

**Therapeutic Riding and Adaptive Yoga as a Focus of Adaptive Sports Participation for
Individuals with Upper Limb Absence (ULA)**

A Doctoral Experiential Capstone Project Presented to the Faculty
of Western New England University in Partial Fulfillment of
the Requirements for the
Entry-Level Doctorate
in
Occupational Therapy

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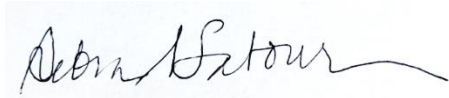
Therapeutic Riding and Adaptive Yoga as a Focus of Adaptive Sports Participation for
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A Doctoral Experiential Capstone Project

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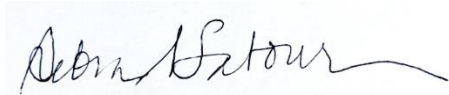


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Abstract

Upper limb absence (ULA) can be attributed to congenital differences or acquired as a result of traumatic injury, or related to a medical condition such as cancer. This may also have an effect on an individual's activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Latour, 2022). Individuals with ULA remaining active through sports participation can lead to enhanced wellbeing and quality of life (Webster et al., 2001). Sports participation grants the opportunity of socializing with peers while also improving motor coordination, strength, endurance and balance (Bragaru et al., 2011; Webster et al., 2001). A prominent gap in care was the lack of psychosocial interventions, specifically concerning wellbeing (Latour, 2019). Three doctorate of occupational therapy students from Western New England University (WNEU) created a virtual-based adaptive sports program for individuals with ULA to address this. The goal of the program was to enhance the well-being and independence of individuals 18 years of age or older with ULA. The study specifically, the adaptive sports include functional fitness training, adaptive yoga and cross-over function with diverse prosthetic technologies. Effectiveness of the program was determined through the use of pre-surveys, post-surveys, an initial focus group, and a final focus group. A participant satisfaction survey was also administered to gain participant feedback. Following program completion, the results demonstrated an improvement in the participant's well-being and independence in their daily lives. Further research should address the limitations of the program to improve reliability and validity.

Keywords: upper limb absence (s) (ULA), Doctoral Experiential (DEx), education, adaptive sports

Introduction/Background

Purpose

The purpose of this Doctoral Experiential Capstone Project (DEx) is to design and implement a community experiential and a scholarly project that meets the needs of a specific population and setting (WNEU, 2022). Following the completion of didactic coursework and level II fieldwork, student apply their acquired skills in order to complete a 14-week project under the advisement of their faculty mentor (WNEU, 2022). The intent is to teach students to grow as a future practitioner, leader, and professional (WNEU, 2022).

The goal behind this specific project was to expand the Unlimbited Wellness© program developed by Debra Latour, PP-OTD, M. Ed., OTR/L. The Unlimbited Wellness© program educates and empowers individuals with ULA. This extension of the Unlimbited Wellness© program focuses on adaptive sports participation of individuals with ULA. One aspect of the project is to create virtual-based educational and instructional modules focusing on adaptive sports for the ULA population. The modules include functional fitness videos, adaptive yoga videos and cross-over function featuring diverse prosthetic technologies. In addition to the video modules, an Unlimbited Wellness© resource guide was developed in summation of the virtual-based adaptive sports program. Another aspect of the project involved developing a groundwork program that caters to individuals with ULA in preparation for therapeutic horseback riding. This DEx Capstone project aims to engage individuals with Upper Limb Absence (ULA) in adaptive sports to increase their overall independence and well-being.

Theoretical Framework

The Model of Human Occupation (MOHO) will also be utilized to develop a greater understanding of each individual's occupations or activities of interest and how they interact

with their environment (Wook Lee et al., 2012). This model will allow us to build rapport with the participants during the focus groups and discussion, which may allow for the participants to be more invested in the program. This supports our plan to use our program to not only have an improvement in physical fitness but also sense of an improved sense of self concept, quality of life and make a true connection with their peers.

Literature Review

Overview of Population.

In the United States, there are about two million individuals who have limb loss/absence. About 35% of those individual's experience Upper Limb Absence(s) (ULA) due to acquired or congenital factors (Ziegler-Graham et al., 2008). Acquired limb loss can occur when the limb is amputated as a result of vascular diseases such as diabetes, trauma, or cancer. Congenital limb loss is present at birth, often with no one exact cause (Orthoinfo, 2020; Hangar Clinic, 2022). The upper extremities are crucial for activities of daily living and instrumental activities of daily living and can affect an individual's daily occupations (Ostlie et al., 2011).

Gaps in care for individuals with ULA are present due to the lack of professionals who are equipped to serve the population and regarding psychosocial interventions, specifically concerning wellbeing (Latour, 2019; Latour, 2022). Involvement in sports and recreational activities is particularly crucial because it provides the opportunity to develop motor skills, socialize with peers and adjust to differences in physical abilities (Blauwet et al., 2016; Webster et al., 2001). Generally, sports participation has the potential to improve both physical and mental fitness. There is a strong positive association between an individual consistently participating in physical activity, for overall health, and psychosocial wellbeing (Chinn, 2019). In the same sense, individuals with ULA remaining active through sports participation can lead

to enhanced wellbeing and quality of life (Bragaru et al., 2011; Webster et al., 2001). An in-depth literature review for this project can be found in Appendix A

Identification of Target Population

According to the Amputee Coalition, there are about 1.9 million people who have experienced limb loss currently residing in the United States (Amputee Coalition, 2019). The target population for this project is individuals with upper limb absence aged over 18 years old. That includes both individuals that utilize prosthetic devices and individuals that do not. The existing data and research is limited for this population. Upper limb absence (ULA) is commonly a result of traumatic injury, followed by congenital differences or acquired due to a medical condition such as diabetes or cancer (Fletcher, 2016). Congenital ULA makes up about 4.1 per 10000 live births. Upper limb amputations occur at a 1:4 ratios to lower limb amputation (ISHN, 2014). ULA can occur at any level particularly if it is due to trauma e.g. above (transhumeral) or below the elbow (transradial), partial hand (transcarpal), an elbow disarticulation or shoulder disarticulation etc. (Fletcher, 2016).

Resource Availability and Barriers of Identified Problem

Currently, there are several available resources for individuals with limb loss but not necessarily ones that cater specifically to upper limb absence. Even fewer resources address adaptive sports participation for the population. Potential barriers to participation in these prevention programs could include limited time to participate, and being a part of a small distinct population. The time that this program requires could interfere with the other many demands of daily life e.g. work, school, and childcare. This program requires consistency, and need enough time to thoroughly educate the participants and monitor their progress. Forming a program for a specific population such as individuals with upper limb loss can be difficult because of how

small the population is. Since the population is, small there will most certainly be a limited number of people that are able to participate. *Table 1* includes organizations that provide support and resources for individuals who have experienced limb loss e.g. connections to support groups or other beneficial programs, information on prosthetics, referrals to relevant healthcare providers, etc. Appendix B details the comprehensive needs assessment for the identified target population.

Table 1

Resources for ULA

Organization	Mission and Vision
The Amputee Coalition	<ul style="list-style-type: none"> • To empower individuals who have experienced limb loss to reach their greatest potential through advocacy, education, and awareness • Provides access to National Limb Loss Resource Center and numerous support groups/peer support
The Handsmart Group	<ul style="list-style-type: none"> • To support and empower people world-wide by creating and updating open access, easily understandable consensus resource based on evidence, for those engaged in upper limb loss/difference rehabilitation. • To provide the most holistic rehabilitation approach for every person with upper limb loss or upper limb difference, now and in the future
Handspring Clinical Services	<ul style="list-style-type: none"> • To provide a holistic approach for individuals in need of prosthetic rehabilitation.
TRS Inc. (Therapeutic Recreational Services)	<ul style="list-style-type: none"> • To provide high-quality technology for persons missing a hand(s).

Enhancing Skills for Life	<ul style="list-style-type: none"> • To educate, empower and connect those living with bilateral upper limb loss.
	<ul style="list-style-type: none"> • to financially support individuals missing at least both arms to attend the Skills for Life: Bilateral Upper Limb Loss Workshop with minimal to no cost to them.
Limbs for Life	<ul style="list-style-type: none"> • To provide fully-functional prosthetic care for individuals who cannot otherwise afford it and raise awareness of the challenges facing amputees.
American Board for Certification, O & P	<ul style="list-style-type: none"> • To establish and advocate for the highest patient care and organizational standards in the provision of safe and effective orthotic, prosthetic, and services.
NubAbility	<ul style="list-style-type: none"> • To encourage, and immerse limb different youth into mainstream sports, while also offering mentorship.
Lucky Fin Project	<ul style="list-style-type: none"> • Creates a support network for parents across the U.S. and around the world • Links parents to medical information and resources. • Provides education on limb differences. • Financially support efforts for children to attend specialized camps, obtain prosthetics, and fund other organizations within the limb different communities.

Doctoral Project Overview

Overview of Project

The overarching purpose of the DEx project is to engage individuals with Upper Limb Absence (ULA) and related conditions in adaptive sports to increase their overall independence

and well-being. The project was intended to expand on the *Unlimbited* Wellness program developed by Debra Latour, PP-OTD, M. Ed., OTR/L. The *Unlimbited* Wellness program aims to educate and empowers individuals with ULA (Latour, 2019). This extension of the *Unlimbited* Wellness program focuses on adaptive sports participation of individuals with ULA. It involves the use of virtual-based educational and instructional modules that include functional fitness videos, adaptive yoga videos and cross-over function featuring diverse prosthetic technologies. As a part of this project, researchers partnered with Handspring Clinical Services, an organization that provides a holistic approach for individuals in need of prosthetic rehabilitation (Handspring, 2022). With the support of *Unlimbited* Wellness, Handspring provided the necessary resources for program development including access to client database, YouTube channel and a clinical consultant. Amy Ginsburg served as the site mentor and consultant for Handspring Clinical Services. She was responsible for recruiting participants for this DEX project.

