderate intensity activities (sweat a little or breathe heavier)

Vigorous intensity activities (sweat and breathe hard)

Over the last week, how many hours did you spend participating in any sports, recreational, or leisure time activities that you sustained for a period of time that made you sweat and breathe a little harder than usual (e.g., tramping/hiking, tennis, dancing, skiing, sports fishing)?

Please indicate the total number of hours spent in each intensity of activity over the past week.

Number of hours spent active

-2 0 2 4 6 8 10 12 14 16

Light intensity activities (don't sweat or breathe heavily)

Moderate intensity activities (sweat a little or breathe heavier)

Vigorous intensity activities (sweat and breathe hard)

Over the last week (Monday thru Friday), how many hours did you spend inside your home not including sleeping time?

- Less than 6 hours each day
- 6 to 8 hours a day
- 9 to 10 hours a day
- 11 to 12 hours a day
- 13 or more hours a day

Over the last weekend, how many hours did you spend inside your home not including sleeping time?

- Less than 6 hours each day
- 6 to 8 hours a day
- 9 to 10 hours a day
- 11 to 12 hours a day
- 13 or more hours a day

During the last week, on average how many hours a day did you sleep including naps?

-2 0 2 4 6 8 10 12 14 16

Average number of hours during the last week

During the last week, on average how many hours a day were you sitting or lying down (including work), but excluding sleeping?

-2 0 2 4 6 8 10 12 14 16

Average number of hours during the last week

During the last week, how much time did you spend doing indoor household activities (e.g., cleaning, hanging washing, food preparation) or physical activities you did as a part of your role as caregiver (e.g. parenting activities)?

- No activities
- Less than 1 hour of activity over the week
- 1 to 2 hours of activity over the week
- 2 to 3 hours of activity over the week
- 3 to 5 hours of activity over the week
- More than 5 hours of activity over the week

During the last week, how much time did you spend doing outdoor household activities (e.g., gardening, walking to and from stores)?

- No outdoor household activities
- Less than 1 hour of outdoor household activity over the week
- 1 to 2 hours of outdoor household activity over the week
- 2 to 3 hours of outdoor household activity over the week
- 3 to 5 hours of outdoor household activity over the week
- More than 5 hours of outdoor household activity over the week

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During the last week while you are at home, how many flights of stairs do you climb each day?

- No flights of stairs
- 1-6 flights of stairs each day
- 7-10 flights of stairs each day
- 11 of more flights of stairs each day

When you perform activities of daily living (e.g. dressing or bathing), how much assistance do you need?

- No assistance
- Some assistance
- Full assistance

During the last week how many sessions of physiotherapy or occupational therapy or another type of therapy that involves physical activity did you attend?

- No physically active therapy this week
- 1 session of physically active therapy this week
- More than 1 session of physically active therapy this week

On an average day during most of your work/volunteer or school day, do you:

- Sit
- Stand
- Move around
- Not employed/volunteering or in school

During the last week while you are at work/volunteering or at school, how many flights of stairs do you climb each day?

- No flights of stairs
- 1-6 flights of stairs each day
- 7-10 flights of stairs each day
- 11 of more flights of stairs each day
- Not employed/volunteering or in school

During the last week how much time did you spend being physically active while transporting yourself to work/volunteering or school (e.g. walking or wheeling a wheelchair to and from work)?

- No transport activity
- 1 to 60 minutes of activity over the week
- More than 60 minutes of activity over the week
- Not employed/volunteering or in school

Appendix F. Extent of Disability: modified for self-report

Please indicate which of these options best applies to your mobility:

- I am able to walk without limitation
- I walk with limitations
- I walk with a hand-held mobility device
- I am self-mobile with limitations such as using a power assisted wheelchair
- I am transported in a manual wheelchair

Please indicate which of these options best applies to your ability to interact with objects:

- I handle objects easily and successfully
- I handle most objects with reduced speed or quality of movement
- I handle objects with difficulty or require help to prepare or modify an activity
- I handle a limited number of objects in an adapted setting
- I do not handle objects

Please indicate which of these options best applies to your ability to communicate:

- I am an effective sender and receiver of information
- I am an effective but slow paced sender and receiver
- I am an effective sender and receiver only with familiar partners
- I am an inconsistent sender and receiver with familiar partners
- I am seldom an effective sender and receiver with familiar partners

---

Please indicate which parts of your body are affected by cerebral palsy:

- Face/Head/Neck
- Torso
- Left arm
- Left leg
- Right arm
- Right leg

Appendix G. End of survey and intro to ITT

Thank you for completing the survey!

You will now be directed to a different webpage where you will be asked to complete a computerized brain game.

This brain game will show you images and have you respond to them using the keyboard. There is no time limit for responding and if you need to have assistance in making the button press that is fine. We only ask that you try your best so that your responses are as accurate as possible and reflect your thoughts.

There may be some images that are presented so quickly that you are not sure how to respond, this is perfectly normal and we encourage you to make the response you think is most likely correct.

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