

I. Background

Evidence-Based Aquatic Therapy for Functional Mobility

The use of aquatic therapy for supporting motor function in boys with Duchenne Muscular Dystrophy (DMD) is highly supported throughout the literature. Ferreira et al evaluated the motor performance of individuals with DMD on ground and in water for two years¹. Researchers observed maintenance in the performance of aquatic activities, but worsening of ground-based activities, reporting that the aquatic environment promotes the maintenance of active movement and supports independence for a longer period¹. Hind et al discovered that the addition of aquatic therapy two times a week produced greater maintenance of North Star Ambulatory Assessment scores (NSAA) than land-based physical therapy alone². Both caregivers and participants reported greater improvements in quality of life and conveyed the value of aquatic therapy². The specific interventions utilized included swimming, jumping, gait direct activities, passive stretching, lower extremity strengthening, and transfer training². A scoping review of twenty studies by Lima et al concluded that aquatic sessions of 45-60 minutes, two times a week, for at least six weeks fosters the greatest effectiveness³. The participants in this study ranged from five to twenty-two years of age and were able to tolerate immersion to at least the xiphoid process in an average water temperature of 37.2°C³. The specific activities utilized to promote motor function included active and passive stretching, trunk control, gait, balance, jumping, underwater running, swimming, transfer training, and wheelchair handling³. Aquatic therapy in boys with DMD has also been indicated to decrease BMI and percent body fat; making mobility and functional activities easier for the individual⁴. These changes have been correlated to benefit level

of ADL function and improved mobility⁴. Honorio et al demonstrated that through aquatic therapy consisting of modified swimming with assisted movement, paddle boards, or weighted vests/mobilization devices, boys with DMD could experience a decline in body mass index and percent body fat⁴. Results demonstrated positive trends in maintenance of the functional skills examined as compared to control subjects who did not receive aquatic-based treatment⁴. Amtamturk showcased the holistic impact of aquatic exercise⁵. This study indicated that aquatic therapy is not only safe, but extremely beneficial for emotional, social, and psychological health⁵. Aquatic therapy fosters social interaction, and promotes improved quality of life for both participants and caregivers⁵. Caregivers reported that aquatic therapy gave their son more purpose because he was able to complete a variety of activities in the water that he could not perform on land⁵.

Evidence-Based Aquatic Therapy for Respiratory Muscle Function

Traditional therapy includes using specific inspiratory muscle training that has been indicated to increase respiratory muscle function for adolescents with DMD^{6,7}. There has recently been emerging evidence supporting the use of aquatic therapy programs to improve lung function in this population. Literature indicates working with children during the earlier stages of the disease progression (before respiratory muscles have been critically affected and lung function has been compromised) can contribute to both direct improvements in lung function and prolonged periods of maintenance as the disease progresses^{6,7}. Adams et al cites that the goal should be to introduce these children to the pool and begin building inspiratory muscle strength before the inspiratory muscles are not able to overcome the impact of the hydrostatic pressure, while allowing the participants to reap further benefits from aquatic therapy⁶. In assessing the impact

of aquatic therapy on respiratory function in three boys under the age of thirteen who did not have significant pulmonary compromise, Adams et al demonstrated clinically meaningful change in one of the three participants in chest measurement, positive trends in two of the three in peak flow rate, and clinically meaningful change in all three participants in quality of life measurements⁶. Further, all qualitative comments from participants and families were positive, expressing a desire to continue with the aquatic therapy program⁶. It is important to note the one participant that produced clinically significant results attended every session while the other two participants both missed four out of the nine sessions due to a variety of complications⁶. The interventions utilized throughout this study included swimming laps, tall kneeling on the mat, diving for objects, holding breath underwater, and blowing a ball across the surface of the water⁶. Through an aquatic therapy program that targeted trunk, upper and lower limb control, breathing exercises, and dynamic exercises that focused on respiratory rate as the primary tool for measuring exertion, Voos et al demonstrated a positive effect in timed immersion expiration and forced vital capacity rates not only at the conclusion of the program, but also in a one-year study follow-up⁷. Literature indicates that pulmonary function begins to significantly decrease once restriction to a wheelchair occurs; however, Silva et al was able to exhibit how aquatic therapy can improve oxygen saturation and inspiratory maximal pressure in a non-ambulatory boy with DMD through 10, 60-minute aquatic therapy sessions⁸. Inspiratory muscle weakness is a major component found in DMD⁶⁻⁸. Hydrostatic pressure leads to alterations in respiratory mechanics, increasing respiratory rate. While immersion may be challenging for boys