The virtual-based adaptive sports program was held in one hour weekly sessions over the course of three weeks. Prior to acceptance into the program, there was pre-screening performed in the form of a semi-structured interview. This was done to determine whether the participant was a good fit for the program. A 60-minute focus group was held at the beginning and end of the program. The participants were required to complete the pre and post surveys before attending the focus groups. Two of each video modules (two functional fitness modules, two adaptive yoga modules and two cross-over function featuring diverse prosthetic technologies modules) were released following the first focus group. There was one optional 60-minute debrief session via Zoom on Week 2. The debrief meeting was participant led and held in order to facilitate camaraderie and hear feedback on the video modules. The last three video modules

(one functional fitness module, one adaptive yoga module, one cross-over function featuring diverse prosthetic technologies module) were released following the debrief meeting. The second focus group was held in Week 3 following the completion of the post surveys.

An additional part of this DEx project was to create *Unlimbited* Wellness resource guide was developed in summation of the virtual-based adaptive sports program. This resource serves as a guide for integrating functional fitness, adaptive yoga and diverse prosthetic technologies into their daily lives. In conjunction, the researchers developed and created a supplementary resource regarding therapeutic horseback riding catered to individuals with ULA. The resource is called a groundwork program manual. Jodie O'Connell-Ponkos served as the site mentor and consultant with Destiny's Ride Therapeutic Program Inc.© Destiny's Ride Therapeutic Program Inc.© is a program that provides riding lessons and horsemanship skills to children and adults who would like to benefit from the healing power of horses. Groundwork is the most important aspect of horsemanship. It involves teaching obedience and developing trust, cooperation, and rapport with horses. Groundwork or unmounted activities can include grooming, leading the horse, longeing, and more (Smith, 2007; Stafford & Oliver, 1991). By performing such groundwork, individuals with upper limb absence(s) (ULA) have the opportunity to begin a meaningful and successful therapeutic riding experience. This manual outlines the different groundwork activities, benefits of participation, and related information to prostheses.

Following analysis of the the pre and post survey data, results suggested an improvement in overall well-being and reduced difficulty when participating in sports. The virtual based adaptive sports program connected and educated participants of varying levels of ULA, ages and backgrounds. Further research should be carried out with a larger sample size, and for a longer duration.

Evolution of Project

The DEx project has been a two-year long process that began with the researcher's interest in bridging a gap in care for individuals with ULA and an interest in adaptive sports. As the researchers learned more about the population, it became clear that an adaptive sports program could connect the topics. This led to the implementation of their Shark Tank Project *a Qualitative Study on How Adaptive Sports Programs Can Become More Appealing Towards Children with Upper Limb Loss*. Originally, the program was meant to be held in person, cater to children with ULA and include an in-person therapeutic riding program. However, the resurgence and innovations regarding telehealth following the COVID-19 pandemic and the researcher's attendance at the ATA conference altered their perspective. Thus became the virtual-based program that would allow the researchers to meet the needs of this very specific population.

Another shift in the project was changing the target population from children aged 5-18 years of age to adults over 18 years with ULA. The time constraint and limitations related to the IRB led to this development. In addition, the therapeutic riding program was not deemed feasible due to the time constraints that would not allow the researchers time to gain the necessary experience to run the program and IRB limitations. This led to the development of the groundwork program manual that caters specifically to individuals with ULA.

Community Experiential Activities

The DEx requires students to complete a needs assessment and other daily activities that are required by the site. In addition to an updated needs assessment on the target population, community experiential activities are completed by the researcher. These activities included developing, filming and editing the video modules (three functional fitness, three adaptive yoga

and three cross-over function featuring diverse prosthetic technologies.). During first few weeks of the DEx project, the researchers completed a week long upper limb rehabilitation course. The course included four quizzes and activity sheets to understand the ULA population, the role of occupational therapy throughout the evaluation, assessment, and intervention process, as well as identify the different types of prosthetic technology available to this population (See Appendix C for course certification). The researchers also attended educational webinars held by Amputee Coalition covering topics such as limb loss difference awareness month, advocacy and national limb loss resources. Attending these webinars supplemented the researcher's knowledge and understanding of the population and allowed them to network with specialized providers. Additionally, the researchers participated in groundwork program activities at Destiny's Ride Therapeutic Program Inc.© in order to guide the program development and gain the necessary experience with horses. The researchers attended four educational sessions led by Jodie O'Connell-Ponkos. Furthermore, the researchers developed an Unlimbited Wellness© resource guide to further engage participants for integrate adaptive sports into their daily lives.

Scholarly Component

The scholarly component of the DEx includes a thorough literature review, the research process that was used and the dissemination of the findings. The researchers developed focus group questions to measure program evaluation and a participant satisfaction survey to obtain participant feedback. That data was analyzed and the program limitations and implications were identified. The surveys, informed consent forms, and research methods used during the course of Unlimbited Wellness were approved by the IRB at Western New England University. The IRB application can be found in Appendix D. In order to share the results of the virtual-based

adaptive sports program, researches submitted an abstract poster to the American Academy of Orthotists and Prosthetists (AAOP) Conference and the New England Rural Health Conference (Appendix E).

Discussion and Recommendations

Results

A total of 4 adults were invited to participate in the virtual based adaptive sports program following completion of the informed consent forms. Table 2 summarizes the participant ULA level and type from Handspring's client database. A total of four participants completed both the pre and post surveys. All 4 participants attended the first focus group, but only three participants attended the closing focus group. Lastly, three participants completed the participant satisfaction survey.

Of the 4 quantitative items of the focus group, participant responded to all 4 items with question 3 having the most significant positive change or improvement (1.5). The responses on three items reflect positive changes and item 2 reflecting a negative change (-0.3). Table 3 details the focus group items and changes in ratings from attending the program. All four of the participants (n=4) completed the pre and post surveys from the Quick DASH (Disability of Arm, Shoulder, and Hand) and The Pizzi Health and Wellness Assessment (PHWA). The survey items from the Quick DASH indicate reduced difficulty on all 4 items regarding engagement in the sports. Figure 1 details the changes in the pre and post survey questions derived from the Quick DASH (Disability of Arm, Shoulder, and Hand). The survey items from the PHWA indicate improved health and well-being. Figure 2 summarizes changed in the pre and post survey questions derived from the Pizzi Health and Wellness Assessment (PHWA). Figure 3 describes the common themes derived from the participant responses during the focus groups and debrief

meeting. The concept model/map was used to inform about program development to categorize the common and emerging themes from the research study which was reflected on Figure 3.

Table 2

Participant ULA Level and Type

Participant	Type of Upper Limb Absence	Bilateral or Unilateral	Hand Loss
1	Transradial	Bilateral	Neither
2	Transradial	Unilateral	Neither
3	Transradial	Bilateral	Left Partial
4	Transhumeral	Bilateral	Neither

Table 2 describes the participants' level of upper limb absence

Table 3

Focus Group Item Ratings

Focus Group Interview Questions	Pre (n=4)	Post (n=3)	Changes between Pre and Post Survey Focus Group Interview Questions
1. How would you rate your interest in engaging in adaptive sports and/or recreational activities	3.75	4.50	0.75
2. How do you feel about your overall health?	3.90	3.66	-0.3
3. How satisfied do you feel with your exercise routine?	2.00	3.50	1.5
4. How interested are you in engaging in exercise programs or recreational activity?	4.40	4.66	0.26

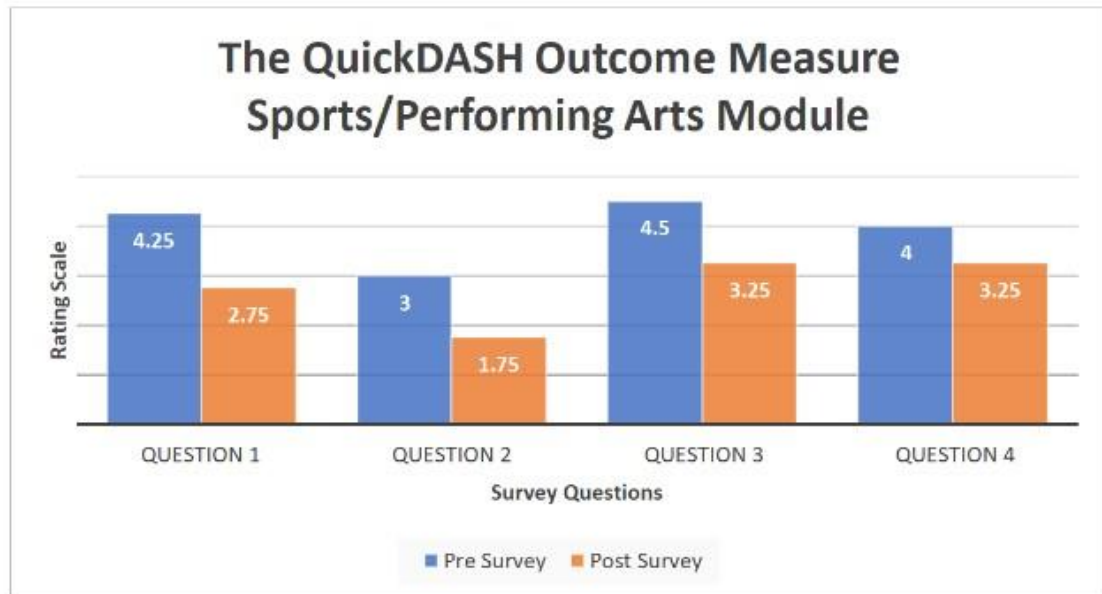
Note. Items were rated on the following Likert scale: 1=being very dissatisfied & 5=being very satisfied

*A total of four participants participated in the pre-survey

*A total of three participants participated in the post-survey

Figure 1

The Quick DASH (Disability of Arm, Shoulder, and Hand) Survey Outcomes



Note. Items were rated on the following Likert scale: 1=no difficulty, 2=mild difficulty, 3= moderate difficulty, 4=severe difficulty, 5=unable.

*Total of 4 participants completed the pre & post survey

*Participant rated questionnaire based on difficulty when engaging in the sport.

