CARDIAC REHABILITATION IN CHILDREN WITH CONGENITAL HEART DISEASE: EXPLORING DANCE AS AN EXERCISE MODALITY AND BARRIERS TO EXERCISE FOR THIS POPULATION

by

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DEDICATION

To grandpa. I wish you could be here to watch me finish this journey, but I am so grateful for the time we did have together.

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First and foremost, I must thank my family. To my parents, I could not have made it this far without your unwavering support and giving me the resources to make it this far. Tyler, my incredible husband, you have been my calm through the storm. You have supported me in every way possible to pursue this dream. I am so grateful for the life we have built together, and I hope one day I will always try to return the favor and support your dreams. My little Evan, it is my greatest joy to be your mom. Your smiles have gotten me through so many tough days. I can't wait to see what you do with your future.

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ABSTRACT

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Heart disease is widespread and complex. Acquired heart disease is the number one killer of Americans and congenital heart disease (CHD) is the most common birth defect. An important aspect of living with heart disease is participating in regular exercise, at least 150 minutes per week for adults and around 60 minutes per day for children. Most Americans do not come close to meeting these guidelines. One way individuals with heart disease can achieve their exercise is through a cardiac rehabilitation program. A hurdle to overcome with cardiac rehabilitation is the high dropout rate due to a variety of factors, including lack of variety in programing. The first project below explores utilizing aerobic dance as a modality of exercise during cardiac rehabilitation with children. A 30-minute dance class was completed with children without heart disease to establish a control and for safety considerations. Utilizing guidelines from the American College of Sports Medicine (ACSM) for moderate intensity, the 45 participants, aged six through 10 years old, all fell within the guidelines for both heart rate reserve and percent of age predicted maximum heart rate. These results demonstrate that this aerobic dance protocol is moderate intensity and is a potential mode of exercise for use within cardiac rehabilitation. The other project aims were to determine

why children with CHD are not meeting the established exercise guidelines. Participants completed an 18-item survey to report their barriers to exercise. The most common barriers came from external factors, with the highest reported being “the weather is too bad”. Another highly reported barrier was “I don’t have enough energy”. Low energy level has been historically noted in persons with CHD. The tool used was reliable within the sample population, but the validity is lacking, and further validation in children with CHD is a prospect for future research. The results of this study may aid in determining how to create exercise interventions for this population. Overall, these two studies fill gaps in the literature of exercise in children, CHD, and pediatric cardiac rehabilitation. They also provide a foundation for many future studies.

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CHAPTER 1
BACKGROUND

Health behaviors in childhood tend to track into adulthood and maintain or increase quality of life while aging [1]. Establishing positive health behaviors early is particularly important for children born with chronic disease, such as congenital heart disease (CHD). The life expectancy of someone born with CHD has increased dramatically over the last few decades, in fact, there are fewer children living with CHD than adults [2] . CHD is the most common birth defect, effecting 1% of all births [3]. About 25% of those born with CHD require surgery within the first year of life [4]. Although 'congenital' is defined as a condition an individual is born with, the condition may not be diagnosed at birth [3]. It is possible to have CHD diagnosed after birth, during childhood or later in life. These conditions can be anatomical abnormalities, disorders in musculature and/or function, and arrhythmias [3]. Levels of severity of CHD by diagnosis are generally classified as mild, moderate, and severe.

Aerobic exercise testing is a common form of assessment for individuals with CHD and participating in regular exercise can be extremely beneficial to testing and health outcomes [5]. Exercise training increases functional capacity, which can improve outcomes of a cardiopulmonary exercise test like VO_2 max in healthy individuals and in most people with CHD [6,7]. These values are extremely important to those with severe heart disease that are being evaluated for advanced therapies like transplantation. A VO_2 max of 14ml/kg/min and/or less than 50% of predicted VO_2 compared to demographically matched individuals (age and sex), are both used as criteria to qualify for a cardiac transplant [8]

Exercise differs from general physical activity by being planned, structured, and having a goal to increase or maintain fitness [9]. Children should participate in both, but overall the physical activity guidelines for Americans recommend that children get at least of 60 minutes of moderate to vigorous physical activity per day [10,11]. Physiologically, children have a similar response to exercise as adults where an increase in systolic blood pressure and heart rate are seen. Children tend to have a higher resting heart rate with a lower resting blood pressure, stroke volume, and cardiac output [12]. By age 12, resting vital signs should be the same as adults, for example, a resting heart rate of 60-100 bpm [13]. For those with CHD who have medical clearance to exercise, adhering to these recommendations increases aerobic capacity and quality of life, and decreases anxiety and depression and likelihood of developing comorbidities such as obesity and diabetes [14]. Cardiac rehabilitation (CR) is one way these children can get structured exercise while being monitored by trained clinicians for safety and creation of proper exercise prescription.

Lakicevic et al. explained the importance enjoyment plays in adherence to exercise [15]. This is reiterated in multiple studies regarding adults in CR [16,17]. Although research has not been reported on the rates in pediatric CR, dropout rates for adults in CR are high, about 25-50% [17,18]. In the adult studies, factors such as lifestyle modification and psychosocial counseling, and providing a wide variety of exercise options are shown to reduce to dropout rates [16,17]. Creating exercise programs for children, like those in CR, need to be different from adult programs to keep children engaged. It is reasonable to conclude having a variety of fun and exciting exercise modalities, like aerobic dance, would be more appealing to pediatric patients as well. When children are asked what physical activity means to them, they include sports and dancing. In the same study, sports and dancing are considered fun, the feeling of fun is a facilitator of physical activity [19].

CHAPTER TWO
RELEVANT LITERATURE

2.1 Problem and Purpose

The American College of Sports Medicine (ACSM) and the American Heart Association (AHA) agree that children over seven years old rarely meet recommendations of at least 60 minutes per day of moderate to vigorous physical activity, and at least three days a week of resistance training and vigorous intensity exercise [20,21]. Establishing the habit of routine exercise during childhood has been shown to carry into adulthood [1]. Studies investigating clinical improvements from exercise interventions in children with CHD have shown to result in an 8-19% increase in exercise capacity from peak VO_2 [22]. The physical activity recommendations for children with CHD match those of typically developing children, with 60 minutes of physical activity per day and inclusion of resistance training [22].