with DMD, it can also be utilized for respiratory training and rehabilitation, improving muscular strength and endurance⁶⁻⁸.

Evidence-Based Interventions in Context with the Social Ecological Model

Children are more likely to engage in activity if it something that involves social interaction and if they believe they will enjoy the activity⁹. Consideration of the Social Ecological Model (SEM) can assist a community-based program by considering the multiple levels that influence health behavior, including intrapersonal, interpersonal, organizational, community, and public policy, and by identifying and alleviating potential barriers to exercise⁹. Potential barriers to participation include activities that might not foster accommodations, fear of injury, peer acceptance, lack of pool access and transportation, time and financial restrictions, and mobility into and out of the aquatic center^{2,8-10}. Ensuring the program is targeted and tailored to this specific population in a manner that offers modifications for all levels, insures safety, provides accommodations for pool accessibility, fosters an environment where boys can relate to one another, and is rooted in the community will help eliminate these potential barriers⁹. This program will also attempt to limit further barriers by serving as an after-school option where transportation is provided and is a subsidized program that is advertised around the community. Implementing the framework of both the Health Belief Model (HBM) and SEM, the perceived health benefit of participation in community-based aquatic therapy program is believed to be both extensive and widespread, focusing on the intrapersonal and interpersonal factors affecting both the child and their caregiver system⁹.

Evidence-Based Outcome Measures

The American Academy of Pediatric Physical Therapy outlines how various outcome measures need to be implemented to track the progression and characterization of DMD in patients throughout physical therapy¹⁰. Literature indicates the use of the Pediatric Quality of Life Inventory assess health-related quality of life as well as the Functional Independence Measure for Children (for any state of the disease progression)^{11,12}. The North Star Ambulatory Assessment (NSAA) is specifically designed for ambulant children with DMD and includes 17 items that are relevant to this cohort¹³. Mazzone et al demonstrated excellent inter- and intra-tester reliability (.995 and .950 respectively) and concluded that the NSAA can be easily performed and completed in 10 minutes¹⁴. The NSAA is able to detect differences in corticosteroid regimens while marking ambulation improvements in younger males (positive mean change scores) and taking into account the significant decrease in functional mobility around 10 years of age^{13,14}. The minimal important difference (MID) has been demonstrated to be 6.9 points on the NSAA scale; however, the clinical course of the disease must be taken into consideration when assessing impact of treatment^{13,14}.

Sheehan et al cites that at age five, boys should start assuming regular measurements of forced vital capacity (FVC) to allow for assessment of pulmonary function over time¹⁵. In conjunction to aquatics, Adams et al argues that chest expansion, peak flow, and inspiratory capacity should be measured as respiratory interventions have been cited to produce change and these particular values decline significantly in DMD⁶. Silva et al furthers this concept by also adding that respiratory rate and peak cough flow should be added to program outcome measures. When

measuring respiratory values, boys should also assume the same immersion point in the water, commonly cited throughout literature as the xiphoid process⁸.

II. Program Goals

Improvement of Participant Health Status

The primary goal of the community-based program, “DMD: Come Swim with Me,” is to improve the overall health status of elementary and middle school-aged boys with Duchene Muscular Dystrophy (DMD). This program will offer both holistic education and evidence-based interventions in an accessible, community-centered way to improve the physical, respiratory, and overall quality of life in boys with DMD. This program aims to equip both the boys and their families with the tools needed to continue on in a lifelong commitment to creative and fun ways to achieve physical activity and promote a healthy lifestyle. Due to the progressive nature of the condition, one primary goal will focus on maintenance of both functional mobility and respiratory measurements; however, the program will also seek to improve both of these skills as outlined below. The program will last for a total of fifteen weeks and at the completion of the program, it is the aim that each child will be able to achieve the following goals.