*Question 1: Did you have any difficulty using your usual technique when playing a sport

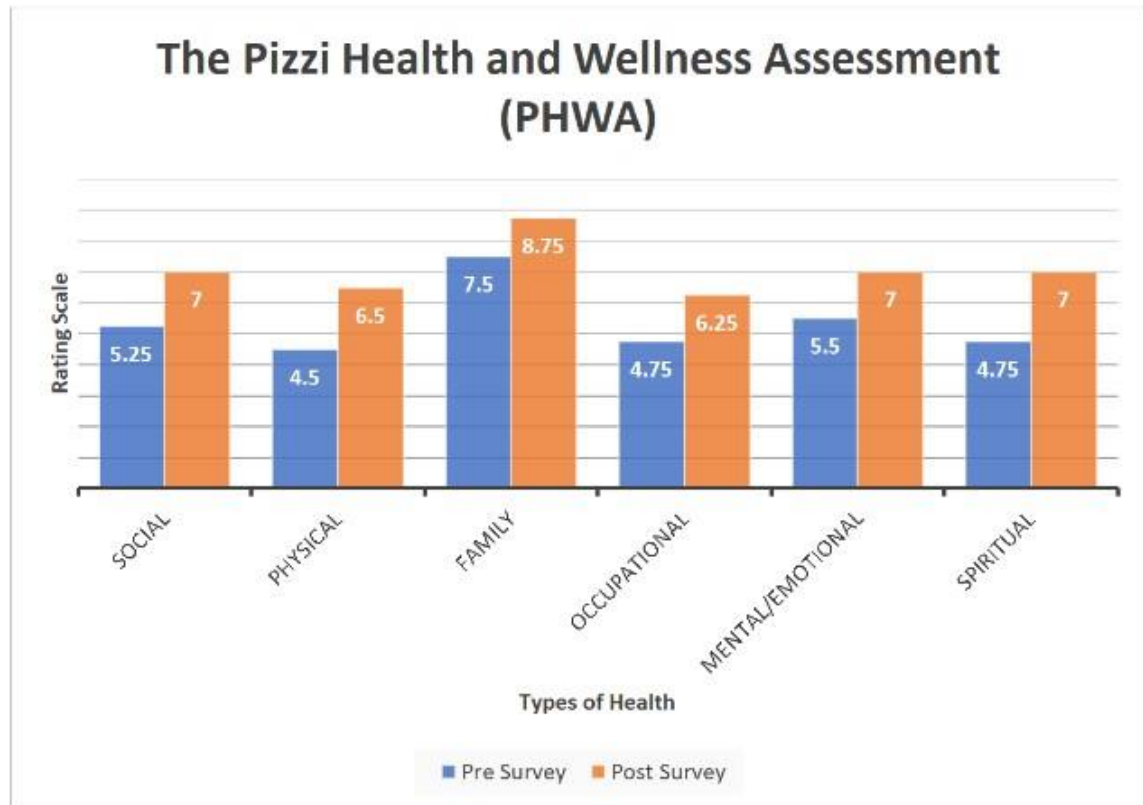
Question 2: Did you have any difficulty when playing sport because of arm, shoulder, or hand pain?

Question 3: Did you have any difficulty playing sport as well as you would like?

Question 4: Did you have any difficulty Spending your usual amount of time practicing or playing sport?

Figure 2

The Pizzi Health and Wellness Assessment (PHWA) Survey Outcomes



Note. Items were rated on the following Likert scale 0= being poor & 10= being excellent

*Total of 4 participants completed the pre & post survey

*Participant rated questionnaire on their health and well-being

Table 4

Participant Satisfaction Self-Reported Outcomes

Participant Satisfaction Survey Questions	Average Rating
The virtual-based adaptive sports program helped to enhance my well-being	4.3
I feel more competent in engaging in adaptive sports and overall exercise	4
The discussion sessions were well formatted and organized	4.6
The video modules enhanced my learning of adaptive sports options for the ULA community	4.3
I would recommend this virtual-based adaptive sports program to friend	4.3

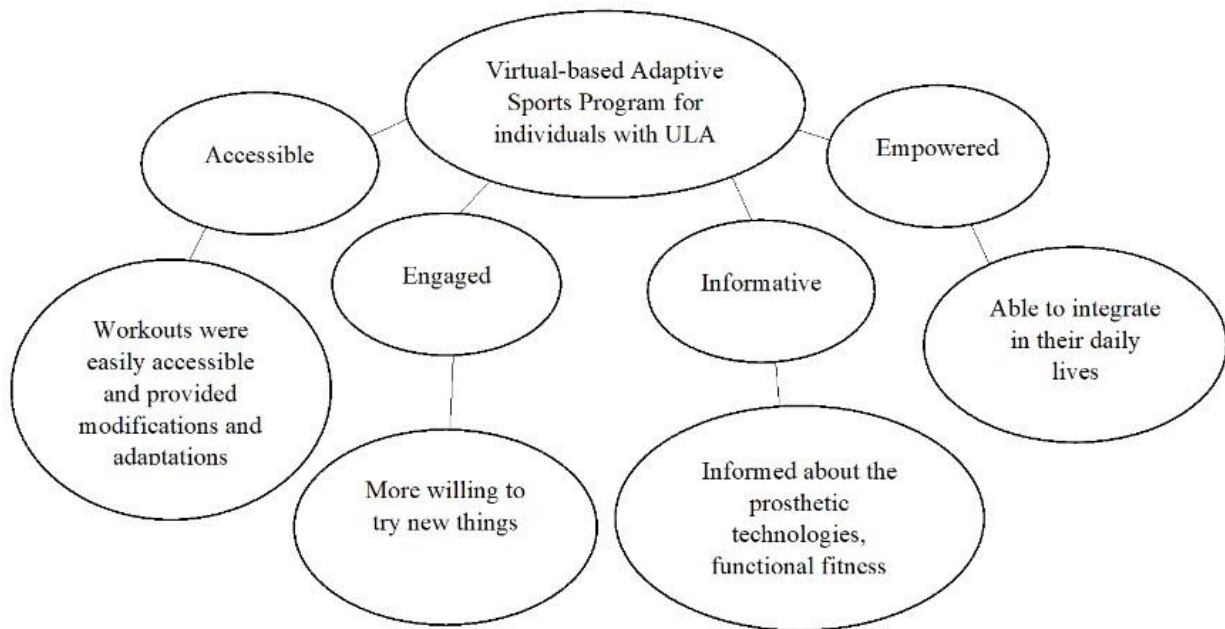
Note. Items were rated on the following Likert scale: 1=Strongly disagree & 5=Strongly Agree

*Total of three participants completed the participant satisfaction survey

Table 4 displays the participant satisfaction survey which was completed by three participants.

Figure 3

Common Themes from Adaptive Sports Program



Discussion

Although there is limited research available on adaptive sports as a whole and, specifically for individuals with ULA, individuals with ULA can indeed benefit from adaptive sports participation (Chinn, 2019.). The results from the virtual based adaptive program suggest that an improvement in overall wellbeing and independence. The data from the Quick DASH and Pizzi Health and Wellness Assessment (PHWA) indicated reduced difficulty when participating in sports, increased knowledge in adaptive sports and an improvement in the participant's perception of their general health and wellbeing.

The participants found the video modules and meetings to be accessible, engaging, informative and empowering. Likewise, all of the program participants enjoyed participating in the program and expressed interest in a continuation of adaptive sports program. Program attendance was only consistent during the debrief meetings, however only three participants

were able to attend the final focus group and complete the participant satisfaction survey.

Nonetheless, the program proved to be effective. Table 5 entails an analysis of the strengths, weaknesses, opportunity and threats (SWOT) of the adaptive sports program.

Table 5

SWOT Analysis of Virtual-based Adaptive Sports Program for Unlimbited Wellness©

Strengths	Weaknesses
<ul style="list-style-type: none">• Consistent participation including the optional discussion session• Can access program virtually and their convenience• Able to provide nine video modules with variety of content• Prosthetic section<ul style="list-style-type: none">◦ Helpful to see demonstration by individual with ULA• Functional Fitness<ul style="list-style-type: none">◦ Easy to follow workouts◦ Easy to access◦ Grading up workout was helpful• Adaptive Yoga<ul style="list-style-type: none">◦ Simple, and easy to follow◦ Adaptable poses geared more towards participant success◦ Easy to integrate into daily routine• Created resource guide highlighting content from the videos	<ul style="list-style-type: none">• Duration of Study• Small sample size• Longer wait-time to receive confirmation to participate in program• Difficulty to cater videos to multiple different types of ULA• Difficult to cater prosthetic section to all participants• Study was shortened to three weeks rather than six
Opportunities	Threats

<ul style="list-style-type: none"> ● Able to build therapeutic rapport with participants ● Able to create support system among participants ● Access to specialized professionals (OT and prosthetist) during groups ● Able to improve quality of life for individuals with ULA, which can be translated into OT practice ● Increased <i>Unlimbited</i> Wellness participant interest for next year's 	<ul style="list-style-type: none"> ● Difficulties finding times for meetings due to prior commitments and time zones ● Differences in technology literacy among participants ● Shorter program may have impacted results ● Difficult for participants to engage in videos due to secondary conditions, bilateral ULA, or lack of modifications
<p>DEx group to create programs</p> <ul style="list-style-type: none"> ● Provide a good foundation for further research and adaptive program development 	

Future Recommendations

Upon formal defense of this project, the following recommendations were to potentially divide the sample size by unilateral ULA and bilateral ULA to further assess the well-being and independence for both of these populations. In doing so, this will also provide more of a social opportunity for the participants. These recommendations could not only improve the effectiveness of the program but also make the results more generalizable to the ULA population.

Learning Outcomes

The learning objectives (Appendix F) are determined to create the guidelines associated with the project. The first objectives numbered 1-8 are general goals provided by the OTD program. This includes the personal goals of the researcher listed under numbers 9-12. The researcher has to accomplish each of the objective in order to receive a passing score for the DEx Capstone Project. This researcher reached all of the goals that were set. The researcher accomplished this by completing the Upper Limb Rehabilitation Course, developed the video modules and gathering results from The Pizzi Health and Wellness Assessment and the

QuickDASH Sports Module.

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Appendix A

Literature Review of Target Populations

In the United States, there are about two million individuals who have limb loss/absence. About 35% of those individuals experience Upper Limb Absence(s) (ULA) due to acquired or congenital factors (Ziegler-Graham et al., 2008). Acquired limb loss can occur when the limb is amputated as a result of vascular diseases such as diabetes, trauma, or cancer. Congenital limb

loss is present at birth, often with no one exact cause (Orthoinfo, 2020; Hangar Clinic, 2022).