The evidence gathered from the studies in this paper may guide and encourage prospective research in finding ways to inspire children with CHD to exercise, their guardians to encourage it, and CR programs to use alternate exercise modalities. Regular exercise can improve health in this population and prevent more significant consequences of their CHD and/or new diseases from developing [22]. CR programs for children with CHD utilizing aerobic dance and other modalities should be studied. It would also be beneficial to create interventions to increase overall exercise participation. The main objectives of these two studies are: 1) to determine if aerobic dance meets the guidelines for moderate intensity exercise in children, and 2) to identify the barriers children with CHD face to participate in regular exercise.

2.2 Alternate Exercise Modalities

Much of the current pediatric exercise literature has examined modalities including high intensity interval training, and utilizing equipment such as treadmills, cycle ergometers, and NuSteps, similar to that studied in literature on adult exercise [23]. Alternative exercise modalities such as dance, sports, and active games (e.g., tag) have not been analyzed in depth as alterative modalities in children, specifically during CR. Dance and boxing, as an alternative to the typically used modalities (e.g., treadmills and Nustep), have been studied for adults in CR [24,25].

Heart failure (HF) is a common diagnosis in children with CHD. Pilates has shown promise in adults with HF; peak VO_2 (exercise capacity) and the amount of exercise time tolerated both increased [26]. In an attempt to add more patient focus and enjoyment of exercise, Nabutovsky et al. created a boxing program for patients in CR [27]. This program resulted in improved engagement with the program and increases in muscle endurance [27]. Lastly, dance programs in CR have exhibited an exercise intensity of 50-80% of peak VO2 for adult participants [25]. Research with children in CR is needed, starting with healthy populations to determine the safety and efficacy of alternate exercise modalities and to establish a comparison group.

2.3 Theoretical Framework for Exercise Barriers

Health behavior theory, specifically the Health Belief Model (HBM), can be used to explore the reasons children with CHD do not meet the recommended amount of physical activity. The HBM includes six different constructs that can determine a health behavior: susceptibility, severity, benefits, barriers, self-efficacy, and cues to action [28]. Barriers to regular exercise must first be evaluated to determine how to encourage a change in children's behaviors. The barriers may involve some of the other constructs of the model. An example is not knowing the benefits or understanding the severity of their disease, not having the confidence, or not having reminders or something to influence the exercise behavior. There may also be external influences coming from parents, peers, or health providers like fear or unclear restrictions [29]. Adolescents (i.e., teenage years) are able to better understand the negative outcomes of their actions (e.g., susceptibility and severity), therefore, this is an appropriate behavior change model to be used with this population [30]. Previous research has utilized the HBM with children with chronic disease and found success in aiding them to adhere to medical treatment. Specifically, it was found that barriers and cues to action were the most beneficial constructs for this population [31]. The second study discussed in this paper uses the barriers construct of the HBM with an older age group (fourth-12th grade).

In previous literature, the HBM's constructs have been split up to study behaviors in children [32,33]. Research carried out by Malik et al. examined how self-efficacy might influence feelings (e.g., pleasure/displeasure and enjoyment) during exercise, specifically high intensity interval training (HIIT) in typically developing children [32]. The participants completed a HIIT protocol on a cycle ergometer and then asked how confident they were that they could complete that activity over the next four weeks. During and after the cycle exercise, they were also asked their level of enjoyment of the exercise on two different scales. The findings highlighted that the individuals with low self-efficacy had lower enjoyment in exercise.

The HBM construct 'cues to action', also referred to as 'calls to action', has been studied in children with CHD by researching what influences them to exercise. Blais et al. examined this in a pilot study with small statistical power [33]. The researchers interviewed 7-10 year old children weekly throughout a 10 week sport program. The main influences found were motivation, confidence, peer influences, and family influences. Thus far, the full HBM has been studied in children with cystic fibrosis and healthy populations [31,34]. These studies used surveys to assess other health behaviors and beliefs in children. For example, a questionnaire developed by Fathian-Dastgerdi et al. to measure the constructs of HBM was utilized to see how behaviors around COVID-19 protection were influenced in adolescents. Interestingly, this study found the adolescents to have a high understanding of the severity of COVID-19 but felt they were not highly susceptible [34]. This could be something to study for other diseases/conditions and the perceptions of children around them. The methodology in these previous studies can be helpful in creating future research with children. The use of HBM and other tools that are known to work with children, like motivational interviewing, would be warranted for future studies [35]. Overall, research in behavior change theory in children is limited and could use further evaluation [31].

2.4 Operational Definitions

Children in the studies presented below are individuals aged between the ages of six and 17 years old. CHD is defined as an abnormality of the heart present at birth that affects how the heart works [36]. Aerobic exercise is repetitive, rhythmic motions of the whole body that increases heart rate and demand on the muscles of the body [37].

CHAPTER THREE
CARDIOVASCULAR OUTCOMES OF AEROBIC DANCE IN HEALTHY ELEMENTARY CHILDREN: A PILOT STUDY

3.1 Introduction

The narrative around exercise in children with congenital heart disease (CHD) has changed in recent years, transitioning from caution to encouraging exercise participation [38]. Cardiac rehabilitation is one way this population can participate in exercise regularly and begin creating healthy exercise habits. Current cardiac rehabilitation programs are centered on adults with heart disease; there is still a lack of pediatric programs in the United States [39–41]. As pediatric programs are increasing in number, it is important to study the ways they should be different from standard adult programs. One way is the possibility of using different exercise modalities.

There has been limited research on aerobic dance in children, but what has been studied highlights improvements in exercise behaviors in addition to other physiologic and psychologic benefits. Prior studies which include participants under 18 years old engaging in some form of dance, highlighted improvements in participants' weekly time of participating in exercise and physical activity [42]. A systematic review by Tao et al. aimed to evaluate the current literature around the benefits of dance in children and adolescents, both psychologically and physiologically [42]. A total of 15 studies were examined that included children between 5-18 years old, but none utilized aerobic dance. The styles used included African dance, Hip Hop, Contemporary, Ballet, and Folk. Some of these studies incorporated children with a variety of conditions, including Down Syndrome. While CHD was not the focus, CHD is a common diagnosis in individuals with Down Syndrome [43,44]. When studying dance in children with Down Syndrome, motor skills improved after programs using a traditional Indian dance program and an adaptive dance program called *Ballet Moves*.

