EFFECTS OF ADAPTED TRICYCLES ON QUAILITY OF LIFE, ACTIVITIES, AND PARTICIPATION IN CHILDREN WITH SPECIAL NEEDS

by

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Abstract

Children with special needs participate in less physical activity than the typically developing child. Physical activity and participation within activities is essential for a child's physical, emotional, and mental health. Riding a bicycle is a typical childhood milestone that many children with special needs are unable to achieve. The American Business Clubs (AMBUCS), a non-profit organization, strives to create mobility and independence for those with disabilities. Through a local chapter of this organization, ENC Ambucs, funds are raised to provide AmTrykes, or specially adapted tricycles, to children with special needs in this region. The increased physical activity that is expected to come from the use of these therapeutic tricycles is projected to improve the children's health related quality of life. To date research has not investigated the effects of AmTrykes.

The purpose of this study was to determine the effects of AmTrykes on health-related quality of life (HRQOL), participation, function, and physical activity in children with special needs. We hypothesized that, after receiving an AmTryke, children would exhibit increased Sports and Physical Functioning and Global Functioning normative scores, on the PODCI, Psychosocial HRQOL, Physical HRQOL, and Total HRQOL, on the PedsQL-PR, and play time with other children, physical activity, feeling of independence, and health benefits, as measured by the APS-A. Reliable measures of HRQOL, participation, function, and physical activity were administered before and after receiving an AmTryke. The assessments that were utilized include the Pediatric Outcomes Questionnaire (PODCI), the Pediatric Quality of Life Inventory Parent Report (PedsQL-PR), and the AmTryke Parent Survey-Adapted (APS-A). Parents/guardians were asked to fill out the PODCI and the PedsQL-PR prior to receiving the AmTryke to be used as a pre-test assessment. Four weeks after the child was given their tricycle, the same

assessments were sent via mail to the parents/guardians to be used as the post-assessment. The APS-A was sent out via an email link, to these new recipients and to all previous recipients of AmTrykes from ENC Ambucs.

Six children, ranging in age from 4 to 18 (mean=8.2 years) received an AmTryke in February 2016 and were subjects for the pre/post assessments. In addition to these six children, 12 past bike recipients were surveyed using the APS-A. These 18 subjects were between the ages of 4 and 18 (mean=10.9 years). The Global Functioning Scale of the PODCI decreased significantly after the four week intervention period (pre=1.33, post=-8.67, p=0.04). Other PODCI and PedsQL-PR data were not significant. On the APS-A, 55.6% of parents reported an increase since receiving the AmTryke. An increase in physical activity was reported by 77.8% of parents, and 88.9% reported an increase in their child's sense of independence. Health benefits were noted by 72.2% of parents. The AmTryke appeared most beneficial for children who were unable to walk independently (n=7, a subset of the 18 respondents to the APS-A). Of those seven parents, 100% reported an increase in their child's sense of independence and an improvement in their child's mood.

Use of an AmTryke appears to improve the quality of life, activities, and participation in children with special needs. In terms of their sense of independence and mood, children with special needs who are unable to walk alone may benefit more than others from the use of an AmTryke. Future studies will be important to increase the evidence that providing children with special needs with opportunities to participate in bike riding has many positive effects on their quality of life and their physical and psychosocial development.

Background

Participation in physical activity for children is a necessity for proper development. It is suggested that children should engage in moderate to vigorous physical activity for at least 60 minutes every day (American Heart Association, 2013), however, this is hard to accomplish for children with disabilities such as autism spectrum disorders, Down syndrome, and cerebral palsy, among others. In a study done in 2009, Shields, Dodd, and Abblitt concluded that 58% of children with Down syndrome fail to reach the recommended duration of physical activity (Shields et al., 2009). This percentage is much higher than the 15-25% of children with typical development who also do not achieve the suggested amount of physical activity (Booth, 2000). Law and King (2000) stated that participation in activities is the "context in which children form friendships, develop skills and competencies, express creativity, achieve mental and physical health, and determine meaning and purpose in life" (pg. 1).

