

Title of Proposal

Assessing the Effects of Adaptive Tricycles on the Quality of Life in Children with Movement Disorders

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Abstract

Background: Children with motor and developmental disabilities are limited in the amount of childhood activities they can participate in, affecting their quality of life. There is limited research in assessing the effects of providing children with therapeutic adaptive tricycles to improve their quality of life.

Purpose: The objective of this study is to determine if the quality of life of children with movement disorders is affected by the use of an adaptive tricycle (Amtryke).

Study Design: Case Series

Methods: Children who have received an Amtryke will be given a quality of life survey to complete with the help of their parent/guardian. The survey takes components from Activity Scale for Kids (ASK), Children's Assessment of Participation and Enjoyment (CAPE), and Preferences for Activities of Children (PAC) questionnaires. The participants will answer the sections of the survey based on the past month. The results of these surveys will be analyzed to determine if the use of an adaptive tricycle has improved quality of life in children with movement disorders.

Significance: This study focuses on the impact an adapted tricycle has on a child's quality of life. This information can be used for organizations, such as AMBUCS (American Business Clubs), to justify future investments. This study is not limited to one disorder as other studies have. Physical and occupational therapists can use the objective findings to justify use of adaptive tricycles as therapeutic exercises. This study could lead to the promotion of insurance companies to cover the cost of these devices for children with movement disorders.

Introduction

Children with movement disorders, such as autism and cerebral palsy, often experience abnormal muscle tone and decreased physical strength.¹ Not only does this affect their ability to participate in activities, but it affects their quality of life due to not being able to partake in childhood activities.¹ Participation and quality of life have emerged as important measures of successful rehabilitation.¹ It is important to provide these children with the means to participate in childhood activities to improve their overall quality of life and increase participation in recreational and leisure activities.² The act of riding a bike, which promotes societal participation, independence, self-efficacy and decreases the exclusion that children with disabilities can experience.³⁻⁵

A qualitative study conducted by Bell, et al.⁵ was completed using a survey provided to the parent(s) of children who have received an adaptive tricycle. Retrospective data was used to investigate whether or not the adaptive tricycle had an impact on the emotional, social, and physical aspects of children with special needs.⁵ The results showed that the therapeutic tricycle had a positive impact on all aspects of the children's lives.⁵ The study done by Bell, et al.⁵ was limited due to the use of retrospective data without access to the participants for follow up questions. Also, the survey was completed using the parent's perspective and did not include the children's point of view. This study is completed by the children with the assistance of the parent/guardian, thus will include both perspectives.

National American Business Clubs Incorporated (AMBUCS) is a nonprofit charitable organization dedicated to helping provide mobility and independence for people with disabilities.⁶ Their mission is to provide therapeutic adaptive tricycles to children with motor/developmental disabilities who are unable to operate a more traditional bike.⁶ Currently, they have provided over 400,000 Amtrykes to children with disabilities all over the United States.⁶ AMBUCS works closely with Physical Therapists (PT) and Occupational Therapists (OT) to help fit riders to bikes that are unique

to their disabilities. PT and OT acknowledge that Amtrykes offer many therapeutic benefits, including improved motor skills, strength development, and self-esteem.³⁻⁵

Williams⁷ conducted a study involving an adaptive static bicycle was done to determine the effects of a muscle-strengthening exercise program on motor function with children and adolescents who were non-ambulatory and had cerebral palsy.⁷ Children were placed on the static bicycle and asked to pedal for as long as possible with a load of 75% of the maximum resistance achieved in a modified graded exercise test.⁷ Then, participants had to pedal as fast as possible in three short bursts against the previously determined maximum resistance.⁷ The exercise program was repeated three times a week for six weeks, allowing recovery time.⁷ The results showed the exercise program was clinically relevant in the improvement of gross motor function and safe, effective means of exercise for these subjects with cerebral palsy.⁷

Another study conducted by Bloswick, et al.⁸, focused on how a modified tricycle that isolated the hip extensor muscles, in children with cerebral palsy, improved their gait pattern after 8 weeks of use in the home.⁸ This study by Bloswick⁸, along with the previous study by Williams⁷, shows how adding a bi/tricycle to a therapeutic exercise program can have many positive effects.^{7,8} However, both studies were only conducted over a short period of time and the children did not have access to the bi/tricycles upon completion of the study.^{7,8} Thus, no lasting benefits can be observed. Furthermore, both studies had a limited focus on children with cerebral palsy. This study evaluates children with disabilities, including but not limited to cerebral palsy, who receive their own adapted tricycle that can provide long term benefits.