Literature examining aerobic dance specifically, aimed to study improvements in exercise participation, or other outcomes like executive function or balance [45–47]. Most of these studies had dance as one piece of physical activity and did not study it separately from other modalities or assess cardiovascular responses. If cardiovascular response was assessed, it was not utilizing heart rate data. For example, Trost et al. compared the energy expenditure of aerobic dance using metabolic equivalence of task (MET) data compared to other activities. The participants only danced for five minutes to obtain the data. This was a longitudinal study which did find that METs increased with age while performing aerobic dance, therefore this aerobic dance required more energy as they aged [48].

In adults, aerobic dance as a modality of exercise is comparable to other modalities like treadmills and cycle ergometers. According to the American College of Sports Medicine (ACSM) guidelines, the heart rate (HR) response during aerobic dance in adults is within the appropriate range for cardiovascular benefits [49]. ACSM guidelines state, and previous research agrees, that the majority of cardiac rehabilitation exercise should be done at a moderate intensity [20]. ACSM defines moderate intensity to be 64-76% of age predicted maximum heart rate (MHR) and/or 40-59% of heart rate reserve (HRR) [20].

It is necessary to study alternate forms of exercise such as dance due to the high dropout rate that is observed in adult cardiac rehabilitation programs [16,18]. Recent studies report approximately a 40% dropout rate of patients during a cardiac rehabilitation programs, with the lack of variety and excitement in these programs being a contributing factor [16,50]. These factors are likely to be similar problems for children as they may desire more fun and engaging ways to exercise during rehabilitation than what is typically seen in adult CR programs. The purpose of this study is to assess the exercise intensity achieved by healthy children during an aerobic dance class. It is hypothesized that aerobic dance in this population will fall within moderate intensity by ACSM heart rate guidelines [20].

3.2 Methods

3.2.1 Participant Recruitment

This was a cross sectional study approved by the Institutional Review Board of Oakland University. Participants were recruited from a local elementary school via their physical education teacher. All students first through fifth grade, aged six to 10 years, were invited to participate. Children were excluded from participation if they had any known heart defects, arrhythmias, or other cardiac related problems. Given the lack of extant literature on this topic, it was determined that starting with a population of typically developing children is most appropriate. At the time of this study, the state of Michigan did not have a pediatric cardiac rehabilitation program. Testing healthy children was necessary to ensure safety while exercising outside of a medically supervised facility. This study design has been done in previous literature as it is important to determine the safety of the modality [51].

Parents were provided a parent permission form and given the opportunity to watch a recorded video of the principal investigator (PI) explaining the study and what it would entail. Parental permission and child assent were obtained for each child prior to participation.

3.2.2. Procedures

An exercise professional certified as a Personal Trainer and Primary Group Exercise Instructor by the Aerobics and Fitness Association of America was recruited to be the instructor of the aerobic dance class. This individual recorded the 30-minute dance class on video. Two, 30 second breaks were included. A familiarization session during their regularly scheduled physical education class was conducted approximately one week prior to data collection. The dance video was then used during data collection.

Each child wore a Polar Heart Rate Monitor version H7 (Polar Electro Inc., Bethpage, NY) around their chest to measure HR and Actigraph accelerometers version wGT3X-BT (ActiGraph, LLC., Pensacola, FL) on the right wrist to record HR data [52,53]. The Polar Heart Rate Monitor was connected with the Actigraph accelerometers via Bluetooth to record HR data. The 30-minutes dance class and approximately two to five minutes before the class was recorded. Only 10 Polar HR monitors were available to use in this study. Therefore, if there were more than 10 students in a class that had parental permission, only 10 of them were able to participate with the amount of equipment available. As a result, five students with parental permission were not able to participate. The data were then downloaded to a computer for statistical analysis.

All students were closely monitored by the PI, research assistants, and their physical education teacher throughout the class to ensure no injuries occurred. Study participants were observed to determine if they were participating fully for the duration of the video and were excluded if they did not participate fully, which included taking bathroom breaks and poor effort during the class as determined by the PI. Only one student had to be excluded because of this. The subjects had the opportunity to withdraw from the study at any time if they chose.

3.2.3 Measures

The equation, 208 – (0.7 x age), was used to calculate age predicted maximum heart rate (MHR). This equation was selected from literature discussing the most appropriate equation for children [54]. Participant ages ranged from six to 10 years. Age-predicted MHRs were 201-203.8 bpm (see Table 1). The mean HR over the entire 30-minute class was calculated for each participant. These mean HRs were sorted by age and averaged for each age, and age with sex. The percent of age predicted MHR was found by dividing the mean HR for each group by the age predicted MHR for that age group.

HRR was calculated using [(MHR – resting HR) x % intensity desired] + resting HR [20]. The ACSM recommendations for moderate intensity utilizing HRR are 40-59%. The HRR calculation using both 40% and 59% as the desired intensities are shown in Table 1. Due to time constraints of the physical education class, a true seated (for at least five minutes) resting HR was not feasible. Therefore, resting HRs were taken from the HR data at two minutes prior to the dance class beginning. This data was not available on all participants; 27 of the 45 participants were included in the HRR calculations. Once HRRs were calculated, they were grouped averaging together both the age groups including both sexes and age groups with sexes separately.

3.2.4 Statistical Analysis

Stata/BE 17.0 was used for statistical calculations with alpha value set at 0.05. Statistical tests included: one-way analysis of variance (ANOVA) comparing age groups and percent of maximum heart rate achieved during the class; and an unpaired, two-sample t-test comparing maximum heart rate by sex. The HRR and percent MHR results were compared to ACSM guidelines for exercise intensity.

3.3 Results

Permission forms were given to all students within the age range at this elementary school, approximately 300 students, and 50 responses were received, a 15% response rate. Five students who responded were unable to participate due to equipment constraints, further detailed in the limitations section. Therefore, a total of 45 participants were included in the study.

The mean HR achieved by participants throughout the dance class and their percent of predicted MHR is presented in Table 1. Participant groups ranged between 64.1-69.2% of predicted MHR, within the ACSM guidelines of 64-76% for moderate intensity exercise. The ANOVA and t-test results showed no significant difference between age and sex groups for percent of predicted MHR, $p = 0.15$ and $p = 0.28$ respectively. HRR mean calculation results separated by age and sex are presented in Table 1. Only one participant, a 10 year old female, did not achieve the ACSM guidelines of 40-59% of HRR for moderate intensity exercise.