Physical activity and participation not only create a healthier lifestyle, but also assist in the development of social skills and interactions with other individuals. Law et al. (2006) reported that the primary factors that directly affected participation among children with disabilities included age, gender, and functional abilities pertaining to cognition, common daily activities, physical motor skills, and communication. Hilton, Crouch, and Israel (2008) examined out-of-school participation patterns among children with high-functioning autism spectrum disorder and found that this group of children was involved in a more narrow range of activities than their peers. In summary, children with special needs are less physically active and participate less frequently and in a more restricted range of recreational activities compared to their typically developing peers.

The lack of physical activity and participation among children with disabilities not only affects their physical well-being, but also their mental and emotional health which contributes to a lower health-related quality of life (HRQOL). Health-related quality of lifehas been defined as "an 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 concerns" (The WHOQOL Group, 1998, pg. 1). The concept of quality of life is associated with health, which is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1946). Numerous authors have reported that children with cerebral palsy have a decreased quality of life compared to typically developing peers; this finding correlates directly to the level of functioning of the child (Arnaud et al., 2008; Beckung et al., 2008; Majnemer et al., 2007). The level of functioning takes into account physical, mental, and emotional aspects of life. Lower quality of life has also been found in children with autism spectrum disorders and Down syndrome (Ikeda, Hinckson, Krageloh, 2013). A challenge in accurately determining a child's quality of life is that often children are not able to self-report due to their age and/or condition. If this is the case, a proxy-report is most often completed by the parents of the child. Although parents are quite accurate on evaluating the physical functioning of their child, parents' perspectives on mental and emotional well-being have only a moderate correlation to their child's self-report (Eiser and Morse, 2001). Children's HRQOL can be impaired by the lack of physical activity and participation in everyday activities. For example, riding a bike, a common childhood activity that allows a child to achieve a certain level of independence, is a difficult task for children with disabilities such as autism spectrum disorders, Down syndrome, and cerebral palsy. Many of these children will never accomplish this milestone of typical childhood.

Ulrich et al. (2011) found that less than 10% of children between the ages of 8 to 15 years of age diagnosed with Down syndrome were able to ride a two-wheel bicycle. The authors reported that it was feasible for children with Down syndrome to learn how to ride a two-wheel bicycle in a five day period when provided sufficient instruction. After 12 months of riding a bicycle the children were more physically active and had decreased their subcutaneous fat (Ulrich et al., 2011). In 2012, Pickering at el. conducted a study which involved children diagnosed with cerebral palsy participating in adapted dynamic cycling. Improvement in health aspects, cycling skills, and social participation were all reported (Pickering at el., 2012). Additional research is needed on the short and long-term effects of adapted cycling and its role in overall participation.

Research thus far regarding the usage and effects of AmTrykes, adapted therapeutic tricycles, throughout the United States, shows that the tricycles have made improvements in several areas of children's lives, including play time, leisure activities, and independence (AMBUCS, 2011). AmTrykes can be used by children with a wide range of special needs, to improve coordination, strength, range of motion, and participation. The most common diagnoses of the children that have received an AmTryke include autism, cerebral palsy, developmental delay, Down syndrome, and spina bifida (AMBUCS, 2011). Of those who responded to an AmTryke parent survey, 96.6% of parents reported that their child enjoyed using their AmTryke and 97.7% reported that the AmTryke had an overall positive impact (AMBUCS 2011).

The non-profit organization that funds the AmTrykes is the American Business Clubs (Ambucs).Their objective is to create mobility and independence for those with disabilities ("AMBUCS," 2011). Through this organization funds are raised to provide AmTrykes to children with special needs, with the hope that this will improve their physical activity,

independence, and self-efficacy. In 2014, an Eastern North Carolina chapter of Ambucs (ENC Ambucs) was created in order to provide AmTrykes to the children with special needs in this region. Since then approximately 50 therapeutic tricycles have been bought or donated through ENC Ambucs and given to children in this area. Now that children in Eastern North Carolina are receiving AmTrykes, it is important to measure how the therapeutic tricycles have affected the lives of the children regarding health-related quality of life, participation in everyday events, function, and physical activity.