The upper extremities are crucial for activities of daily living and instrumental activities of daily living and can affect an individual's daily occupations (Ostlie et al., 2011).

Background and Need

Based on the literature, there is a great need for adaptive sports programs, particularly for this population. Generally, sports participation has the potential to improve both physical and mental fitness. There is a strong positive association between an individual consistently participating in physical activity, for overall health, and psychosocial wellbeing (Chinn, 2019). In the same sense, individuals with ULA remaining active through sports participation can lead to enhanced wellbeing and quality of life. This can be attributed to sports participation granting an opportunity to socialize with peers, participate in recreational activities while also working on motor coordination, strength, endurance and balance (Bragaru et al., 2011; Webster et al., 2001). Gaps in care for individuals with ULA are present due to the lack of professionals who are equipped to serve the population and regarding psychosocial interventions, specifically concerning wellbeing (Latour, 2019; Latour, 2022). Involvement in sports and recreational activities is particularly crucial because it provides the opportunity to develop motor skills, socialize with peers and adjust to differences in physical abilities (Blauwet et al., 2016; Webster et al., 2001).

Consideration for the Use of Prosthetic Technology

Engaging in recreational activities is known to improve both physical and psychosocial and health. Additionally, it is important to consider whether the individual utilizes prostheses. Few seek the use of a prosthesis for recreational and work activities. Prosthetic devices are more often utilized for cosmetics. Although the use of upper limb prostheses can be helpful, they are not

absolutely necessary for adaptive sports. Notably, upper limb prosthetic devices can facilitate muscle strengthening of the residual limb. The role of the prosthesis also plays a large part in participation e.g. the weight or construction of the prosthesis may hinder certain movements, sensory input, and may even cause injury to self and the high cost of a secondary sports-specific prosthesis. High cost along with a number of other factors contribute to whether or not an individual would utilize prostheses. This includes whether the prosthesis is also for everyday wear or activity-specific, demand and frequency of the activity, prosthesis strength, durability, general preference and much more. However, depending on the activity and level of extremity involvement, a prosthetic has the potential to provide more stability and functionality. It is essential to consider these many factors because whether or not the individual utilizes a prosthetic can impact how the individual participates in adaptive sports. Subsequently, it is essential to fully understand the reasons an individual does or does not use prostheses and how to best support them during an adaptive sports program (Coppard & Loman, 2020; Latour, 2022; Webster et al., 2001; Chinn, 2019).

Need for Specialized and Collaborative Care

Individuals with ULA require specialized, multidisciplinary and collaborative care. An ideal team typically consists of providers who have specialized training and/or previous experience serving the population. The interprofessional team can include the family, physician, prosthetists, psychologist, hand therapist and more. This team should then be knowledgeable in prosthetic technology, able to anticipate challenges faced by individuals with ULA and confident in developing individualized adaptive strategies/solutions. Such a team would be equipped to facilitate maximal independence and success in occupational performance, while also considering the needs and priorities of the individual. Unfortunately, there is limited access to providers that can meet the needs of the population (Coppard & Loman, 2020; Latour 2019;

Latour 2022).

Role of Telehealth in Health Education

Telehealth is a growing form of healthcare delivery that addresses barriers that interfere with access to care. Those barriers could include geographical distance, time, affordability, access to transportation, and health literacy (Adam et al., 2019; Latour 2019). For individuals with ULA particularly, telehealth provides an opportunity to gain access to specialized professionals without physical distance being an issue (Cason, 2014). An emerging method of providing health education is through video-based platforms that are easily accessible, cost-effective, and adaptable to the needs of the targeted community. Video-based health education content can be shared on numerous platforms and can include live and asynchronous technologies. Both of these methods can empower a community with health awareness and provide continuous community support (Adam et al., 2019; Latour 2019; McDonald et al., 2019).

Appendix B

Needs Assessment

Identification of Problem or Unmet Need

For individuals with upper limb absence (ULA), psychosocial interventions are often neglected (Latour, 2019). Participation in sports is generally known for having both physical, social and psychological benefits. In addition, individuals with limb absence who participate in sports have increased self-esteem and quality of life. Barriers to participation are often due to physical difficulties, difficulty acquiring the appropriate prosthesis and accessibility (Bragaru et al., 2011; Webster et al., 2001). There is limited research available on virtual based adaptive sports as a whole and, specifically for individuals with upper limb loss or differences. The

majority of research and present adaptive sports programs concerns lower limb loss, individuals who have undergone amputations specifically, or solely those with similar conditions. This provides the necessary information to support creating an adaptive sports program that meets the need of this population.

Identification of Target Population

According to the Amputee Coalition, there are about 1.9 million people who have experienced limb loss currently residing in the United States (Amputee Coalition, 2019). The target population for this project is individuals with upper limb absence aged over 18 years old. That includes both individuals that utilize prosthetic devices and individuals that do not. The existing data and research is limited for this population. Upper limb absence (ULA) is commonly a result of traumatic injury, followed by congenital differences or acquired due to a medical condition such as diabetes or cancer (Fletcher, 2016). Congenital ULA makes up about 4.1 per 10000 live births. Upper limb amputations occur at a 1:4 ratios to lower limb amputation (ISHN, 2014). ULA can occur at any level particularly if it is due to trauma e.g. above (transhumeral) or below the elbow (transradial), partial hand (transcarpal), an elbow disarticulation or shoulder disarticulation etc. (Fletcher, 2016).

Resource Availability and Barriers of Identified Problem

Currently, there are several available resources for individuals with limb loss but not necessarily ones that cater specifically to upper limb absence. Even fewer resources address adaptive sports participation for the population. Potential barriers to participation in these prevention programs could include limited time to participate, and being a part of a small distinct population. The time that this program requires could interfere with the other many demands of daily life e.g. work, school, and childcare. This program requires consistency, and need enough

time to thoroughly educate the participants and monitor their progress. Forming a program for a specific population such as individuals with upper limb loss can be difficult because of how small the population is. Since the population is, small there will most certainly be a limited number of people that are able to participate. *Table 1* includes organizations that provide support and resources for individuals who have experienced limb loss e.g. connections to support groups or other beneficial programs, information on prosthetics, referrals to relevant healthcare providers, etc.

Table 1 *Resources
for ULA*

Organization	Mission and Vision
The Amputee Coalition	<ul style="list-style-type: none"> • To empower individuals who have experienced limb loss to reach their greatest potential through advocacy, education, and awareness • Provides access to National Limb Loss Resource Center and numerous support groups/peer support
The Handsmart Group	<ul style="list-style-type: none"> • To support and empower people world-wide by creating and updating open access, easily understandable consensus resource based on evidence, for those engaged in upper limb loss/difference rehabilitation. • To provide the most holistic rehabilitation approach for every person with upper limb loss or upper limb difference, now and in the future
Handspring Clinical Services	<ul style="list-style-type: none"> • To provide a holistic approach for individuals in need of prosthetic rehabilitation.
TRS Inc. (Therapeutic Recreational Services)	<ul style="list-style-type: none"> • To provide high-quality technology for persons missing a hand(s).

Enhancing Skills for Life	<ul style="list-style-type: none"> • To educate, empower and connect those living with bilateral upper limb loss. • to financially support individuals missing at least both arms to attend the Skills for Life: Bilateral Upper Limb Loss Workshop with minimal to no cost to them.
Limbs for Life	<ul style="list-style-type: none"> • To provide fully-functional prosthetic care for individuals who cannot otherwise afford it and raise awareness of the challenges facing amputees.
American Board for Certification, O & P	<ul style="list-style-type: none"> • To establish and advocate for the highest patient care and organizational

	standards in the provision of safe and effective orthotic, prosthetic, and services.
NubAbility	<ul style="list-style-type: none"> • To encourage, and immerse limb different youth into mainstream sports, while also offering mentorship.
Lucky Fin Project	<ul style="list-style-type: none"> • Creates a support network for parents across the U.S. and around the world • Links parents to medical information and resources. • Provides education on limb differences. • Financially support efforts for children to attend specialized camps, obtain prosthetics, and fund other organizations within the limb different communities.

SWOT Analysis

Table 2

SWOT Analysis

<p><u>Strengths:</u></p> <ul style="list-style-type: none">● Client centered, and catered to specific individuals with ULA● Participation is free to all participants● Virtual based and can watch videos at their convenience● Accessible to participants● Resources catered to population● Ongoing program feedback is encouraged● Debrief meetings are guided by the participant's	<p><u>Weaknesses:</u></p> <ul style="list-style-type: none">● Difficulty recruiting individuals to form this population● Limited time to run program● Unable to troubleshoot technical issues that arise during meetings/program● Time requirement for participants● Potential difficulty with participants developing a bond
<p><u>Opportunities:</u></p> <ul style="list-style-type: none">● Opportunity for peer support● Can improve general wellbeing and independence as a result of program participation● Opportunity for participants to educate and share resources with community● Provide a good foundation for further research and adaptive program development.	<p><u>Threats:</u></p> <ul style="list-style-type: none">● Potential broadband interference with wireless signal● Weather interferences with wireless signal● Confidentiality concerns as a result of video and audio use

Appendix C

Certificate of Upper Limb Rehabilitation Course Completion

CERTIFICATE OF COMPLETION

THIS CERTIFIES THAT

Jeanne Uwera

has successfully completed the requirements for the
Upper Limb Prosthetic Rehabilitation for
Occupational Therapy Practice:
Professional Education Mini-Course



DR. DEBRA LATOUR, PP-OTD, M.ED., OTR

APRIL 30, 2022

Appendix D: IRB Form

The following appendix contains the Institutional Review Board application that researchers
submitted to Western New England University.