Table 1. HR data by age and sex

Age (yr)	N	Age Predicted MHR (bpm)	Mean HR (bpm) (mean ± SD)	% of predicted MHR	HRR at 40% intensity (bpm)	HRR at 59% intensity (bpm)
10	10	201	137.61 ± 6.61	68.46%	n = 5 133	151
Male	6		136.46 ± 7.03	67.89%	n = 4 127	145
Female	4		139.34 ± 6.48	69.32%	n = 1 155	179
9	7	201.7	139.65 ± 12.03	69.24%	n = 4 131	151
Male	4		141.52 ± 16.69	70.16%	n = 1 141	165
Female	3		137.15 ± 0.19	68.00%	n = 3 128	146
8	7	202.4	138.11 ± 9.31	68.24%	n = 4 127	144
Male	3		139.85 ± 3.09	69.10%	n = 2 129	146
Female	4		136.81 ± 12.72	67.59%	n = 2 125	142
7	10	203.1	137.62 ± 7.51	67.76%	n = 7 129	148
Male	5		138.91 ± 5.39	68.39%	n = 4 129	148
Female	5		136.34 ± 3.01	67.13%	n = 3 130	149
6	11	203.8	130.64 ± 6.53	64.10%	n = 7 126	144
Male	6		130.07 ± 7.78	63.82%	n = 4 132	150
Female	5		131.91 ± 5.39	64.73%	n = 3 120	137

3.4 Discussion

The current study evaluated HR response to aerobic dance in elementary aged children using validated accelerometers and HR monitors. Results from mean HR achieved are shown through percent of MHR and HRR, and both of these meet ACSM guidelines for moderate intensity exercise [20]. Thus, the hypothesis was accepted. While this is a promising start, future research is warranted.

One study examining cardiovascular response to dance in children had similar outcome measures to the current study but examined different types of ballroom style dance, not aerobic dance, and included only fifth grade participants [55]. The results were similar in that the children spent time in a moderate intensity zone, overall, the average HRs were less; 124.4 bpm for ballroom vs. 137.6 bpm for fifth graders in this aerobic dance study. This suggests aerobic dance elicits a greater HR response [55]. A similar study with children in only fourth and fifth grades examined HRR in ballroom dance [56]. In their participants, 71% were above 25% of HRR for over half of the class. As ACSM says 40-59% of HRR is moderate intensity, 25% is not sufficient to determine the participants were in a moderate intensity zone [20].

Interactive dance video games are available and used to be very popular with children. Studies done between 10-20 years ago, assessed exercise intensity while participating in dance video games. In children between ages 11-18 years, the Kinect game *Dance Central* elicited an average HR of 118 bpm, which is considered light intensity activity at 59-61% of MHR [57]. The game *Dance Dance Revolution* provoked greater HR response at 65% of MHR on average, which is within ACSM moderate intensity guidelines [58]. The aerobic dance protocol in the current study created a larger HR response than both of these dance video games.

Including adult participants, two studies have been conducted examining energy expenditure during aerobic dance [59,60]. Both studies report that adults spent most of their time in a moderate to vigorous intensity zone as calculated by the percent MHR achieved. These studies also reported that calorie expenditure ranged from 6.8 to 10 kcal per minute. Diverse types of aerobic dance and differences in population could account for this. Adding calorie and/or metabolic equivalent (MET) data to a future study would give a better idea of the exact cardiovascular benefits of aerobic dance for the pediatric population.

Other steps in validating aerobic dance as a suitable form of exercise for cardiac rehabilitation programs would be to compare it to the other modalities that are generally used in rehabilitation programs, and then to create a pilot aerobic dance program. Rate of perceived exertion (RPE) is often used in cardiac rehabilitation settings as a way for patients to self-limit their exercise intensities [20]. As long as the children demonstrate understanding of the RPE scale, or an adjusted scale that is more age appropriate, the scale can be used to instruct patients to work at the same intensity for different exercise modalities, then compare the cardiovascular response. If there are no significant differences in HR and METs data between dance and the other forms of exercise, it can be argued that similar cardiovascular benefits will occur if aerobic dance is used during rehabilitation.

Aerobic dance may be used to improve the high dropout rates in CR with this new data supporting the appropriate cardiovascular response. It is important to continue to study alternative modalities that may motivate patients to continue a rehabilitation program for the full duration. ACSM recommends a minimum of 12-18 supervised exercise sessions to maximize benefits [20]. Previous research has shown that a 12-week program with a weekly volume of 60-90 minutes has positive effects on high- and low-density lipoprotein cholesterol, blood pressure, oxygen consumption, and left ventricle ejection fraction [61]. The availability to offer exercise like aerobic dance may help ensure children with CHD desire to complete at least 12 sessions of CR and potentially up to a full 12 weeks.

3.4.1 Limitations

Equipment malfunctions were possible and the most likely case would be the Polar (Polar Electro Inc., Bethpage, NY) HR monitors. Each child had a different size chest, and the chest straps of these monitors did not all fit perfectly. The other limitation to this study was lack of participation and equipment, as not every class had 10 students with parental permission where some classes had more than 10 which then had to be excluded.

As a pilot study, these results are not generalizable to a population of children with CHD due to lack of pediatric CR infrastructure in Michigan. This study does demonstrate the possibility of conducting this protocol with children with CHD between six-10 years old.

3.5 Conclusion

HR response to aerobic dance in healthy children aged 6-10 years, averaged 67.56% of predicted MHR. This falls within ACSM guidelines for moderate intensity activity [20]. Moderate intensity is recommended for participants in a Phase II cardiac rehabilitation program. Heart rate data provide evidence that aerobic dance is an appropriate modality of exercise for pediatric cardiac rehabilitation patients. This study could be expanded into a randomized control trial in multiple ways in the future. A comparison of aerobic dance to other exercise modalities that are typically used in CR and including children with CHD is a start. Pediatric cardiac rehabilitation programs are growing in number. Alternative exercise modalities are one way to increase participation in these programs to maximize their effectiveness.