Purpose

The purpose of this study was to determine the effects of AmTrykes on HRQOL, participation, function, and physical activity in children with special needs. Questionnaires were given to parents of children before and after they received the AmTrykes. A survey was also sent to parents of children who had received AmTrykes previously. We hypothesized that, after receiving an AmTryke, children would exhibit:

1) An increase in the normative scores of the Sports and Physical Functioning Core Scale and the Global Functioning Scale, as measured by the Pediatric Outcomes Data Collection Instrument (PODCI).
2) An increase in the summary scores of Psychosocial HRQOL, Physical HRQOL, and Total HRQOL, as measured by the Pediatric Quality of Life Inventory Parent Report (PedsQL-PR).
3) An increase in play time with other children, physical activity, feeling of independence, and health benefits, as recorded by the AmTryke Parent Survey-Adapted (APS-A).

Methodology

Participants

Children 18 years of age and younger who received an AmTryke in February 2016 were asked to participate in the study. Children who previously received an AmTryke through ENC Ambucs were asked to participate in a follow-up survey as well. Due to limitations in communication for most participants, parents/guardians completed the questionnaires. Parental consent was obtained before data was collected. Subjects included those who qualified for an AmTryke, that is children with special needs, especially those with developmental delays, cerebral palsy, autism, Down syndrome, and spina bifida. Subjects were 18 years of age and younger. Examples of the AmTrykes used by these children can be seen in Figure 1.

Outcome Measures

The assessments used were the Pediatric Outcomes Data Collection Instrument (PODCI), the Pediatric Quality of Life Inventory Parent Report (PedsQL-PR) for specific age groups, and the AmTryke Parent Survey-Adapted (APS-A). The PODCI evaluates the areas of activities of daily living, physical activity, function, mood, limitations, and expectations (American Academy of Orthopedic Surgeons, 2005). Sub-scales within each of the core instruments exhibited high internal reliability, as well as discriminant and convergent validity (American Academy of Orthopedic Surgeons, 2005).

The PedsQL-PR assesses overall function including that of physical, emotional, social, and academic. This tool was developed for use within the community, school, and clinical pediatric populations. Multiple appropriate age-based parent proxy forms of the PedsQL-PR (e.g., ages 2-4, ages 5-7, ages 8-12, and ages 18-25) were used. The parent proxy reports have a

reliability coefficient of 0.90 (Varni JW, 2001). The PedsQL-PR is valid for distinguishing HRQOL in children with chronic health conditions (Varni, 1998). Variables obtained from the PedsQL-PR were Total HRQOL, Physical HRQOL, and Psychosocial HRQOL.

The APS-A includes questions pertaining to the benefits and usage of the adapted therapeutic tricycle. The original AmTryke Parent Survey, developed by Ambucs, was created to better understand parent perspective of the AmTryke and its effects on their child. The survey has been adapted for use in this study by removing questions regarding problems with and suggested improvements to AmTrykes, and adding questions regarding health, mood, and participation. While validity and reliability have not been established, this tool provides an overview of AmTryke use and of families' perception of effects.

Standardized and normative core scales were used to organize the results from the PODCI (American Academy of Orthopedic Surgeons, 2005) and the PedsQL-PR (Varni JW, 1998). The PODCI includes five subscales and one global scale. The five subscales are "Upper Extremity and Physical Function Core", "Transfer and Basic Mobility Core", "Sports and Physical Functioning Core", "Pain/Comfort Core", and a "Happiness Core." The PedsQL-PR standardized scores range from "0" poor outcome/worse health to "100" best possible outcome/best health. The normative scores of the PODCI compare the subject's functioning to that of a healthy population. The PODCI normative mean score is 50, with higher scores indicating better functioning. Normative scores can be negative depending on the subject's functioning. The scoring dimensions for the PedsQL-PR included physical functioning, emotional functioning, social functioning, and school functioning. Scores for the PODCI and PedsQL-PR were calculated according to established criteria for each assessment. Both the

PODCI and PedsQL-PR have established validity and reliability (Kunkel S, Eismann E, Cornwall R, 2011; Varni JW, Seid M, Kurtin PS, 2001).