WESTERN NEW ENGLAND UNIVERSITY
INSTITUTIONAL REVIEW BOARD (IRB) SUBMISSION FORM
FOR PROPOSAL TO USE HUMAN PARTICIPANTS IN RESEARCH
FWA00010736

Last Modified June 23, 2016

Information regarding the annual meeting schedule of the Institutional Review Board, submission deadlines and requirements, and contact information may be found on the IRB section of the Academic Affairs website located at:

<http://www1.wne.edu/academic-affairs/>

Date of Application:
(MM/DD/YYYY)

05/05/2022

1. Responsible
Project Investigator:

Dr. Debra Latour

Phone No.:

413-782-1449

Address (Campus
address, including
box #, if available):

1215 Wilbraham Rd.
Blake Law 220
Springfield, MA 01119

E-mail:

debra.latour@wne.edu

2. Investigator (e.g.,
Graduate Student):

See Appendix A

Phone No.:

Address (Campus
address, including
box #, if available):

E-mail:

3. Title of Project:

Impact of adaptive sports participation on well-being and independence for individuals with upper limb absence (ULA)

4. Nature of the Research and Expected Benefit:

Appendix I

5. Anticipated Duration of the Project

From MM/YYYY:

06/2022

To MM/YYYY:

06/2023

NOTE: Any research project that continues for longer than one (1) calendar year requires that an application be submitted annually for renewal.

6. Is this a request for renewal? ☐ Yes ☒ No

NOTE: If "Yes" please attach the original proposal and committee approval form plus one (1) copy of this proposal and proceed to question number 20.

7. Type of research participant (Include all that apply.) Indicate the approximate number in each category.

Undergraduate WNE student (18 years old or older) #

Undergraduate WNE student (less than 18 years old) #

Graduate or Law WNE student #

WNE employee (18 years old or older) #

WNE employee (less than 18 years old) #

Minor not otherwise specified (less than 18) #

Off-campus participants (specify including age and #)

Special population (e.g., prisoner, pregnant, disabled) (specify including age and #)

Other (specify including age and #)

20 individuals who are 18 years of age or older with ULA

8. Recruitment of participants (Check all that apply.)

- ☐ Unpaid classroom volunteer ☐ Paid classroom volunteer
☒ Unpaid nonclassroom volunteer ☐ Paid nonclassroom volunteer
☐ Other (Please specify)

9. Expected participant duration and compensation.

Expected Duration
(e.g., total hours and
length of involvement
(days, months) per
participant):

Appendix J

Expected participant compensation (Check all that apply.)

- ☒ No compensation ☐ \$\$ compensation
☐ Other (Please specify)

If applicable, please
specify \$\$ rate

10. Location of the research (Check all that apply)

- ☒ On-campus ☒ On-Line ☒ Off-Campus

Please specify site (e.g., Springfield campus, Southborough, specific off-campus location)

See Appendix B

NOTE: If off-campus locations are included, please attach a signed permission from a responsible individual (e.g., business owner, school superintendent, principal) for each location.

11. Will the participants be exposed to more than minimal risk?

- ☐ Yes ☒ No

If "Yes" please elaborate in the space below.

12. Attach copies of consent and assent procedures. Consent forms are required if more than minimal risk is involved. Both consent and assent forms are required for any research involving minors. Please see <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html> (Refer to 46.101.)

13. Procedure(s) used to ensure that participants are aware of their right to refuse to participate in the study, of the behavior they will be asked to manifest and any possible discomfort they may experience, and of their right to withdraw from the study at any time.

Appendix K

14. Confidentiality and anonymity of information obtained (Check all that apply)

- ☐ Participants' responses will be anonymous. (Data are collected in a way that no one (including the researcher) can identify the individual associated with any particular result or response, e.g., a survey with no names or other identifying information.)
- ☒ Participants' responses will be confidential. (Records are maintained in a way that ensures only the researchers have access to any information or results linked to a specific individual.)
- ☐ Other (Please specify)

15. Does the research involve the use of deception?

- ☐ Yes ☒ No

If "Yes" please elaborate in the space below, describing the deception used and providing a justification of the need for deception.

16. Does the research involve debriefing of participants?

- ☒ Yes ☐ No

If "Yes" please provide an explanation in the space below describing how (e.g., spoken, with written statement) and when the participants will be debriefed. If "No" please provide an explanation of why debriefing is not necessary.

There will be an optional discussion session after completing each of the video modules. The discussion will occur the following week after the video is released. Each session will last approximately for 60-minutes via Zoom.

17. Is the proposed research consistent with the Belmont Principles and the American Psychological Association's* ethical principles concerning research with human participants?

☒ Yes ☐ No

18. In the space below, please provide a brief description of the methods to be employed in the research, including a description of the participants and how you plan to recruit them, the materials to be used, and the research procedure(s).

Appendix L

19. Are you applying for an exemption? ☒ Yes ☐ No

NOTE: If "Yes" please submit the Exemption Code # in the space below, citing your specific reason. For a listing of reasons, go to <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html> (Refer to 46.101.)

46.104.d.2.ii: uses educational tests, surveys, interviews; any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

20. I certify that I have read the the Belmont Principles (<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the responsibility for the ethical conduct of the study rests with the responsible faculty investigator. I agree to report any participant's complaints that may arise to the IRB.

NOTE: It is strongly recommended that all researchers consult the education training materials available on human subjects research protection at: <http://www.hhs.gov/ohrp>

(*Departments or Colleges/Schools that have established their own Human Subjects Committee may substitute the appropriate professional organization's ethical guidelines for research after approval from the IRB.

All applications should be submitted electronically. An electronic signature can be used or alternatively, in addition to the electronic copy, a hard copy with a written signature can be scanned and emailed/mailed. If a full review is required, ten (10) signed copies must also be submitted in hard copy.

1. Responsible
Project Investigator's
Signature:

See Appendix M

Date 06/01/2022

2. Investigator's
Signature, If Different:

See Appendix M

Date 06/01/2022

You may not begin conducting any aspect of the proposed study until such time as you have received written approval for the proposal.

Appendix A - Investigators

Primary Investigator:

Debra Latour
1215 Wilbraham Road
Springfield, MA 01119
Blake Law Center Room 220 413-
782-1449 debra.latour@wne.edu

Secondary Investigators:

Mary Grace Sansait
203 Gardners Way Enfield,
CT 06082 740-513-6853
marygrace.sansait@wne.ed
u

Ariane Sudenfield
3305 Kristins Way
Bloomfield, CT 06002 978-304-
6679 ariane.sudenfield@wne.edu

Jeanne Uwera
313 Conestoga St
Windsor, CT 06095 857-777-
8109 jeanne.uwera@wne.edu

Appendix B- Recruitment Email & Virtual Flyer

Dear Potential Participant,

We are occupational therapy doctoral students from Western New England University and we are working towards our doctoral project which focuses on the impact of adaptive sports participation for individuals with upper limb absence (ULA) or any other related conditions. Related conditions include hemiplegia, brachial plexus injuries, etc. This project includes virtual-based adaptive sports modules that will be available for you to participate in at your convenience within a week of receiving them. The video modules may include a functional fitness module, adaptive yoga module, and a cross-over function module which includes diverse prosthetic technologies. Following your participation in the module, you will be encouraged to attend a weekly discussion with other participants via Zoom.

This study has been approved by the Western New England University Institutional Review Board (IRB). All information gathered will be confidential and no names will be included in findings to the public. We received your contact information from Amy Ginsburg and are looking for you to participate in our study. The virtual-based adaptive sports program is a 4 week program composed of video modules that range from 15-30 minutes and viewing of modules will occur during weeks one and three. You will be required to complete at least one virtual-based adaptive sports module of your choice. Then it will be followed up with an optional 45-60 minute discussion session during weeks two and four after viewing the video modules. Please respond within a week for your interest in participating in our program. If interested, please reach out to at least one of the secondary investigators who are occupational therapy students at Western New England University. Their emails are marygrace.sansait@wne.edu, ariane.sudenfield@wne.edu, jeanne.uwera@wne.edu.

Thank you,

Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, and Jeanne Uwera OT/s

PARTICIPANTS NEEDED FOR RESEARCH STUDY ON VIRTUAL-BASED ADAPTIVE SPORTS PROGRAM FOR INDIVIDUALS WITH UPPER LIMB ABSENCE

The IRB has been approved by WNEU IRB Board

WHAT IS THE STUDY ABOUT?

This research study seeks to identify the impact of adaptive sports participation on well-being and independence for individuals with upper limb absence (ULA) or related conditions

WHO QUALIFIES?

- Must be 18 years or older
- Any form of acquired or congenital upper limb absence, or related conditions

WHAT ARE THE BENEFITS OF PARTICIPATING?

- Understand the impact of virtual based exercise program with ULA
- Improve independence and general well-being
- Will have the opportunity for peer support and connect with others in the population

PARTICIPATION INVOLVES

- 4-week program video modules range from 15-30 minutes
- Required to choose at least one module of your choice
- Video modules include functional fitness, adaptive yoga, cross-over function module which includes diverse prosthesis technologies
- Optional 45-60 minute discussion sessions every other week via Zoom

FOR MORE INFORMATION, PLEASE CONTACT THE INVESTIGATORS:

Marygrace.sansait@wne.edu, Ariane.sudenfield@wne.edu,
Jeanne.uwera@wne.edu

Appendix C-Part 1 Pre-Screening Interview Questions

This survey will include a series of questions that determine your eligibility to participate in this program.

Participant Name: _____

Participant Age: _____

1. Do you have congenital or acquired upper limb absence? If yes, please state what type. If not, please list any related conditions that you may have (e.g. hemiplegia, brachial plexus injuries, etc).
2. Are you interested in participating in virtual-based adaptive sports (such as a functional fitness, adaptive yoga, and a cross-over function module which includes diverse prosthetic technologies) in order to improve your general well-being and independence? Video modules will be sent bi-weekly and will be completed at your own pace.
3. Do you have any other secondary health conditions? (e.g. traumatic brain injury, post-traumatic stress disorder, heart condition)
4. Do you use a prosthesis/prostheses when exercising? And if so, what type of prosthesis/prostheses?
5. How can we help you succeed in our program?

Appendix D - Part 2 Welcome Email

Dear Potential Participant,

We are writing to inform you that you are eligible to participate in the virtual-based adaptive sports program for individuals with upper limb absence (ULA) or any other related conditions. Related conditions include hemiplegia, brachial plexus injuries, etc. We received your contact information from Handspring due to your possible interest in participating in our program. If you agree to participate in our research project, please reply to us in the next 48-72 hours with your response of either Yes or No to participate in this study.

If yes, we will be sending follow up emails of consent forms to be signed prior to starting the program, focus groups, instructions to access the video modules, and optional discussion meetings.