Program Goals (using the SMART outline)

1. Program participants will improve their North Star Ambulatory Assessment (NSAA) scores by 6.9 in accordance to the minimal importance difference to improve functional mobility and ability to independently participate in activities of daily living within fifteen weeks^{13,14}.
2. Program participants will report at least a 4.4 point change on the PedsQL 4.0 (Pediatric Quality of Life self-report measure) to indicate the minimally clinically

important difference (MCID) for improved health-related quality of life in fifteen weeks^{10,16}.

3. Program participants will demonstrate a positive trend of forced vital capacity (FVC) throughout the fifteen week program to demonstrate an improvement in lung function during a period of time when respiratory function typically decreases or plateaus^{15,17,18}.
4. Program participants will demonstrate the ability to independently ambulate throughout the pool (25 feet) when submersed to the xiphoid process to promote independent functional mobility and the ability to continue with aquatic exercise upon completion of the program at the fifteen week mark^{1,2,5-9}.

III. Methods for Implementation

Who

This program is designed for boys with DMD who are 8 to 14 years of age. Boys of all levels who fall within this age range will qualify; however, the program is specifically designed for boys who are still able to ambulate (at least five feet) with assistance¹⁹. The program will operate on a 1:1 ratio of participants to program volunteers to insure safety and maintain quality standards^{2,19}. Each participant will be required to have medical clearance from a physician as well as a current physical in order to participate. Enrollment in the program will function on a first come first serve basis and capacity will be set on the number of volunteers available. The program will be advertised through local schools, community centers, and medical facilities (primary care offices and physical therapy clinics). Due to the rarity of this condition, the

program is designed for 4 to 8 participants, but if needed and volunteer number allows, can be expanded to reach more participants.

This program will be coordinated and led by trained physical therapists who volunteer their time and will be set on a rotating schedule, having one primary lead for each session. Then, additional trained program volunteers will be utilized to achieve the 1:1 ratio. Each volunteer will be trained in how to best assist the participants through each intervention and how to maintain safety at all times. Licensed physical therapists will lead each session and implement all interventions. All participants will participate in program interventions at the same time as to further promote socialization, sense of community, and increase acceptance/friendships among participants⁹. This will help address the barriers defined through the social ecological model such as peer acceptance and help foster interpersonal, intrapersonal, and community-based relationships^{9,10}. All personnel will be volunteers and both word of mouth and flyers will be used for recruitment. Local healthcare facilities, community-buildings, and colleges will be targeted locations for flyers and recruitment. Licensed physical therapists will complete all entry testing, follow-up measures, and final outcome measure assessments throughout the length of the program. If needed, all exercises will be modified to fit the activity level of each participant.

What

This program will consist of planned programming two days a weeks (Monday and Thursday) for fifteen weeks. Literature indicates the need for both aerobic and anerobic conditioning for DMD; however, rest and recovery is equally important and must be prioritized^{2-4,16}. Due to this concept, only two sessions each week will be

implemented to allow for adequate rest time in between. Each session will incorporate both evidence-based interventions: functional mobility and respiratory function. Each session will be built around the parameters outlined in the chart below. Each session will begin with a warm-up and then transition into activities based around functional mobility, aimed at consisting of 40 to 45 minutes of activity. The last 15 to 20 minutes will then be focused on respiratory care and addressing respiratory functioning, followed by a five minute cool down. The total treatment time will be around 65 minutes per a session. Fatigue levels will be actively monitored throughout each session, and if participants ever report a greater than 5 out of 10, all exercise will be immediately terminated^{1,5}. Further, every ten minutes, participants will take a short rest break from activity as to help diminish and prevent fatigue^{1,5}. All sessions will take place in a 34 degree Celsius pool that offers adaptable/handicap stairs, a ramp, and a lift system. All equipment needed such as kick boards, weights, pool noodles, and more will be provided at the facility. Each session will present varied activities as decided upon by the lead physical therapists, but all session will be outlined from the chart below. As mentioned above, sessions will take place on Monday and Thursday. Participants are encouraged to commit to attending every session throughout the fifteen week period, but program leaders understand that issues and further commitments may arise. At the end of the fifteen weeks, the program will be reevaluated and if enough interest persists, will be continued for further rounds. Attendance for a second round will be first opened to other individuals in the community, but if there is available room, then current participants will be allowed to enroll in a second course.