There is currently no published research that has been completed looking at the effect these adaptive tricycles have on the children's quality of life after they have received the adaptive tricycle. Investigating this topic could promote the benefit of organizations, such as AMBUCS, to allow more children with disabilities to receive these adaptive tricycles. This will allow the children to have an

alternate form of exercise, both therapeutic and recreational. The study will also provide objective data about the use of Amtrykes and how they affect the quality of life in the children. Unlike previous research, this study is not limited to one disorder. Objective findings regarding the effectiveness can justify future investments for the tricycles. Positive results could lead to the promotion of insurance covering the cost of such devices, allowing the tricycles to be available to more children with disabilities.

Variables

Dependent Measures:

The dependent variable is quality of life. This will be measured using a premade quality of life survey. This survey takes components from the Activity Scale for Kids(ASK), Children's Assessment of Participation and Enjoyment(CAPE), and Preferences for Activities of Children (PAC) questionnaires.

Independent measures:

The independent variable is the presence of the Amtryke.

Confounding Variables:

One confounding variable is the cognitive level of the children. Another confounding variable is biased answers. The surveys will be presented to the children and their guardians in a way to hopefully avoid this.

Aims/Objectives

The overall objective of this study is to determine if the quality of life of children with movement disorders is affected by the use of an Amtryke (adapted tricycle). The purpose of this study is to determine if the Amtrykes have a positive effect on quality of life.

Research Questions / Hypothesis

Question 1: How will the use of an adapted tricycle affect the quality of life of children with movement disorders?

Methods

Study Design: Case Series

Participants: 17 Children and their families completed the survey.

Recruitment: Participants were referred by the Bluegrass AMBUCS organization. A flyer and link to the online survey was distributed electronically to families who have received an Amtryke. Families completed the survey online using Qualtrics Survey Solutions. The survey was also linked on Bluegrass AMBUCS website.

Inclusion: Participants will be included in the study if they meet the following inclusion criteria. 1) The participant is between the age range of 4-18 years old. 2) Has a movement disorder such as, but not limited to, cerebral palsy or autism 3) Meets AMBUCS requirements to receive an AMBUCS adapted tricycle. 4) Has received an Amtryke from Bluegrass AMBUCS or is currently on the waitlist to receive an Amtryke.

Exclusion: Participants will be excluded from this study based on the following criterion. 1) Non-English speaking or unable to comprehend English. 2) Does not meet inclusion criteria.

Participant number justification/Power Analysis: This number was determined based on the number of Amtrykes delivered and the number of requests for Amtrykes in the Bluegrass area. The survey was sent to 97 families, but responses were limited. The number of participants was affected by the COVID-19 pandemic.

Equipment/ Tools:

A prewritten quality of life survey was used for this case series. This is a self-reported survey that takes components of ASK, CAPE, and PAC quality of life questionnaires. The ASK questionnaire is a valid and reliable tool to report physical function.⁹ The CAPE and PAC questionnaires proved to be valid and reliable upon testing.¹⁰ These questionnaires have been used in several studies and pediatric journal articles.^{9,10} This survey was uploaded to Qualtrics Survey Solutions to generate more responses during COVID-19.

Procedures:

The Bluegrass AMBUCS organization distributed a recruitment flyer and link to the electronic survey to families. An electronic survey was utilized using Qualtrics Survey Solutions due to the COVID-19 pandemic and social distancing precautions.

The child and their parent/guardian were given the quality of life survey link to complete online. The participants answered the sections of the survey based on the past month. Each task of the survey was rated using the following scale: never, almost never, sometimes, most of the time, always, or not applicable.

Data/Statistical Analysis:

The results of the quality of life surveys were assessed using graphs generated by Qualtrics Survey Solutions.

Results

There were 17 participants who completed the survey. The data from the survey is presented in Figure 1. Of the 17 participants, all responded yes to the question “Do you feel as if the adaptive tricycle has affected your child’s quality of life, or the way they feel about themselves?”. Since there was not a control group, a formal statistical analysis was not performed.