Procedures

Parents/guardians were asked to fill out the PODCI and the PedsQL-PR prior to their child receiving an AmTryke in February 2016. The parents were given these two assessments on "bike evaluation" day, which is the day the children were first fitted and measured for their AmTryke. During this visit, written consent was obtained from parents/guardians, and a research team member assisted them as needed to complete the two questionnaires. This information was used as a pre-test assessment of the child's physical activity, participation, and quality of life before using the AmTryke. Four weeks after the child received his/her AmTryke, the same assessments were sent via mail to the parents/guardians. The package also included instructions, a contact number for study team if needed, and a postage-paid return envelope. These post-assessments were used to determine the effect the AmTryke had on the child's participation, function, physical activity, and HRQOL.

In order to expand our overall understanding of usage and effects of the AmTrykes, the APS-A was sent to the parents of current recipients as well as parents of previous AmTryke recipients. This was done electronically by sending a link to the APS-A on Survey Monkey via email. The message to parents clearly stated the purpose of this survey and that their completion implied consent to use their results for this research. All surveys/data were coded to protect the identity of participants. To increase the likelihood that surveys would be completed and returned, incentives in the form of gift cards were offered to participants. New AmTryke recipients

received a $30 gift card for completing all pre- and post-assessments. Previous AmTryke recipients received a $15 gift card for completing the APS-A through Survey Monkey.

Data Analysis

Descriptive statistics and graphic analysis was used to summarize responses of the APS-A. Paired Student's t-tests were used to compare the PODCI and PedsQL-PR data from the pre-test to the post-test. For example, a child's participation in physical activity before the AmTryke was compared to the child's participation in physical activity after receiving the AmTryke, to determine whether physical activity increased or decreased after receiving the AmTryke, and by how much. Statistical significance was defined as $\alpha<0.05$.

Results

All six families (100% response rate) who received AmTrykes in February 2016 completed the pre and post PODCI and PedsQL-PR assessments. The six participants were between the ages of 4 and 18 (mean=8.2 years). The participants had diagnoses of cerebral palsy, Down syndrome, and autism. Demographic data for these six participants can be seen in Table 1.

The Global Functioning Scale of the PODCI decreased significantly after the four week intervention period (pre=1.33, post=-8.67, p=0.04). Other PODCI and PedsQL-PR data were not significant; the findings from these assessments can be found in Table 2.

Of the 40 families who received the APS-A, 18 responded (response rate = 45%). These families included the new/February 2016 AmTryke recipients as well as previous AmTryke recipients. Respondents ranged in age from 4 to 18 years (mean=10.9 years). The diagnoses seen among these children included cerebral palsy (7), autism spectrum disorder (5), Down syndrome (2), seizure disorder (1), chromosome abnormality (2), and developmental delay (1). The APS-A

was comprised of 10 questions specific to the usage and benefits of the AmTryke. For this study, we looked at four questions specifically. The responses for these four APS-A questions are summarized in Figure 2. If parents answered "somewhat" or "yes", their response was considered positive. Parents reported overall positive effects of the AmTryke on their child (Figure 2). When asked about play time with other children, 55.6% of parents reported an increase since receiving the AmTryke. An increase in physical activity was reported by 77.8% of parents, and 88.9% reported an increase in their child's sense of independence. Health benefits were noted by 72.2% of parents. The AmTryke appeared most beneficial for children who were unable to walk independently (n=7, a subset of the 18 respondents to the APS-A). Of those seven parents, 100% of them reported an increase in their child's sense of independence and an improvement in their child's mood.

