

Western New England University

Digital Commons @ Western New England University

OTD DEx Reports - College of Pharmacy and
Health Sciences

College of Pharmacy and Health Sciences

2021

Addressing the Needs of Individuals with Upper Limb Loss/ Difference(s) by Proposing Global Expansion of a Virtual Support Group

Maccabee Gabay
Western New England University

Follow this and additional works at: <https://digitalcommons.law.wne.edu/otd>

Recommended Citation

Gabay, Maccabee, "Addressing the Needs of Individuals with Upper Limb Loss/Difference(s) by Proposing Global Expansion of a Virtual Support Group" (2021). *OTD DEx Reports - College of Pharmacy and Health Sciences*. 25.

<https://digitalcommons.law.wne.edu/otd/25>

This Report is brought to you for free and open access by the College of Pharmacy and Health Sciences at Digital Commons @ Western New England University. It has been accepted for inclusion in OTD DEx Reports - College of Pharmacy and Health Sciences by an authorized administrator of Digital Commons @ Western New England University.

**Addressing the Needs of Individuals with Upper Limb Loss/Difference(s) by Proposing
Global Expansion of a Virtual Support Group**

Maccabee Gabay

Western New England University

Division of Occupational Therapy

Author Note

Doctoral Experiential Mentor: Dr. Debra Latour, PP-OTD, M. Ed., OTR/L

Doctoral Experiential Peer Mentors: Maccabee Gabay, OT/s, Alison Johnson, OT/s, Samantha
Pagano, OT/s, and Maura Pitluck, OT/s

No conflicts of interest to disclose. Address correspondence concerning this report to

Maccabee.gabay@wne.edu

Addressing the Needs of Individuals with Upper Limb Loss/Difference(s) by Proposing Global
Expansion of a Virtual Support Group

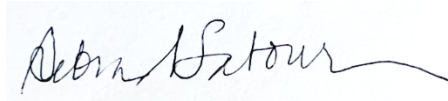
A Doctoral Experiential Capstone Project

by

Maccabee Gabay

July 2021

APPROVED BY:

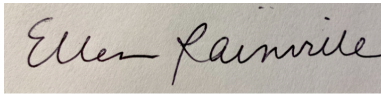


7/30/2021

The name and credentials go here
Faculty Mentor

Date

APPROVED BY:



8/1/2021_____

Ellen Berger Rainville OT, OTD, MS, FAOTA
Doctoral Experiential Coordinator

Date

Abstract

Unlimbited Wellness, which was developed by Dr. Debra Latour is a program designed to link individuals with upper limb absence as peers. Dr. Latour used telehealth (TH) to address the unmet needs of adults with upper limb absence through this program. The Unlimbited Wellness program successfully used TH to meet the specific needs of individuals with upper-limb absence to better their quality of life and empower them.

Our main goal for this project was to expand Unlimbited Wellness and provide services in a one-hour, weekly virtual group that ran for eight weeks. The goal of Unlimbited Wellness was to promote health and well-being through community support and engagement. It was designed to empower and educate group members to improve their quality of life. Part of a program planning process was to develop research questions to identify the population. The research questions that we developed mainly focused on program effectiveness on this population and if virtual support groups are effective.

The overarching goal of this project is to connect, educate, and empower individuals with upper limb absence(s) (ULA) through virtual community engagement with a focus on expanding the program to include varying ages, levels of ULA, and etiology.

Participants were recruited from Handspring Clinical Services using convenience sampling (Handspring n.d.). A total of 39 adults affected by ULA were invited to participate in the *Unlimbited* Wellness program. Nine individuals provided consent to participate in the program and filled out the pre-program survey developed by the researchers.