10-Minute Warm-up	
<p>40-minutes of Functional Mobility¹⁻⁵</p> <p>Divided into sections based on transitional movements, strengthening, stretching, walking, kicking, balance, and equipment management/movement</p> <p>Multiple rest breaks taken throughout</p>	<p>Stretching, underwater weights, backwards walking, swimming with paddleboard, tossing weighted ball, movement into and out of pool, tall kneeling on mat, stair navigation if possible underwater, marching, stepping, assisted swimming, further strengthening, and more</p>
<p>20-minutes of Respiratory Function Training⁶⁻⁸</p> <p>Divided into section based on breathing exercises, trunk control, upper and lower limb control, and dynamic exercises for respiratory management</p> <p>Multiple rest breaks taken throughout</p>	<p>Diving for objects, holding breath underwater for various intervals, blowing ball across water surface, obstacle course, increase chest expansion with moving paddles outwards in the water, blowing bubbles from wand, and more</p>
5-Minute Cool Down	

When

Each session will take place immediately following the end of the school day to help eliminate potential barriers including lack of transportation^{9,10}. As participants will need time to ride the provided bus from their elementary and middle schools, the

program will begin at 3:30 and last till 4:35. Program volunteers will be available beginning at 3:15 to help participants change clothes and greet any participants who opt for personal transportation. The program will take place on Monday and Thursday afternoon, which exceptions being made for holidays, teacher work days, and any major conflicts.

Where

This program will take place at Lenox Baker Children's Hospital in Durham, NC²⁰. This location was chosen as it offers many equipment options, is easily accessible, and due to the idea that many children may already use this facility if they receive school-based physical therapy through Chapel Hill City Schools²¹. Through this designed community partnership, program participants will have access to the pool during the designated time slot and will receive a discounted rate for pool membership beyond program hours. To further address the potential SEM barriers of financial limitations, restricted opportunity, or lack of community involvement, all cost of participation will be subsidized by various community sponsors and donors⁹.

How

One large barrier the SEM presents is the lack of transportation⁹. This program will help address this potential issue by offering free transportation from local elementary and middle schools to Lenox Baker. This will also allow the program to increase community and intrapersonal involvement while decreasing further barriers such as lack of opportunity, time or financial limitations, and the inconvenience transportation may present for a family⁹. If a family does wish to provide personal transportation, this will be allowed and the family members will be able to wait at the

facility while the program is taking place. This will also allow the program to reach participants who may not attend local public schools and further increase involvement.

The program is planned to begin at the start of the year when schools return in January. This timing was selected because it is believed that physical activity, especially aquatic based participation may decrease throughout the winter months as less individuals have access to indoor facilities²². Program enrollment will take place from the start of the school year and continue throughout January 1st. Caregivers may register participants online or at the facility. Once enrolled, participants must present medical clearance from their primary care provider as well as provide an up to date physical. The first session will consist of each participant completing initial outcome assessments. This will include the Pediatric Quality of Life Measure (PedQL), North Star Ambulatory Assessment (NSAA), and Forced Vital Capacity Screening (FVC)^{6,7,8-11,13-15}. Height and weight will also be recorded during this initial evaluation and at the end of the first session, participants will learn how to safely enter and exit the pool (with support provided as needed). Fatigue level scored on a 0-10 scale will also be recorded at the beginning and end of each session. All equipment needed for evaluation will be located at the facility. After initial assessment, each outcome measure will then be repeated during the eight week of the program and then again at the end of the program. Each participant will be provided with information from their assessments and lead physical therapists will provide information as to what each assessment and correlated values showcase.