CHAPTER FOUR
IDENTIFYING BARRIERS TO REGULAR EXERCISE FOR CHILDREN WITH CONGENITAL HEART DISEASE

4.1 Introduction

CHD is the most common birth defect, affecting 1 in 100 births [3]. Throughout the lifetime of patients with CHD, exercise testing is conducted to assess functional capacity and other important health markers (arrhythmias, symptoms, etc.) [7,62]. These tests can also determine the effectiveness of a new medication, readiness for a procedure, and qualification for a heart transplant [7]. Lack of exercise can heavily impact exercise test outcomes. As a result of more regular exercise participation and improved performance on exercise tests, children have a better quality and length of life and decreased morbidity into adulthood [63–65]. The American Heart Association notes that American children do not participate in the recommended amount of physical activity, with only about 25% of teenagers being physically active for 60 minutes every day [21]. Identifying barriers to exercise, particularly in children with CHD, will help providers intervene with education and behavior change methods.

There is a shortage of literature on exercise and behavior change in children with CHD. The population of children with CHD living into adulthood is growing [62]. There is a need to develop interventions, including exercise, that may decrease morbidity for this population, for example, exercise training [2]. While the health effects of and barriers to exercise has been studied extensively in adults with cardiac disease, similar studies in children are lacking [29,66,67]. Research with childhood heart disease, on the other hand, has primarily focused on exercise recommendations and benefits, but exercise barriers or not why those recommendations are not being followed [68–70].

Existing research shows that children with CHD have similar attitudes toward exercise as those without CHD [71]. Generally, the child's beliefs about physical activity are not a barrier, therefore exploring the challenges these children face to participate in physical activity requires additional research [71]. Barriers can be divided into two groups, internal and external [72]. These are obstacles that the children experience coming from their own thoughts and from outside sources, respectively. Looking at these two categories will aid in narrowing down the barriers to draw conclusions and create interventions.

When asked their barriers to exercise, healthy, typically developing elementary children (aged 7-9 years) cite mostly external barriers to being physically active [19]. Some examples include restrictions from parents (e.g., time constraints, safety, and costs), lack of time/space in school, and poor weather. Fewer internal barriers were expressed, with the main ones being tired after school or feeling unfit [19]. Typically developing adolescents have historically voiced more internal barriers [72]. This age group (i.e., 10-14 years) shows more ability to overcome external barriers but have less self-efficacy when it comes to exercise [72]. It will be helpful to determine if children and adolescents with CHD cite the same barriers as their healthy counterparts in order to create interventions.

Children with CHD have a lower exercise capacity than those without and these differences increase with age, where the older the child with CHD is, the larger the gap in exercise capacity [73]. To successfully address barriers to exercise, it is important to implement interventions early in life [74]. These interventions can aid in promoting healthy exercise behaviors and improving functional status. Previous trials had zero adverse events while children with CHD were participating in exercise training [75]. They showed improvements in peak workload and VO_2 max as evidenced by cardiopulmonary exercise testing, as well as an increase in average daily exercise minutes [75]. The evidence gathered from the study described in this paper may foster prospective research in finding ways to encourage children with CHD to exercise, potentially tailored to CHD disease severity.

Researching the relationship between severity and exercise barriers is important because regular participation in exercise can improve health and prevent more significant consequences of their CHD and/or new comorbidities from presenting [22]. Moons et al. reported that in adults with CHD, the severity of CHD was negatively associated with quality of life, but this relationship with moderated by functional status [76]. The relationship between disease severity and exercise is unclear in children with CHD [70,77–80]. A narrative review by Van Deutekom and Lewandowski reported mixed findings about how CHD severity impacts physical activity levels in youth [70]. In addition to CHD severity, age, sex, and race influence exercise behaviors in young populations [81,82]. The objectives of this study are (1) to identify barriers to exercise in children with CHD and (2) determine if the severity of CHD diagnosis plays a role in these barriers.

4.2 Methods

<u>4.2.1 Participant Recruitment</u>

This study was a cross-sectional survey to identify barriers to participating in exercise for children with CHD. Children between fourth and twelfth grade with at least one CHD diagnosis were recruited to participate in the study. Participants were recruited online via CHD support and advocacy groups, social media, word-of-mouth, and through snowball sampling. A guardian confirmed the child met the inclusion criteria and could read above a third grade reading level. Parents gave parental permission and the children gave assent prior to participation.

Approval for the study was obtained from the Oakland University Institutional Review Board. Participants in the study were compensated with a $10 gift card, supported by the Oakland University Provost Graduate Student Research Grant.

4.2.2 Survey Selection

To assess barriers to regular exercise, the Perceived Barriers for Moderate-Vigorous Physical Activity (PB-MVPA) survey was administered to study participants [72]. In the survey, participants were directed to respond to a series of “I don’t often do physical activity because…” statements with “false,” “sometimes true,” “usually true,” or “very true”, which corresponded to Likert scale response options of 1 to 4, respectively. Higher scores were indicative of the statement presented being a barrier to exercise for the participant. Eighteen total barriers were addressed by the survey, but only 14 were validated as subscales within the instrument. Four barriers were classified as internal barriers and 10 were external barriers. The remaining four barriers were not classified under the internal or external subscales due to the results of a confirmatory factor analysis. However, these barriers were still included when reporting total mean barrier scores.

This instrument has been previously validated to address perceived barriers in children, with a composite reliability of over 0.80 [72]. Participants were sorted by grade level to ensure reading abilities. If the participant had a lower reading level than their grade, they were asked to select the younger grade level group. The grade levels used in the study have been previously found to be reliable and valid.

4.2.3 Procedures

Demographic data included age, grade in school, sex, race, and CHD diagnosis. Race was treated as a binary variable and participants were categorized as “White” or “Non-white” based on their survey responses. The binary variable was chosen due to non-White participants only making up 29% of respondents. Sex at birth was a binary variable categorized as male or female. Age was reported as a discrete variable but was transformed into a categorical variable corresponding to two quantiles. Parents of the participants reported the demographic data and CHD diagnosis of the child. The surveys were completed online through Qualtrics by both the child and guardian. The severity of CHD was classified as mild, moderate, or severe based on the 2020 European Society of Cardiology classification system [83].

4.2.4 Statistical Analysis

Descriptive statistics were calculated as n (%) and mean (SD) of demographic data and internal and external barrier scores. Kruskal-Wallis was used to test for differences in internal and external barriers, separately, by severity of CHD diagnosis (i.e., mild, moderate, or severe) and to examine potential relationships between internal and external barriers by age (categorical), sex, and race in three separate tests.

