SELF-DETERMINATION THEORY AND FRAGILE X SYNDROME

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Introduction

According to the American Psychological Association (2023), Fragile X syndrome is defined as a genetic condition that causes a range of developmental problems, including learning disabilities and cognitive impairments. Autism Spectrum Disorder (ASD) is defined as a developmental disability that can cause significant social, communication, and behavioral challenges (CDC, 2023). The Centers for Disease Control and Prevention (CDC, 2021) recommends a total of 150 minutes per week of moderate-intensity exercise which equates to 30 minutes per day, 5 days per week (CDC, 2021). Due to the challenges listed above, individuals with Fragile X syndrome may not be able to exercise consistently without additional support (e.g., coach, trainer). Self-Determination Theory (SDT) represents a broad framework for studying human motivation and personality (Ryan & Deci, 2000). SDT focuses on conditions supporting the individual's experience of autonomy, competence, and relatedness, which is argued to support the highest form of motivation and engagement for activities, including enhanced performance, persistence, and creativity (Ryan & Deci, 2000). With that being said, increasing exercise to the recommended guidelines for people with Fragile X syndrome may increase the quality of life and longevity, as well as reduce the occurrence of chronic diseases (e.g., obesity, high blood pressure) that are associated with low levels of exercise. This will be analyzed using the SDT and the effect of SDT on exercise performance/physical activity.

"Fragile X syndrome is a genetic disorder that affects a person's development, especially that person's behavior and ability to learn (*Fragile X Syndrome*, 2018). Fragile X can affect communication skills, physical appearance, and sensitivity to noise, light, or similar information" (*Fragile X Syndrome*, 2018). Fragile X syndrome is caused "from a change or mutation in the Fragile X Mental Retardation 1 gene, which is found on the X chromosome" (*Fragile X Syndrome*, 2018). This gene typically produces a protein called "Fragile X Mental Retardation Protein (FMRP)" (*Fragile X Syndrome*, 2018). Fragile X syndrome has an array of symptoms ranging from cognitive functioning, physical features, behavioral, social, emotional, speech and language, and sensory. Cognitive functioning symptoms include things like "learning disorders or problems with mathematics, to the severe, such as intellectual or developmental disabilities. The syndrome may affect the ability to think, reason, and learn." Some physical features include "a narrow face, large head, large ears, flexible joints, flat feet, and a prominent forehead." Behavioral, social, and emotional include general behavior challenges, eye contact with others, attention, aggression, or shyness (*Fragile X Syndrome*, 2018). Some speech and language features include "trouble speaking clearly, may stutter, or may leave out parts of words. They may also have problems understanding other people's social cues, such as tone of voice or specific types of body language" (*Fragile X Syndrome*, 2018). Sensory symptoms may include a sense of bothersome to certain sensations such as bright light, loud noises, or the way a piece of clothing may feel on their body. These sensory symptoms could sometimes result in acting out or a display of behavior problems (*Fragile X Syndrome*, 2018).

Children with Fragile X syndrome don't always have apparent features; however, they may have developmental delays or borderline intellectual disabilities, resulting in a diagnosis of ASD. When diagnosed, children should undergo more testing, such as molecular testing for Fragile X syndrome resulting in 2-6% of the population having an FMR1 mutation (*Health Supervision for Children With Fragile X Syndrome | Pediatrics | American Academy of Pediatrics*, n.d.).

Method

The purpose of this study was to increase the exercise capacity levels of an individual with Fragile X syndrome and ASD by applying the major components of self-determination theory. Exercise capacity was measured by walking distance completed during the 6-min walk test and the total number of push-ups and curl-ups completed within separate 1-min time spans.