We thank you for your time and patience, if you have any further questions regarding the research study, please email us back at marygrace.sansait@wne.edu, ariane.sudenfield@wne.edu, jeanne.uwera@wne.edu

Thank you,

Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, Jeanne Uwera OT/s

Appendix E - Pre/Post Surveys Focus Group Interview Questions

Please consider the following topics and questions in preparation for our focus group discussion activity. For the following questions with a rating scale, please rate each answer on a scale from 1-5, with 1 being very dissatisfied/not interested and 5 being very satisfied/very interested. Please answer the other questions without a rating scale as you see fit.

- How would you rate your interest in engaging in adaptive sports and/or recreational activities?
1 2 3 4 5
- How do you feel about your overall health?
1 2 3 4 5
- How many hours do you exercise in a week? _____
 - How satisfied do you feel with your exercise routine?
1 2 3 4 5
 - How interested are you in engaging in exercise programs or recreational activity?
1 2 3 4 5
- How do you perceive your prosthesis? Some examples for discussion include:
 - a. As a tool that you use purely for function
 - b. As a tool that you use for social purposes

- c. As an extension or a part of your body or self-identity
- d. As a combination of any, all or other purposes e.g. activity specific

-
- Please share with us your experiences, if any, with seeing others with upper limb differences participating in sports.

Appendix F - Consent Forms



Western New England University College of Pharmacy / Health Sciences Informed Consent Form for Participants

Title of Study: Impact of adaptive sports participation on well-being and independence for individuals with upper limb absence (ULA)

Investigators/Institution: Dr. Debra Latour PP-OTD, M.Ed.,OTR/L acts as the primary investigator. Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, and Jeanne Uwera OT/s act as secondary investigators

Introduction

We are inviting you to participate in a virtual-based adaptive sports program for Western New England University (WNEU). The adaptive sports modules will be available for you to participate in at your convenience within a week of receiving them. A 60-minute focus group that will occur at the beginning and end of the program. The video modules may include a functional fitness, adaptive yoga, and a cross-over function module which includes diverse prosthetic technologies. Each video module will take approximately 15-30 minutes. Following your participation in the module, you will be encouraged to attend 60-minute weekly discussion sessions with other participants via Zoom. You are invited to participate in this program because you are 18 years of age or older and have any form of acquired or congenital ULA, or any related conditions. This research consent form explains why the program is being done, what is involved in participating, possible risks and benefits of participation, and rights as a participant in this study. Please read this form carefully and ask any questions that you may have.

Purpose of the Study

The purpose of the study is to understand the impact of adaptive sports participation for individuals with ULA or any other related conditions. The data will be collected to understand the importance of adaptive sports programs for individuals with ULA or any other related conditions.

Descriptions of Study

Prior to your participation in the program, you will need to complete the pre-screening interview questions to determine your eligibility. A 60-minute focus group that will occur at the beginning and end of the program. The 4-week program consists of viewing 4-10 video modules that can range from 15-30 minutes every other week. There will also be optional 45-60-minute discussion sessions every other week via Zoom. You will be provided with pre and post surveys during the virtual-based exercise program.

Risks of Discomforts of the Study

As with any physical activity, it is recommended to consult your physician prior to participating in the video modules. At most, you may find the adaptive sports session may cause physical fatigue. In addition, it is important to note that the topics discussed during the discussion may be triggering. You may find that the video modules cause mental or physical fatigue if you are following along with the instructor. You may decline to participate in any portion of the module that you are not comfortable with and may voice concerns to the investigators at any time.

Benefits of Being in the Study

The purpose of the study is to understand the impact of virtual-based adaptive sports programs for individuals with ULA or any other related conditions. You will potentially improve independence, and general well-being. In addition, you will have an opportunity to connect with others in the population and receive peer support. You will receive no payment for participating in this study.

Confidentiality

The pre-screening interview questions and the video module creation have a risk for some loss of privacy. To help prevent the loss of privacy, your name will not be recorded on any study documents. We will assign each participant a client number which will be included in all study documentation. All records will be kept strictly confidential. Only the site mentor, Amy Ginsburg, who is part of Handspring Clinical Services, will have access to the password protected files. None of the data that we may publish or present in any reports, presentations, or papers will include any information that can identify you as a participant in this study. The pre-screening interview questions and the video modules data will be stored in a password protected file on Handspring's electronic record system for 3 years. Interviewee names and agencies will be coded for confidentiality and only Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, Jeanne Uwera OT/s will have access to codes.

Right to Refuse or Withdraw

The decision to participate in this program is entirely up to you. You have the right to choose not to sign this form. You can stop participating in the program at any time. Tell the investigators immediately if you are thinking about stopping or decide to stop.

Right to Ask Questions and Report Concerns

You have the right to ask questions about this program before, during, or after. If you have any questions about the study at any time, please contact investigators Mary Grace Sansait at marygrace.sansait@wne.edu or (740)-513-6853 Ariane Sudenfield at ariane.sudenfield@wne.edu or (978)-304-6679, Jeanne Uwera at jeanne.uwera@wne.edu or (857)-777-8109, or Dr. Debra Latour at debra.latour@wne.edu or (413)-782-1449.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this project, you may contact the Chair of the WNEU Institutional Review Board, Jessica Outhouse, at jessica.outhouse@wne.edu or 413-796-2325 and /or WNEU COPHS Institutional Review Board member, Dr. Diptiman Bose, at diptiman.bose@wne.edu or 413-796-2442.

Statement of Consent

Your signature indicates that you have decided to volunteer as a research participant for this study and that you have read and understood the information provided on this form. You must be at least 18 years of age and have ULA or any other related condition. Related conditions include hemiplegia, brachial plexus injuries, etc.

You will be given a signed and dated copy of this form to keep. The original signed consent form will be stored in a locked room for a minimum of three years.

**Western New England University College of Pharmacy / Health Sciences Audio and Video Release Form for Participants Completing the Program**

Title of Study: Impact of adaptive sports participation on well-being and independence for individuals with upper limb absence (ULA)

Primary Investigator/Institution: Dr. Debra Latour PP-OTD, M.Ed.,OTR/L acts as the primary investigator. Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, and Jeanne Uwera OT/s act as secondary investigators

Introduction

This study will involve video and audio recording for your participation in the focus groups in the beginning and end of the program. These focus groups will be recorded and saved on the Handspring Clinical Services website. Your participation will last anywhere from to 60 minute sessions.

Confidentiality

The pre-screening interview questions and the video module creation have a risk for some loss of privacy. To help prevent the loss of privacy, your name will not be recorded on any study documents. We will assign each participant a client number which will be included in all study documentation. All records will be kept strictly confidential. Only the site mentor, Amy Ginsburg, who is part of Handspring Clinical Services, will have access to the password protected files. None of the data that we may publish or present in any reports, presentations, or papers will include any information that can identify you as a participant in this study. The pre-screening interview questions and the video modules data will be stored in a password protected file on Handspring's electronic record system for 3 years. Interviewee names and agencies will be coded for confidentiality and only Mary Grace Sansait OT/s, Ariane Sudenfield OT/s, Jeanne Uwera OT/s will have access to codes.

Right to Refuse or Withdraw

I may withdraw at any time while being interviewed for the project, and even after the interview(s) are complete. Should I withdraw, I understand that all recordings and copies of my interview(s) shall be destroyed. I also acknowledge that I do not have the authority to edit any recordings shown to me. Should I object to any recording, my only options will be to withdraw from the project, resulting in destruction of my interview recording(s), or request additional recorded interview time.

Right to Ask Questions and Report Concerns

You have the right to ask questions about this program before, during, or after. If you have any questions about the study at any time, please contact investigators Mary Grace Sansait at marygrace.sansait@wne.edu or (740)-513-6853 Ariane Sudenfield at ariane.sudenfield@wne.edu or (978)-304-6679, Jeanne Uwera at jeanne.uwera@wne.edu or (857)-777-8109, or Dr. Debra Latour at debra.latour@wne.edu or (413)-782-1449.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this project, you may contact the Chair of the WNEU Institutional Review Board, Jessica Outhouse, at jessica.outhouse@wne.edu or 413-796-2325 and / or WNEU COPHS Institutional Review Board member, Dr. Diptiman Bose, at diptiman.bose@wne.edu or 413-796-2442

Statement of Release

I hereby authorize Western New England University and those acting pursuant to its authority to:

- a. Record my likeness and voice on a video, audio, photographic, digital, electronic or any other medium

I release the University from liability for any violation of any personal or proprietary right I may have in connection with such use. I understand that all such recordings, in whatever medium, shall remain the property of the University. I have read and fully understand the terms of this release.

Participant's Printed Name

Participant's Signature

Date

Appendix G - Confidentiality Agreement

Program facilitators will be using a videoconferencing platform to deliver the *Unlimbited* Wellness program. This platform meets all privacy protection and standards related to the Health Insurance Portability and Accountability Act (HIPAA). It will be provided to you at no cost and will be accessible through a link that is sent to your email.

Please read the following Group Responsibilities for additional information regarding group confidentiality. * Required

Your Responsibilities as a Group Participant in *Unlimbited* Wellness:

1. You must use a secure (non-public) internet connection to participate in the group.
2. Recording of the discussion sessions by members is strictly prohibited. Group members have the right to legal action if you create or share any audio or video recordings of focus group sessions.
3. In order to maintain the focus group's privacy, it is important to connect from a quiet and private room with no interruptions or distractions from people or other devices. It is imperative that no persons, other than yourself, are in hearing or visual proximity to you during the group meeting.
4. Group members must agree to maintain the confidentiality of other group members. This means that you may not disclose names or other identifying information about group members, nor may you discuss the personal issues and experiences of other members. This includes, but is not limited to, written posts and pictures on social media forums. Discussing your own experience of being in the group with non-members is acceptable.
5. It is important that group members arrive on time and consistently attend sessions in order to minimize disruptions, maximize benefits of the program, and facilitate the group process.

Confidentiality agreement: *

You have the right to confidentiality and privacy by the facilitators and other group members. Confidentiality within the group setting is a shared responsibility of all members and facilitators. While facilitators are bound by HIPAA to protect participant information, group members' communications are not protected by law. As such, confidentiality within the group setting is often based on mutual trust and respect.