One further potential barrier created by an aquatic-based program is the inability to swim⁹. Due to the 1:1 ratio the program provides and the types of activities that will

take place in shallow water, participants do not have to have a history of swimming; however, it will be strongly encouraged that participants feel comfortable around water. The first session will also be designed to help acclimate participants to the water. Floatation devices and life jackets will be provided for every patient. A lifeguard will be on duty at all times as well as further medical staff will be present throughout Lenox Baker if needed.

IV. Program Evaluation

Outcome Measures

In order to evaluate the effectiveness of the program, outcome measure assessments will be calculated and published to show participant progression throughout the program. Goals attainment will be evaluated for each individual participant and these values will be evaluated to demonstrate the effectiveness of the program. While it will be the goal of the program for each individual participant to achieve the outlined goals, due to the nature of DMD, the program will be considered a success if each participant progresses or maintains initial functional mobility and respiratory function¹⁻⁵. Further, the program will be evaluated on each participant reporting an increase in PedsQL scores as well as qualitative feedback from both participants and caregivers^{11,16}. Outcome measure progression from initial, middle, and end points of the program as well as goal attainment and qualitative reports will all be used to evaluate the effectiveness of the program and published for further evidence-based practice.

To further evaluate the quality of the program and participant satisfaction, each family will be given a survey to take upon completion of the program. These surveys

will be used to obtain data about what went well, what factors may need to be altered, how each family felt about the effectiveness of the program, and to see if the participant plans to continue with aquatic activity upon program completion. Further questions will also be utilized to assess opinions as to the transportation system, schedule, safety, quality of care provided by volunteers, social opportunities provided, fatigue levels of participants following each session, and overall enjoyment. Surveys will be conducted at both the 8-week halfway point (in conjunction with outcome measure assessment) and again at the end of the study. Survey results at the 8-week mark will be used to improve the study for the remaining time.

Board of Directors Committee

In conjunction with the CDC framework for program evaluation, the program will form a committee to ensure program quality and commitment to providing topnotch evidence-based practice²³. This committee will be charged with the task of continually evaluating the program and assessing for opportunities to make improvements. They will also be asked to consider all stakeholders involved and to make as many community resources and partnerships as possible²³. The program aims to provide the highest level of evidence and community-based care as possible, and the Board of Directors will help to ensure the program remains transparent regarding predicted outcomes and comprehensive goal achievement²³. With the help and support of the Board of Directors, the program will be committed to continual evaluation and advancement, optimizing the level of care provided to boys in the community with Duchene Muscular Dystrophy.

V. Conclusion

“DMD: Come Swim with Me” attempts to offer boys in the local community an avenue for fun, effective, and safe physical activity that provides them with opportunities not afforded on land. A community-based program that is focused on promoting and improving the physical, respiratory, and social health of children with Duchene Muscular Dystrophy is pertinent in order to address quality of life for these children. This evidence-based program will target an age group where boys with DMD typically start to lose or plateau in functional mobility, which can ultimately impact their peer to peer socialization and possibly increase both physical and mental isolation²⁴⁻²⁷. Through targeting physical activity, healthy behaviors, and social interaction, this program will help address multiple levels of the SEM and help alleviate potential barriers such as peer acceptance, pool access, transportation, time, and financial restrictions^{9,34-27}. This program is tailored to fit this specific population by fostering an environment where participants can relate to one another and through offering perceived health benefits that implement the Health Belief Model and focus on the intrapersonal, interpersonal, and community levels of the SEM⁹. Furthermore, this program seeks to foster an environment that promotes the continuation of aquatic activity for boys with DMD even after the program ends. This program will allow boys with Duchene Muscular Dystrophy opportunities they may not have access to otherwise. “DMD: Come Swim with Me” is a program that offers children in the local community an experience that can benefit and positively impact their lives forever.

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