Participant

The participant was a 15-year-old male with a height of 68 inches and a weight of 118.4 pounds. The participant had a diagnosis of Fragile X syndrome and ASD. The participant is currently attending a life skills class at a local high school. He is also placed in his high school's Adapted Physical Education class. Based on conversations with the family and the Adapted Physical Education teacher, the participant does not enjoy physical activity. The participant participated in walking, doing push-ups, and curl-ups. Walking consisted of no running at all, even if the participant wanted to, and the participant was prompted at times on occasion to walk. Push-ups were done on the knees with physical guided practice by the instructor towards the beginning of the study meaning week 1. During week 2 and so on, the participant was able to complete push-ups on his own. Curl-ups were done with verbal prompting such as "up" and "down." These verbal prompts were implemented weekly throughout the study.

Setting

This study was conducted in the student recreation center (SRC) at Cal Poly Humboldt over the course of 6 weeks. The SRC provided an indoor space with artificial turf and an exercise area with treadmills, elliptical machines, machine weights, and free weights.

Design

This study followed a single-case changing-criterion design. A single-case changing-criterion design is used to determine an independent variable's effects when the target behavior's final version cannot be emitted initially. This is done when repeated changes in the dependent measure as the criterion is changed (*Single Subject Design Guide*, n.d.). One benefit of a single-case changing-criterion design is that it can be used to measure multiple things simultaneously. Single-Case criterion designs are also credible and show strong causal inferences that should contribute to discussions of effective practices and policies (Shadish, Cook, & Campbell, 2002).

Dependent variable

This study included three separate dependent variables. The first was total walking distance. Walking distance was measured through cones and laps, 100 feet to a cone and 100 feet back to the starting cone. The second dependent variable was the number of curl-ups completed within 1-min. Curl-ups were measured by having the participant lie flat with knees bent and feet on the ground, and the participant was prompted to slide hands forward in a sit-up motion. The final dependent variable was the number of push-ups completed in 1-min. Push-ups were defined as the participant on his knees, bending the elbows so the chest could touch the ground and the bottom flat like the back. The participant was measured on their 6-minute walking time distance in feet, the number of push-ups in 1 minute, and the number of curl-ups achieved in 1 minute.

Independent variable

The independent variable within this study was the major components of self-determination theory (i.e., autonomy, competence, and relatedness). Competence is essentially a feeling that comes from interactions within the social environment and an opportunity to express one's capacities (Deci, 1975; Harter, 1983; White, 1959). Relatedness is the feeling that one is connected to others, whether it's caring for others or being cared for. It also encompasses the idea of having a sense of belonging with other individuals within a community (Baumeister & Leary, 1995; Bowlby, 1977; Harlow, 1958; Ryan, 1995). Lastly, autonomy is where the participant has a perception that originates from one's own behavior, or it is the source of the individual implementing it (deCharms, 1968; Deci & Ryan, 1958; Ryan & Cornell, 1989).

Results

This study utilized a single-subject changing-criterion design over the course of 6 weeks. Following the SDT, the participants were provided the opportunity to establish their exercise goals. Below is a demonstration of the participant's performance across the 6-week time frame in meeting their goals.

Baseline Phase

All baseline data was collected on the first day of the program. For the 6-minute walk, the participant completed 1636 feet (ft.). Additionally, the participant completed 1 push-up and 13 curl-ups within the 1-minute time frame. During the exercise portion of this study, the participant's heart rate (HR) was at a resting level of 60 beats per minute (BPM) and 14 minutes at a moderate HR level and a peak level of 155 HR.

Criterion Phase 1

During criterion phase 1, the participant completed 1575 ft. within the 6-minute walking phase. Additionally, the participant completed 1 push-up and 25 curl-ups within the 1-minute time frame. During the exercise portion of this study, the participant's HR was at a resting level of 59 BPM and 12 minutes at a moderate HR level and a peak level of 151 HR.

Criterion Phase 2

During criterion phase 2, the participant completed 1700 ft. within the 6-minute walking phase. Additionally, the participant completed 5 push-ups and 24 curl-ups within the 1-minute time frame. During the exercise portion of this study, the participant's HR was at a resting level of 60 BPM and 1 minute at a moderate HR level and a peak level of 123 HR.