- ☐ I agree to the above information and will uphold my responsibility as a group member. I
- ☐ do not agree with the above information. I understand that selecting this box disqualifies me from participating in this program.

Appendix H - Participant Satisfaction Survey

Please complete this participant satisfaction survey to help us gain more insight on how we can improve the program. For the following questions with a rating scale, please rate each answer on a scale from 1-5, with 1 being strongly disagree and 5 being strongly agree. Please answer the other questions without a rating scale as you see fit.

1. The virtual-based adaptive sports program helped to enhance my well-being
1 2 3 4 5
2. I feel more competent in engaging in adaptive sports and overall exercise
1 2 3 4 5
3. The discussion sessions were well formatted and organized
1 2 3 4 5
4. The video modules enhanced my learning of adaptive sports options for the ULA community.
1 2 3 4 5
5. I would recommend this virtual-based adaptive sports program to friend
1 2 3 4 5

Appendix I- Nature of Research and Expected Benefit

The nature of this research is to develop, implement, and evaluate a virtual-based adaptive sports program for individuals with ULA or any other related conditions. Amount of time to complete virtual-based adaptive sports modules varies from 8 hours, 2 hours to complete the focus groups, and 3 hours to attend discussion sessions. The three modules include functional fitness, a cross-over function module which includes diverse prosthetic technologies, and adaptive yoga. The modules will be completed by individuals with certifications or specialty in their area. This is a

qualitative study conducted with audio recorded videos, semi-structured interviews, and discussion sessions. Participants to complete the program will be selected by convenience sampling and will complete at least one virtual-based adaptive sports module. The participants will watch at least 1 module of their choice. The benefits to participate include enhancing well-being and independence for individuals with ULA or any other related conditions.

Appendix J - Expected participant duration and compensation

- A 4-week program consisting of viewing 4-10 video modules every other week
 - The minimum time spent on one video module can be 15 minutes with a maximum time of 30 minutes
- There will be a semi-structured interview for a screening
 - The minimum time spent on the semi-structured interview can be 15 minutes with a maximum time of 30 minutes
- Participants will read and sign the informed consent form, audio and release form, and the confidentiality agreement via Google Forms.
 - The minimum time spent to read and sign the informed consent form, audio and release form, and confidentiality agreement can be 10 minutes with a maximum time of 15 minutes
- Participants will be required to attend a meeting to review their informed consent forms, audio and video release forms, and confidentiality agreements
 - The minimum time spent reviewing the informed consent forms, audio and video release forms, and confidentiality can be 10 minutes to a maximum time of 15 minutes
- Participants will be required to complete the pre and post surveys.
 - The minimum time spent completing the pre surveys will take 15 minutes with a maximum of 25 minutes. The minimum time spent completing the post surveys will take 15 minutes with a maximum of 25 minutes.
- There will be a focus group that will occur at the beginning and end of the program. There will also be optional discussion sessions every other week via Zoom. There will be no compensation for completing the program.
 - The two focus groups will be 60 minutes each session. The two optional discussion sessions during weeks two and four will be a minimum of 45 minutes with a maximum of 60 minutes.

TIMELINE OF THE VIRTUAL-BASED ADAPTIVE SPORTS PROGRAM

PRE-SCREENING INTERVIEW

CONSENT FORMS

**4 WEEK PROGRAM VIDEO
MODULES
15-30 MINUTES
(OCCURS WEEKS 1, 3)**

**OPTIONAL 45-60 MINUTE GROUP
DISCUSSION SESSION OF THE
MODULES
(OCCURS WEEKS 2, 4)**

Appendix K - Procedure(s) used to ensure that participants are aware of their right to refuse to participate in the study, of the behavior they will be asked to manifest and any possible discomfort they may experience, and of their right to withdraw from the study at any time.

The participants who agree to complete the study will also be sent an audio and video release form and an informed consent form through Google Forms. The audio and video release forms and informed consent forms will be reviewed via Zoom to review and answer any questions regarding the right to refuse and the right to withdraw from the study entirely. The release forms will be signed and sent back to the researchers. Refer to the release forms in Appendix F.

Appendix L - In the space below, please provide a brief description of the methods to be employed in the research, including a description of the participants and how you plan to recruit them, the materials to be used, and the research procedure(s).

This research is oriented towards program development, with the aim to further develop an existing program, *Unlimbited* Wellness is a remote program/virtual that serves to inform and empower individuals with upper limb absence to likelihood of secondary conditions, managing physician appointments, managing awkward social situations, communicating with medical professionals, and organizing one's own medical information toward self-advocacy. The first part of the program is to create virtual-based educational and instructional modules focusing on adaptive sports for the ULA population. The second part of the program measures the efficacy of the program regarding overall well-being and independence.

The research procedure for the participants will include gathering information on the ULA population or any other related conditions, recruiting participants to take part in the program, providing a pre-screening interview questions, sending a welcome email to the program, signing and reviewing the informed consent form, completing and reviewing the audio and video release form, completing and reviewing the confidentiality agreement via Zoom, providing pre surveys and attending the initial focus group, establishing and implementing the program, providing post surveys and attending the closing focus group, and discussing data collected. For more information on the pre-screening interview questions, see Appendix D Part 1. For more information on the pre and post surveys, see Appendix E. The pre and post survey question will be the same before and after completing the program.

Inclusion criteria for participants completing the study includes being 18 years of age or older, having any form of acquired or congenital ULA or any other related conditions. Related conditions may include hemiplegia, brachial plexus injuries, etc. Exclusion criteria for participants completing the study includes being under the age of 18.

Individuals with ULA will be researched and recruited via email by Mary Grace Sansait OT/s,

Ariane Sudenfield OT/s, Jeanne Uwera OT/s, Dr. Debra Latour, Assistant Professor and Doctoral Experiential Capstone Coordinator at Western New England University, and Amy Ginsburg CPO and Upper Limb Prosthetist at Handspring Clinical Services. Amy Ginsburg will act as the site mentor for this program. Researchers will gather an email list from Handspring Clinical

Services. The facility letter of support to partner with Handspring Clinical Services is included in Appendix N. *Unlimbited* Wellness is a program developed, owned, and distributed by Single-Handed Solutions, LLC, owned by Dr. Debra Latour. Researchers also requested written approval from Single-Handed Solutions, LLC to utilize the *Unlimbited* Wellness program. The approval letter from Single-Handed Solutions, LLC is included in Appendix M. Virtual flyers and recruitment emails included in Appendix C will be sent via email to the clients of Handspring Clinical Services by either Amy Ginsburg. Once the virtual flyers and recruitment email are sent out, potential participants have one week to notify the researchers of their interest to participate in the program.

Pre-screening interview questions will be asked to individuals willing to participate in the program. The individuals will be emailed the pre-screening interview questions two days prior to the semi-structured interview which will be conducted via Zoom. They will be sent and asked the pre-screening interview questions in Appendix D Part 1. Participants will be deemed eligible if they meet the inclusion criteria, which includes being 18 years of age or older, having any form of acquired or congenital ULA or any other related conditions. After being deemed eligible for the program, the participants will be sent a welcome email included in Appendix D part 2. Participants who will be completing the program will sign the audio and video release form and informed consent form through Google Forms in Appendix F and will need to return the form via email within one week. The pre and post surveys will include sections of The Pizzi Health and Wellness Assessment and sections of The QuickDASH Sports Module. The initial focus group will be conducted via Zoom with the pre survey and the closing focus group will also be conducted via Zoom with the post survey. The participants will be emailed sections of The Pizzi Health and Wellness Assessment and sections of The QuickDASH Sports Module. They will have one week to return the two assessments. The questions for the initial and closing focus groups for the participants are included in Appendix E. A higher score on the pre and post The Pizzi Health and Wellness Assessment and sections of The QuickDASH Sports Module will indicate improved independence and well-being. Also, a higher score on the 5 point Likert scale from the pre and post focus group interview questions indicates increased education in adaptive sports and recreational activities. Following the end of the program, each participant will complete the participant satisfaction survey on Google Forms, the questions are located in Appendix H. The forms will be stored in a password protected file for three years on Handspring's electronic record system for the virtual-based adaptive sports programs. Participant names will be coded for confidentiality. Participants who are completing the program will also need to complete a confidentiality agreement form sent through Google Forms before attending

the focus group sessions in Appendix G. Ariane Sudenfield OT/s, Jeanne Uwera OT/s, Mary Grace Sansait OT/s, Amy Ginsburg, and Dr. Debra Latour will have access to the codes.

Materials used will include laptop computers for Zoom.us, word processing, excel processing, audio and video release form, pre-screening template, virtual flyers, and two survey templates.

Appendix M -Letter of Approval from Single-Handed Solutions, LLC



June 1, 2022

To Whom It May Concern;

As the Owner of Single-Handed Solutions, LLC, I give my permission to WNE OTD students Mary Grace Sansait, Ariane Sudenfield, and Jeanne Uwera to use the *Unlimb*ed Wellness program © 2018 as part of their Doctoral Experiential Capstone project.

With Kind Regards;

A handwritten signature in black ink, appearing to read "Debra Latour".

Debra Latour, PP-OTD, M.Ed., OTR/L

Appendix N- The Facility Letter of support from Handspring Clinical Services



Handspring
A division of POA Inc.

www.myhandspring.com

**Specializing in Upper
Limb Prosthetic Care**

Handspring Clinics

5 Penn Plaza, 19th floor
8th Ave at 33rd Street
New York, NY 10001

4 Riverside Drive
Middletown, NY 10941

1245 E Colfax Ave
Suite 200
Denver, CO 80218

750 E 100 S
Salt Lake City, UT 84102

Phone: (800) 593-9318
Fax: (845) 344-6829

Clinical Staff

Founder & Clinical Advisor:
Thomas Passero, CP

Director of Clinical Services:
Laura Katzenberger, L/CP

Upper Limb Specialists:
Tim Bump, MSPO, CPO
Chris Fink, MSPO, CPO
Amy Ginsburg, CPO
Megan Hodgson, CPO
Clinical Therapy Consultant:
Debra Latour, OTD, M.Ed.,
OTR/L



June 1, 2022

Re: Support for *Unlimb*ed Wellness program

Dr. Diptiman Bose,
Chair,
Institutional Review Board at Western New England University:

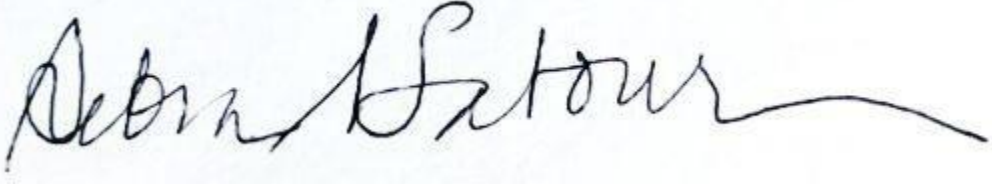
I agree to support the work of Debra Latour and her doctoral students: Mary Grace Sansait, Ariane Sudenfield, and Jeanne Uwera during the proposed development of the *Unlimb*ed Wellness program. As Chief Operating Officer of Handspring, I have given Debra Latour, PP-OTD, M.Ed., OTR/L and the named students permission to use our resources to conduct the telehealth portion of their project.