Internal consistency for both the internal and external subscales was assessed using Chronbach’s alpha in a post-hoc analysis. To align with reliability reporting from Gunnel et al, Cronbach's alpha was calculated including the four barriers not formally assigned to a subscale [72]. P-values and rank sums are reported, and findings are considered statistically significant at an alpha of less than 0.05. Analyses were conducted using Stata/BE 18.0 [84].

4.3 Results

Demographic information and mean barrier scores are displayed in Table 2. There were 14 complete data sets available out of 17 survey responses. The barrier scores overall were low, and a score of 1 means no barriers. Participants reported higher mean external barriers than internal, except for the non-White participants, whose mean internal and external barrier scores were similar. Those with moderate CHD severity reported the highest external barrier score, with a mean of 1.5. Both moderate and severe CHD groups had an internal barrier score of 1.2. Participants with mild CHD severity reported the lowest internal barriers, with an overall mean score of 1.0, meaning these items were not considered a barrier by anyone in the sample with mild CHD severity.

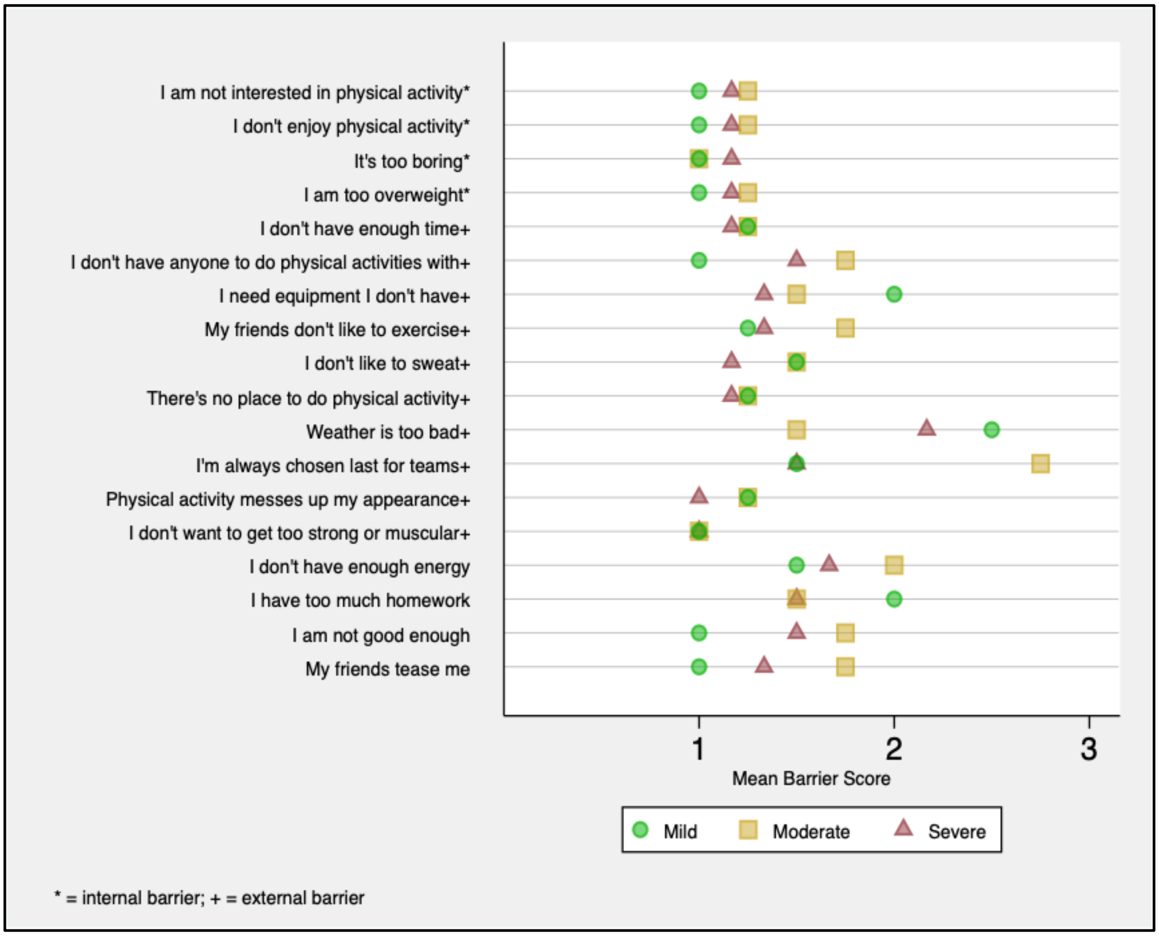
Table 2. Participant Demographics and Mean Barrier Scores

	Summary N(%)	**Internal Barriers** Mean (SD)	**External Barriers** Mean (SD)
Age- Mean (SD)	11.93 (2.02)		
Race			
White	10 (71.4%)	1.10 (0.17)	1.50 (0.36)
Non-White	4 (28.6%)	1.20 (0.38	1.20 (0.15)
Sex at Birth			
Male	6 (42.9%)	1.20 (0.29)	1.50 (0.36)
Female	8 (57.1%)	1.10 (0.18)	1.20 (0.15)
CHD Severity			
Mild	4 (28.6%)	1.00 (0.00)	1.40 (0.52)
Moderate	4 (28.6%)	1.20 (0.24)	1.50 (0.39)
Severe	6 (42.9%)	1.20 (0.24)	1.30 (0.22)

Total sample: N = 14
CHD: congenital heart disease

The mean of each barrier by CHD severity is displayed in Figure 1. Barriers are classified as “internal” or “external” where appropriate, with mean scores for all barriers reported in the figure. The most frequently reported barriers were “the weather is too bad,” “I don’t have enough energy,” and “I’m always chosen last for teams.” These barriers were reported by 71.4%, 57.1%, and 50.0% of participants respectively. Zero participants reported not wanting to get too strong/muscular as a barrier to exercise.

Figure 1. Mean Exercise Barrier Rankings by CHD Severity



Detailed results of Kruskal-Wallis tests can be found in Table 3. After testing for differences in internal and external barriers between groups by CHD severity, neither subgroup was found to significantly differ by CHD severity ([internal: $\chi2(2) = 2.21$, $p = .33$], [external: $\chi2(2) = 0.78$, $p = .68$]). Comparison in both internal and external barrier scores by age, sex, and race, also found no statistically significant differences.