Criterion Phase 3

During criterion phase 3, the participant completed 1710 ft. within the 6-minute walking phase. Additionally, the participant completed 2 push-ups and 23 curl-ups within the 1-minute time frame. During the exercise portion of this study, the participant's heart rate (HR) was at a resting level of 59 BPM and 7 minutes at a moderate HR level and a peak level of 134 HR.

Criterion Phase 4

During criterion phase 4, the participant completed 1800 ft. within the 6-minute walking phase. Additionally, the participant completed 10 push-ups and 25 curl-ups within the 1-minute time frame. During the exercise portion of this study, the participant's HR was at a resting level of 81 BPM and 0 minutes at a moderate HR level and a peak level of 132 HR. Below is an illustration of the participant's performances across the 6-minute walking phase, 1-minute curl-up, and 1-minute push-up assessment phases.

Figure 1
The Total Number of Distance Completed by the Participant

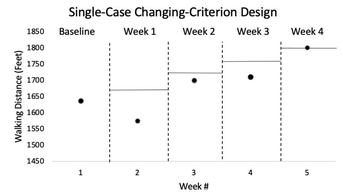


Figure 2
The Total Number of Curl-ups Completed by the Participant

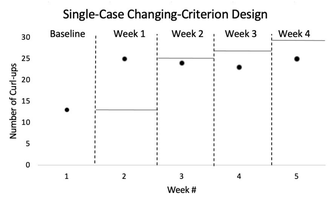
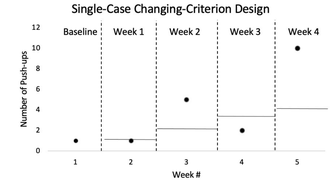


Figure 3
The Total Number of Push-ups Completed by the Participant



Discussion

This study aimed to increase the exercise capabilities of an individual with Fragile X syndrome and ASD. This was done by using the major components within SDT (autonomy, competence, and relatedness). Exercise capabilities were measured by the walking distance measured in feet over the course of 6 minutes, the total number of push-ups in 1 minute, and the total number of curl-ups in 1 minute. The participant participated in all exercise components in each session for the entire duration, and he was able to meet his push-up and walking distance goals. However, he was not able to meet his curl-up goal, as demonstrated in the graphs above. Compared to other studies, functional skills shall be considered for individuals with Fragile X syndrome in order to really focus on the development of SDT (Villagomez, 2016). Parent support and involvement in the development of self-determination are important factors for youth with disabilities, including youth with Fragile X Syndrome and ASD (Abery, 1994, Field & Hoffman, 1994; Martin & Marshall, 1998; Wehmeyer, 1996).

Limitations

Limitations within the study consisted of meeting once per week throughout the course of the study, the length of the study, and the number of participants. Meeting once per week was a limitation; however, during that time, the participant partook in a structured system in which each session consisted of a warm-up, walking, push-ups, and curl-ups. Another limitation within the study was the number of participants that were a part of the study. Despite this limitation, substantial evidence supports SDT across individuals with disabilities (Saebu et al., 2013). Specifically looking at individuals with autism spectrum disorder (ASD). There are person-specific variables that focus on motivation. More specifically, looking at self-management and the promotion of self-regulation, which in turn, promotes social effectiveness, social capital, and social inclusion. (Wehmeyer et al., 2010) Also, students with ASD need autonomy, competence, and relatedness to satisfy the participant's social context and need satisfaction. They also have a need for more motivation, including intrinsic and extrinsic motivation, all resulting in a positive Physical Education outcome (Vasconcellos et al., 2019).

Future Research

Future research should include participants meeting more often than once per week to progress better and meet the criteria for each week. There could also be much more participants within the study, including individuals with one particular disability, such as all participants having autism or all participants having Down Syndrome. There could also be a focus on an improvement within SDT, specifically focusing on one thing, such as competence or relatedness. Lastly, future research could focus on a more structured approach to improving walking distance, curl-ups in 1 minute, and push-ups in 1 minute as measured within the study.