Discussion

Results from the six families who completed the PODCI and PedsQL-PR pre/post receiving an AmTryke did not support our hypotheses that scores on these instruments would improve after children received an AmTryke. In fact, scores decreased for most of these outcome measures for most subjects (Table 2). The only statistically significant change was a decrease in the Global Functioning Score of the PODCI. Many factors may have contributed to these findings, including cold temperatures/winter weather, child illnesses/concern about exposure to others who were ill, inconsistency of pre and post responses, and a short intervention period. The AmTrykes were delivered to families in early February, and families were surveyed four weeks later. During this period of time, colder temperatures could have prevented the use of the AmTryke outdoors. Child illness was reported by several families during this time period, and given the susceptibility of many of these children to respiratory illnesses, their outside

activity is likely decreased during the winter months. Confusion among parents regarding how to interpret/score questions on the PODCI and PedsQL-PR, and having a different parent answering questions on pre- vs post-assessments, may well have led to the type of inconsistent results noted in this study. In addition, the four week intervention period was likely not long enough to produce full effects of the AmTryke on quality of life, activities, and participation among these children, and the wide range of physical and intellectual abilities in this small group (n=6) may have added too much variability to the outcomes, decreasing the likelihood of finding true effects. Thus many factors may have contributed to the unexpected results on the pre/post PODCI and PedsQL-PR.

On the APS-A a majority of parents reported an increase in their child's physical activity, health, and social participation with bike use, similar to previous findings in children with Down syndrome and cerebral palsy (Ulrich at el., 20ll; Pickering at el., 2012). While six of the respondents were the families of children who had just received their bikes, the majority (n=12) of parents who responded had children who had been using their AmTrykes for at least one year. Thus these APS-A data may give a more accurate indication of the effects an AmTryke can have on a child's life. For children who are not able to walk alone, the increased sense of independence gained since receiving their AmTryke, reported in all seven such children in this study, is surely a significant finding. Perhaps the AmTryke provides children opportunities to develop this sense of independence that typically developing children achieve during their first few years of life, by moving around in their environment with minimal/no help from others.

Limitations

The number of participants in this study was small, especially for the PODCI and PedsQL-PR pre/posttests. The number of participants for these "new" bike recipients was limited

by funding available for the AmTrykes. The PODCI and PedsQL-PR assessments may not be sensitive and responsive enough to detect changes especially in such a small, heterogeneous sample, and over a short intervention period. Our timing of the intervention period (during winter months) was less than ideal given cold temperatures and threat of illness. Several families did report child illnesses during the period of this study. The inconsistencies in PODCI and PedsQL-PR pre/post-assessments was puzzling, but may have been due to lack of understanding of questions and/or different parents completing the pre and post-assessments.

Conclusion

Use of an AmTryke appears to improve the quality of life, activities, and participation in children with special needs. In terms of their sense of independence and mood, children with special needs who are unable to walk alone may benefit more than others from the use of an AmTryke. Future research should measure these same outcomes with larger samples and longer intervention periods which include non-winter months. Specific directions should be given to parents regarding how to complete the assessments, and who should complete the assessments (i.e., same individual pre/post). These studies will be important to increase the evidence that providing children with special needs with opportunities to participate in bike riding has many positive effects on their quality of life and their physical and psychosocial development.