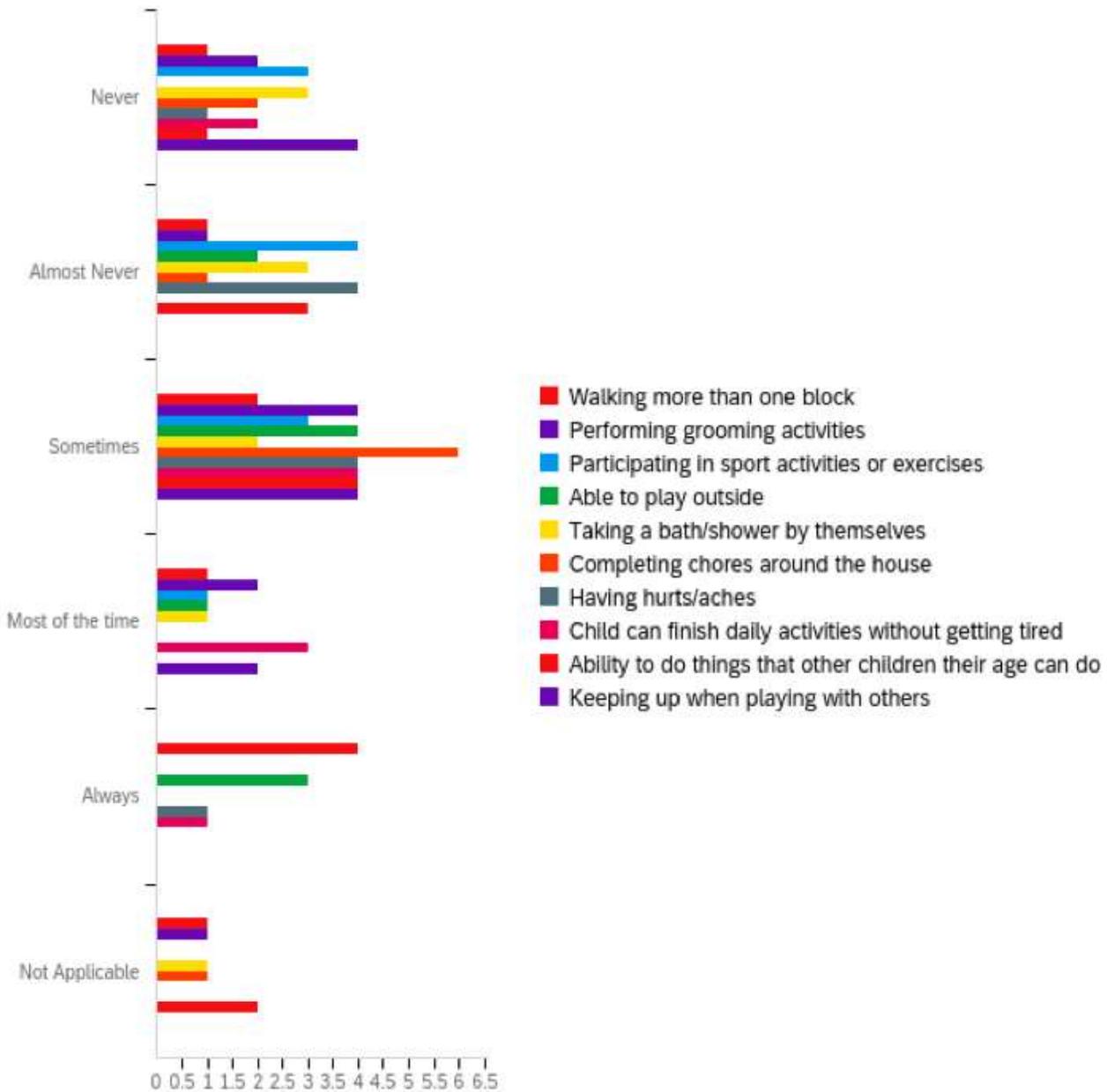


Figure 1. Qualtrics Survey Solutions Data Analysis of quality of life questionnaire.

Discussion

The quality of life survey confirmed that children with movement disorders are unable to fully participate in activities at the same level as their peers. All participants responded that the adaptive tricycle has affected their child’s quality of life. Many participants went on to describe in more detail how their child’s quality of life was affected in fill-in-the-blank portions of the survey. For example, many participants described improvements physically, emotionally, socially, and improved participation.

Previous studies have focused on specific diagnoses. This study differs because it included multiple diagnoses and did not exclude participants based on their diagnosis. Participant diagnoses included: trisomy 21, cerebral palsy, Joubert syndrome, hypoxic ischemic epilepsy, Angelman syndrome, spina bifida, autism, visual impairments, global developmental delays, peri-ventricular leukemia, mitochondrial disease. Including multiple diagnoses in this study will allow the results to be able to be applied to more patient cases.

Although the hypothesis was confirmed, future studies would be beneficial to analyze improvements overtime. For example, a cohort study would be beneficial to have a baseline before receiving an adaptive tricycle and then track the improvements over time.

Limitations:

This study was limited by the COVID-19 pandemic. Due to social distancing precautions there were decreased opportunities to participate in adaptive tricycle giveaways and a reduced number of tricycles given away. This reduced the number of participants and thus decreased the number of survey respondents resulting in a small sample size and did not allow for a comparison or control group.

Certain conditions and ages may have prevented children from completing the survey on their own. Parents were encouraged to help the children but allow the children involvement and to answer to the best of their ability. However, it is to be noted that parents may not be able to understand the child's true emotions and thoughts.

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