Cronbach's alpha calculations for the internal reliability of the survey was 0.77 for internal barriers and 0.72 for external barriers. This is within the acceptable range. As explored in Gunnell et al, Cronbach's alpha was also calculated for internal and external subscales while including the four barriers not assigned to a subscale [72]. With the modified subscales, Cronbach's alpha was 0.84 for internal barriers, and 0.77 for external barriers. Including the four additional barriers increased the reliability of the PB-MVPA scale in this study population.

Table 3. Kruskal-Wallis Results

	CHD Severity	**Observations**	**Mean Rank**	**df**	**x^2**	**p-value**
Internal Barriers	Mild	4	22.00	2	2.21	0.33
	Moderate	4	35.50			
	Severe	6	47.50			
External Barriers	Mild	4	29.00	2	0.78	0.68
	Moderate	4	36.00			
	Severe	6	40.00			
	Age	**Observations**	**Mean Rank**	**df**	**x^2**	**p-value**
Internal Barriers	9-11 years	7	59.00	1	1.09	0.30
	12-15 years	7	46.00			
External Barriers	9-11 years	7	53.50	1	0.02	0.90
	12-15 years	7	51.50			
	Race	**Observations**	**Mean Rank**	**df**	**x^2**	**p-value**
Internal Barriers	White	10	74.50	1	0.01	0.93
	Non-White	4	30.50			
External Barriers	White	10	88.00	1	3.45	0.06
	Non-White	4	17.00			
	Sex	**Observations**	**Mean Rank**	**df**	**x^2**	**p-value**
Internal Barriers	Male	6	53.50	1	1.90	0.17
	Female	8	51.50			
External Barriers	Male	6	44.50	1	0.00	0.95
	Female	8	60.50			
Total sample: N = 14 CHD: congenital heart disease						

4.4 Discussion

This study determined barriers to exercise in children with CHD, and is the first study examining the relationship between CHD severity and perceived barriers to exercise in this population. The top barriers reported in this sample were external barriers (i.e., poor weather and chosen last for teams) and a non-subscale barrier of low energy. There was no statistical evidence found to support a relationship between CHD severity and a child's perceived barriers to exercise. These results suggest a better tool is needed to assess barriers for children with CHD.

The PB-MVPA is currently the only self-reported tool validated to assess barriers to exercise for children, which is why it was chosen for this study [72]. External barriers and the four barriers not included in the subscales had higher mean scores in the study population than the internal barrier items. This is consistent with previous research which also found external barriers, like weather, are common barriers in younger, typically developing children (7-9 years old) [19]. In contrast, typically developing adolescents (over 10 years old) generally have higher internal barriers as mentioned in Gunnell et al. where the PB-MVPA survey was validated [72]. Future studies need to revalidate the PB-MVPA with children with CHD to make stronger conclusions and/or determine the need to create a new scale. A validated scale used for children with CHD would be a helpful tool for practitioners to use within a treatment plan for these children because their individual barriers could be addressed.

One of the highest-ranked barriers, not having enough energy, was one of the barriers not reported in a subscale in the final version of the instrument [72]. Gunnell et al.'s confirmatory factor analysis in the original validation study indicated not to include the 'no energy' barrier because it was not consistent with the rest of the items in the scale[72]. This should be considered when validating the PB-MVPA in children with CHD. It may fit this population better if there were no subgroups, internal and external, and each barrier was examined individually. These scales were utilized in the data analysis to maintain consistency with the original survey validation. With little similar literature, it is helpful to look at studies that utilized other surveys in this population.

Using the Pediatric Quality of Life Inventory (PedsQL), studies have shown measures of physical health vary by CHD severity [85,86]. One section of the PedsQL specifically asks about physical function, including statements like “it’s hard for me to run,” “it’s hard for me to do sports activity or exercise,” and “I have low energy.” There is evidence that children with CHD have decreased exercise capacity, but the PedsQL questions do not ask specifically about barriers to participating in exercise [65]. The physical function section of the PedsQL also has shown statistically significant differences by CHD severity group in past research [87]. It is not certain if the difference in results with the current study is due to small sample size or real lack of effect in this sample. This reinforces the need for a better tool for measuring exercise barriers in this population in addition to a larger sample size.

4.4.1 Scale Reliability

Utilizing Cronbach’s alpha, the internal consistency of the PB-MVPA scale in this study was acceptable, 0.72 and 0.77 for internal and external barriers respectively. Scientific literature generally supports a Cronbach’s alpha of 0.7 or higher as acceptable [88]. When the four non-scale items were included in their proposed subscale, higher reliability was observed (i.e., 0.84 for internal and 0.77 for external). Gunnell et al. reported higher reliability with those items included but chose to exclude them from subscales based on goodness of fit as determined by confirmatory factor analysis [72]. This result demonstrates reliability, but not the validity of the scale. Again, validity should be tested in a future study for the PB-MVPA in children with CHD.

4.4.2 Important Findings

Results of this study indicate intervention to address barriers to exercise for children with CHD should target external factors, such as access to exercise equipment, weather-appropriate areas to exercise, or more equitable ways to engage kids in team-based physical activity. Previous literature has shown that for children with CHD, beliefs towards physical activity are not a limiting factor to participating in exercise [71]. Therefore, this study agrees that internal thoughts are not as much of a barrier as external factors. The most common barrier reported was bad weather, further supporting this point. Practitioners and public health professionals should use this and other studies to demonstrate the need for more accessible exercise facilities and the need for more exercise in schools.

Another relevant finding is the need for interventions that take into account the low energy levels in children with CHD. As mentioned previously, this factor is not considered internal or external, but it does play a key role in exercise behaviors [72]. Literature supports that the ‘no energy’ barrier plays an important role in people with CHD pertaining to exercise participation; adults with CHD mention low energy being a barrier for them to exercise regularly [29]. This is reiterated in multiple studies utilizing the PedsQL in children and adolescents with CHD [86,89,90]. Regular exercise is known to increase energy levels and decrease fatigue [91]. Creating exercise opportunities for children with CHD may also help address this barrier.