In summary, I support the intent of this proposed study and am pleased to provide the venue for conducting the telehealth program development portion. Please feel free to contact me with any questions or concerns.

Sincerely yours,

Laura Katzenberger, CP, LP
Director of Clinical Services & Chief Operating Officer
Handspring
laura@myhandspring.com
(845) 956-0001

Appendix O - Signatures

A handwritten signature in black ink that reads "Debra Latour". The signature is written in a cursive style with a long horizontal flourish at the end. It is positioned to the left of a vertical line.

1. Responsible Project Investigator's Signature: Dr. Debra Latour OTD, OTR/L Date: 6/01/2022

A handwritten signature in black ink that reads "Mary Grace Sansait". The signature is written in a cursive style with a large, stylized "M" and "G".

2. Investigator's Signature: Mary Grace Sansait OT/s Date: 06/01/2022

A handwritten signature in black ink that reads "Ariane Sudenfield". The signature is written in a cursive style with a large, stylized "A" and "S".

2. Investigator's Signature: Ariane Sudenfield OT/s Date: 06/01/2022

A handwritten signature in black ink that reads "Jeanne Uwera". The signature is written in a cursive style with a large, stylized "J" and "U".

2. Investigator's Signature: Jeanne Uwera OT/s Date: 06/01/2022

Appendix P – Belmont Principles

I certify that I have read the Belmont Principles

(<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the responsibility for the ethical conduct of the study rests with the primary investigator. I agree to report any participant's complaints that may arise to the IRB.

Dr. Debra Latour OTD, OTR/L

I certify that I have read the Belmont Principles (<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the responsibility for the ethical conduct of the study rests with the secondary investigator. I agree to report any participant's complaints that may arise to the IRB.

Mary Grace Sansait OT/s

I certify that I have read the Belmont Principles (<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the responsibility for the ethical conduct of the study rests with the secondary investigator. I agree to report any participant's complaints that may arise to the IRB.

Ariane Sudenfield OT/s

I certify that I have read the Belmont Principles (<http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>) and the American Psychological Association's* ethical principles concerning research with human participants (<http://www.apa.org/ethics>). I will adhere to the policies and procedures explained therein. Should changes in the procedure or consent form described above (or in related documents) become advisable, I will submit them to the IRB for approval. I understand that the

responsibility for the ethical conduct of the study rests with the secondary investigator. I agree to report any participant's complaints that may arise to the IRB.

Jeanne Uwera OT/s

Appendix Q – Certificates

11/4/2020

Proficiency - Certificate of Completion for Ethics and Human Subject Protection: A Comprehensive Introduction



Certificate of Completion

Association of Clinical Research Professionals certifies that

Debra Latour

has successfully completed

**Ethics and Human Subject Protection: A Comprehensive
Introduction**

Version: Jan 2020

Date of completion: Nov 4, 2020

A handwritten signature in black ink, appearing to read "Jim Kremidas", is written over a horizontal line.

Jim Kremidas – Executive Director





SOCIETY OF
BEHAVIORAL
MEDICINE

Good Clinical Practice Training for Social and Behavioral Research

CERTIFICATE of COMPLETION

This certifies that

Mary Grace Sansait

SBM tracking ID: 34457

completed the National Institutes of Health Office of Behavioral and Social Science Research good clinical practice for social and behavioral research in clinical trials e-learning course on 7/8/2020.

Lindsay Bullock
Executive Director, Society of Behavioral Medicine

Society of Behavioral Medicine
555 East Wells Street, Suite 1100 * Milwaukee, WI * 53202
Phone: (414) 918-3156 * Fax: (414) 276-3349
www.sbm.org



SOCIETY OF
BEHAVIORAL
MEDICINE

Good Clinical Practice Training for Social and Behavioral Research

CERTIFICATE of COMPLETION

This certifies that

Ariane Sudenfield

SBM tracking ID: 34299

completed the National Institutes of Health Office of Behavioral and Social Science Research good clinical practice for social and behavioral research in clinical trials e-learning course on 6/17/2020.

Lindsay Bullock
Executive Director, Society of Behavioral Medicine

Society of Behavioral Medicine
555 East Wells Street, Suite 1100 * Milwaukee, WI * 53202
Phone: (414) 918-3156 * Fax: (414) 276-3349
www.sbm.org



SOCIETY OF
BEHAVIORAL
MEDICINE

Good Clinical Practice Training for Social and Behavioral Research

CERTIFICATE of COMPLETION

This certifies that

Jeanne Uwera

SBM tracking ID: 34456

completed the National Institutes of Health Office of Behavioral and Social Science Research good clinical practice for social and behavioral research in clinical trials e-learning course on 7/8/2020.

Lindsay Bullock
Executive Director, Society of Behavioral Medicine

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555 East Wells Street, Suite 1100 * Milwaukee, WI * 53202
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www.sbm.org

Appendix E: Submitted Poster Abstracts

Impact of Adaptive Sports Participation on Well-being and Independence for Individuals with Upper Limb Absence (ULA) *Western New England University*

Mary Grace Sansait, OTD, Ariane Sudenfield OTD, Jeanne Uwera OTD

Debra Latour, PP-OTD, M.Ed., OTR/L

A qualitative study was conducted to determine how a virtual-based adaptive sports program impacts the well-being and independence for individuals with upper limb absence (ULA). The program consists of functional fitness, cross-over function featuring diverse prosthetic technologies, and adaptive yoga video modules that specifically cater towards the ULA population. Individuals 18 years of age or older with acquired or congenital ULA and any other related conditions (hemiplegia, brachial plexus palsy, etc.) were included in the study. This poster will share the findings and common themes, data analysis/program evaluation, results, discussion/implications, and future recommendations of our study.

Learning objectives: By the end of the presentation, attendees will be able to:

1. Increase knowledge on how to serve individuals of the ULA population
2. Gain a greater understanding of the benefits of overall participation in adaptive sports
3. Become more knowledgeable on how to modify various exercises and yoga positions specific to different levels of limb absence
4. Increase awareness and access of diverse prosthetic technologies

General Information regarding the speakers:

Western New England University WNEU Faculty Mentor: Debra Latour *PP-OTD, M.Ed., OTR/L*,

- Email: Debra.Latour@wne.edu

Western New England University (WNEU) Doctors of Occupational Therapy:

- Mary Grace Sansait OTD, Ariane Sudenfield OTD, Jeanne Uwera OTD
- Emails: mgracesansait@gmail.com, ariane.sudenfield@gmail.com, uwera96@gmail.com

Author(s)

1. [Ariane Sudenfield, OTD](#) (Role: Presenter;Author)
2. [Mary Grace Sansait, OTD](#) (Role: Author)
3. [Jeanne Uwera, OTD](#) (Role: Author)
4. [Debra Latour, OTD, M.Ed., OTR/L](#) (Role: Author)

Abstract Information

Category

Upper Limb Prostheses

Presentation Description. A short description of the presentation must be provided. This description will be included in Annual Meeting promotional materials if your paper is accepted.

Appendix F: Learning Objectives

1. Collaborate with various professionals as part of an interprofessional team to advocate the role of occupational therapy in a nontraditional setting.
2. Document a needs assessment for a particular population and use said assessment as the foundation for planning a successful Doctoral Experiential Capstone Project. Additional evidence will include feedback from consumers that indicates the impact of the project on the population they represent.
3. Demonstrate proficiency and professionalism with the use of personal computers, learning platforms, zoom meetings, etc. to fully document and implement Doctoral Experiential Project for WNE as well as for members of the population served.
4. Recognize and be able to describe the diverse systems of service delivery that are most cost-effective and considerate for health, social, and educational settings, both traditional and nontraditional. Through both clinical and reflective writing, be able to articulate a sensitivity to cultural, linguistic, and other diversities and describe solutions for care disparities.
5. Demonstrate the ability to work with others to identify meaningful objectives, organize, manage, and motivate people and resources, communicate effectively, and oversee action to accomplish stated program or service goals.
6. Demonstrate the ability to implement in existing programs, and plan for in developing programs, an occupational therapy process that is occupation-based, client-centered, culturally sensitive, and ethically appropriate.

7. Document an experiential and scholarly project that reflects the literature in restorative justice/community re-entry and use responsive, ethical methods. The scholarly process and results should be made accessible to the college and the community, especially to the population served by the project. A report of the project, presented in a professional format that others can replicate or build upon, will be evidence of accomplishment.
8. Through both clinical and reflective writing, be able to articulate a clear awareness of my own personal and professional strengths and boundaries and identify supports and strategies for goal achievement.
9. I will develop a better understanding of prosthetic technology and the rehab process to improve my ability to collaborate with others in this field, as measured by successful completion of upper limb prosthetic rehabilitation course and journal club.
10. I will develop video tutorials (e.g. different series of exercises, basic conditioning) specific to the ULD population in collaboration with Handspring Prosthetics and Destiny's Ride to be published on various platforms.
11. By the end of the diverse recreational and fitness program combined with UnLimbited Wellness, the participants will have gained an improved sense of well-being, as measured by an increase in their post-evaluation scores on The Pizzi Health and Wellness Assessment.
12. By the end of the diverse recreational and fitness program combined with UnLimbited Wellness, the participants will become more independent with sports in their daily life, as measured by a decrease in evaluation scores from The QuickDASH Sports Module that correlates to improved function.