Tables and Figures

Figure 1: AmTryke, adapted therapeutic tricyle

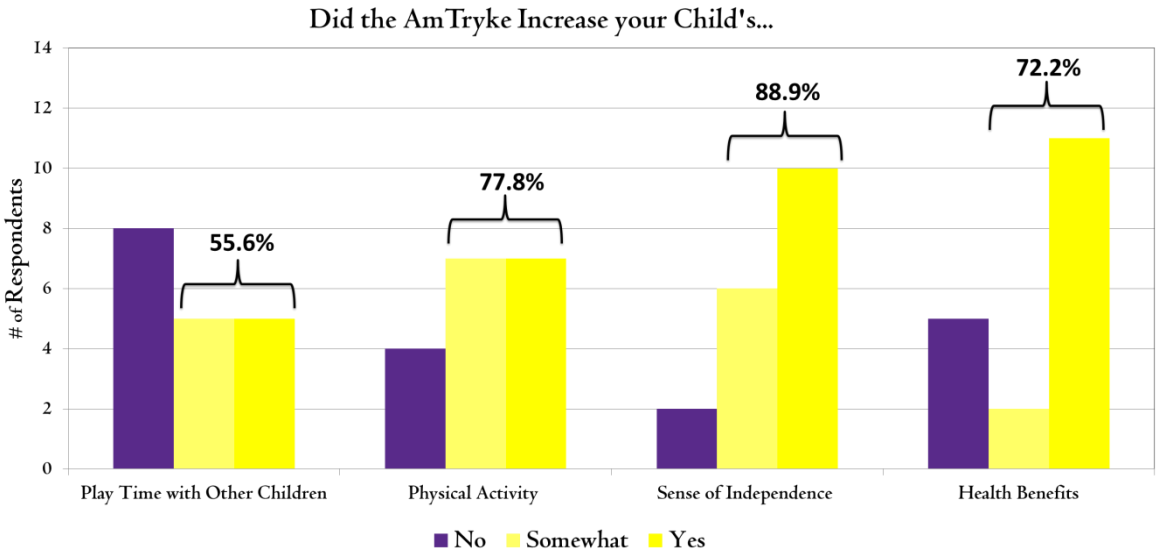
Table 1: Subject Demographics

Subject	Age	Diagnoses
1	5	Autism, Hypotonia
2	9	Cerebral Palsy
3	5	Cerebral Palsy, Cortical Vision Impairment
4	8	Down Syndrome
5	18	Cerebral Palsy, Hypotonia, Scoliosis
6	4	Cerebral Palsy

Table 2: PODCI & PedsQL-PR Scores

Score	Subject #	Pre-Assessment	Post-Assessment	Difference	t-test (p value)
PedsQL-PR					
Physical Health Score	**1**	**46.88**	**62.5**	**15.62**	
	2	**43.75**	**34.38**	**-9.37**	
	3	**0**	**0**	**0**	
	4	**62.5**	**59.38**	**-3.12**	
	5	**21.88**	**10.71**	**-11.17**	
	6	**59.38**	**37.5**	**-21.88**	
Mean (SD)		**39.1 (21.9)**	**34.1 (23.0)**		**0.19**
Psychosocial Health Score	**1**	**60.71**	**55.36**	**-5.35**	
	2	**76.67**	**71.67**	**-5**	
	3	**58.33**	**54.17**	**-4.16**	
	4	**68.33**	**68.33**	**0**	
	5	**54.17**	**47.92**	**-6.25**	
	6	**65.38**	**69.23**	**3.85**	
Mean (SD)		**63.9 (7.3)**	**61.1 (9.0)**		**0.07**
PedsQL-PR Total Score	**1**	**55.68**	**57.95**	**2.27**	
	2	**65.22**	**58.7**	**-6.52**	
	3	**30.88**	**32.5**	**1.62**	
	4	**66.3**	**65.22**	**-1.08**	
	5	**41.25**	**34.2**	**-7.05**	
	6	**63.1**	**57.14**	**-5.96**	
Mean (SD)		**53.7 (13.3)**	**51.0 (12.7)**		**0.08**
PODCI					
Sports & Physical Functioning Score	**1**	**10**	**12**	**2**	
	2	**13**	**6**	**-7**	
	3	**-32**	**-20**	**12**	
	4	**11**	**28**	**17**	
	5	**-36**	**-32**	**4**	
	6	**14**	**-13**	**-27**	
Mean (SD)		**-3.3 (21.8)**	**-3.2 (20.4)**		**0.49**
Global Functioning Score	**1**	**26**	**7**	**-19**	
	2	**34**	**20**	**-14**	
	3	**-40**	**-45**	**-5**	
	4	**24**	**29**	**5**	
	5	**-43**	**-45**	**-2**	
	6	**7**	**-18**	**-25**	
Mean (SD)		**1.3 (31.4)**	**-8.7 (29.5)**		**0.04**

Figure 2: Parent responses to APS-A



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