When creating interventions for children with CHD, it is helpful to know that disease severity may not play a role as demonstrated by these results. With no significant differences between groups, addressing barriers overall is appropriate rather than creating specific interventions for different severities. This is the same for all other demographic factors in this study, including race, sex, and age.

4.4.3 Limitations and Future Research

The primary limitation to this study was sample size. This was unfortunately due to lack of response to recruitment and missing data points. Next steps in this research should also include performing a confirmatory factor analysis to assess differences in model fit as well as revalidation of the survey in this population. Lastly, the creation of a new survey to assess exercise barriers should be considered. A new survey could target children with CHD specifically, or children with any chronic disease.

4.5 Conclusion

The findings of this study suggest that other factors beyond CHD severity may play a more substantial role in influencing perceived barriers to exercise in this population. These factors likely stem from a child's environment and accessibility as noted by the participants of this study. Further research with larger sample sizes and a broader range of variables is warranted to better understand the complex interplay between CHD severity and barriers to exercise. There is also evidence presented to support creating a new scale and/or combining current scales like the PedsQL and PB-MVPA to better address the perceived barriers to physical activity experienced by children with CHD.

This area of literature is sparse, and while the sample included in this study is small, new doors of future research are opened by the presented findings. This study begins the exploration of a wide variety of barriers in the children with CHD population, who could benefit greatly from targeted intervention. Invested care partners, like healthcare providers and guardians of these children can utilize this information to inform potential interventions targeting barriers to exercise for children with CHD.

CHAPTER FIVE
CONCLUSION

Children with CHD deserve the ability and confidence to participate in regular exercise like their peers. These studies give ideas of how exercise and medical professionals can close the research gaps that currently exist for these children. First, children can benefit from cardiac rehabilitation the same as adults with heart disease, but creativity in exercise prescription is necessary. Aerobic dance in children from five to 10 years old meets guidelines for cardiac rehabilitation as a moderate intensity modality of exercise. Future research should randomize a similar methodology with two groups, children with CHD and their age-matched peers. This study also shows the ability to research other alternative exercise modalities that could be more exiting and engaging for children.

An important finding of the second study was the frequency of reporting low energy as an exercise barrier for this population. Low energy level has been found in many other studies involving people with CHD. This confirms that energy specifically influences children with CHD and their activity. Regular exercise can aid in increasing energy level per previous studies. In addition to energy level, barriers from external factors are most frequently reported by children with CHD. Future interventions to increase exercise participation should begin by addressing external rather than internal factors. There is also evidence from this study that a new survey assessing barriers to regular exercise for populations other than healthy children may be warranted.

There is great evidence to support the importance of pediatric cardiac rehabilitation programs both in the second study here and in extensive previous literature.

Cardiac rehabilitation programmed towards children will address many of the barriers identified by creating a safe and reliable place to exercise. They will benefit from exercise prescriptions that offer variety and fun while being monitored by professionals. Pediatric cardiac rehabilitation programs are growing but are still sparce in the United States. Continuing research in this area can help them continue to expand throughout the country, including in Michigan.

APPENDIX A
IRB Letter 1

OAKLAND UNIVERSITY

Institutional Review Board

Date: April 3, 2023

Study #: IRB-FY2023-70

Study Tile: Identifying Barriers to Regular Exercise for Children with Congenital Heart Disease

Submission Type: Initial

IRB Decision: Approved

Research Team:

Based on applicable federal regulations, the above referenced study has been determined to involve no more than minimal risk to participants and to be Approved, with the following expedited categories:

7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Letter and Consent Documents:

This letter along with the two IRB approved (date-stamped) consent documents can be found in Cayuse in the Submission Details page under Letters and Attachments, respectively.

The IRB approved version of the consent documents must be used in consenting participants. Federal regulations require that each participant receive a copy of the consent document unless a waiver is granted by the IRB. Signed consent forms must be retained for a minimum of three years after the completion of the project. Please remember that informed consent is a process that continues throughout the project, starting with recruitment and assurance of participant understanding of the project, and followed by a signed consent form when applicable.

Permission from Research Sites:

Please note the following:

- This IRB approval letter means that the research has met the federal criteria for approval per 45 CFR 46.111 Criteria for IRB Approval of Research
- Before the research is initiated, permission to conduct research at a given site must be obtained from all research locations listed in the IRB submission. You must keep copies of all such permission letters for your records.
    - It is the responsibility of each researcher to follow all applicable policies and procedures of any outside institution where the research will be conducted.

Modifications:

Any changes to the approved project must be approved by the IRB prior to initiation by submitting a MODIFICATION request. Do not collect data while the changes are being reviewed. Data collected during this time cannot be used in research.

Incidents:

All unanticipated problems involving risks to participants or others, serious and unexpected adverse events,

non-compliance issues and/or serious complaints regarding this project must be reported promptly to the IRB by submitting an INCIDENT report.

You are approved to start the research. Please retain a copy of this

notification for your records. If you have any questions, please

contact the IRB office.

Thank you.

The Oakland University IRB

APPENDIX B
IRB Letter 2

Institutional Review Board

Date: October 30, 2024

Study #: IRB-FY2025-157

Study Tile: Heart Rate Response of Elementary Children During Aerobic Dance: A Pilot Study

Submission Type: Initial

IRB Decision: No Human Subjects Research

The above referenced study has been has been determined to be No Human Subjects Research according to federal regulations.

The IRB decision is based on the following:

Research Using De-identified Private Information. The project is limited to the use of existing and/or prospectively collected de-identified private information that meets ALL of the following criteria:

1. The private information was not collected/is not being collected specifically for the currently proposed research through an intervention or interaction with living individuals; and

2. The use of private information in this project is not in violation of the terms under which the private information was originally collected; and

3. The research team will only receive information that is fully de-identified. "De-identified" means that: (i) The identity of the individual cannot be readily

ascertained from the information available to the research team; or (ii) The information available to the research team does not include any of the 18 identifiers defined in the HIPAA Privacy Rule; and (iii) De- identified data cannot be linked back to individuals directly or through coding systems; and

4. The records/images/charts that are being collected for this project are NOT from individuals who are or who will become recipients of an FDA-regulated product or act as a control as directed by a research protocol and not by medical practice, whose results are to be submitted to the FDA or held for inspection by the FDA.

Please retain a copy of this correspondence for your records. If you have any

questions, please contact the IRB staff.

Thank you.

The Oakland University IRB

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