Introduction/Background

Upper extremities (UEs) are fundamental for activities of daily living, instrumental activities of daily living, communication, expression, and affection (Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011). When an UE is missing due to congenital or acquired factors, it is evident that an individual's livelihood is greatly affected (Golchin et al., 2014). Direct effects and the needs of individuals with upper-limb loss or congenital differences (ULL/D) are apparent; however, individuals with ULL/D may also have secondary physical and psychological needs (Latour, 2019; Stevens, 2011; Østlie et al., 2011).

Physically, there are increasing demands on the remaining limb resulting which may cause overuse injuries including pain in the back, neck, or shoulder of the remaining limb (Stevens, 2011). This may in turn may result in secondary psychosocial conditions such as social stigma, decreased self-image, and poor body image (Stevens, 2011; Østlie et al., 2011). The experiences individuals with ULL/D encounter require unique and specialized services. Because of this individuals with ULL/D may feel unsupported in their rehabilitation; they report a lack of access to care and peer support networks, and feel as though their provider lacks education or experience regarding their limb difference (Latour, 2019).

Adolescents with congenital limb deficits and upper limb loss are physically and noticeably different from their friends, classmates, siblings, and other peers. Sociology of adolescence highlights the importance of the individual's environment to the population and the significance of quality of life. Individuals with congenital limb deficits often present boundaries and limitations in social participation and activities. Quality of life and engagement are two critical elements in current pediatric research and are known to be essential in explaining the

health status of an individual with upper limb loss (Colver, 2006). Their involvement in daily activities is dependent on the severity of their deficiency and the lack of resources.

As a result of their differences, they are at a higher risk for lower engagement in leisure and social activities in and out of their home, mainly due to body image related to self-esteem (Deans et al., 2012). This may very well lead to a negative perception of their quality of life and may negatively influence their engagement with peers. Psychosocial functioning and participation can be analogous to a healthier lifestyle. The main focus was on lack of education with prosthetic use, negative self-image, decreased social participation, and decreased overall quality of life in individuals with limb deficiencies and upper-limb loss (Michielsen, Van Wijk, & Ketelaar, 2010).

The target population consisted of children ages 5 and 13 years with upper limb loss and congenital limb deficiencies in the United States. However, the age group for the population was changed due to lack of participants and IRB complications. Severe disability, as in upper limb loss, can alter the individual's position and social role among peers, mainly in the early period of his or her life (Dantona, Tessler, 1967). The environment consistent with this population is primarily at their school, home, social gatherings, and events within the community. Due to the lack of available data, it is important to address problems such as education, self-image, social participation and overall quality of life within this population.

Students will complete needs assessments for their target population, and incorporate this information using the precaution adoption process model (PAPM) to design program modules (Glanz, Rimer, Viswanath, 2008). The needs assessment can be located in Appendix A. The PAPM pairs well with *Unlimbited* Wellness as it offers a linear and systematic progression of

seven steps toward change, including the choice of no change. The stages of the PAPM are dynamic, and a population journeys through them progressively: individuals may revert to a prior stage, decide not to act, or move forward. Additionally, the logic model will be used for program implementation and evaluation to visually organize linkages between the participants, resources, and outcomes (McCawley, n.d.).

The logic model offers a sequential “if/then” type of deduction. Each step of the process builds upon the next and considers the elements of accountability (relevance, quality and impact) to facilitate buy-in from stakeholders. In regards to measuring outcomes, the logic model allows the researchers to analyze the relationship between the situation, or a statement of the problem and how it affects a population, and the necessary resources such as time, funds, materials, and knowledge.

Doctoral Experiential Overview

The Western New England University (WNEU) Doctoral Experiential 2021 group under the mentorship of Dr. Debra Latour is expanding the efforts of the mentor’s doctoral work: *Unlimbited Wellness* (Latour, 2019). *Unlimbited Wellness* is a program directed toward engaging, empowering, and educating individuals with upper limb loss/differences (ULL/D). Many individuals with ULL/D experience secondary physical and psychosocial conditions as well as a lack of access to resources such as quality care and peer support.

This program aims to link members as peers to inform them of diverse secondary conditions with shared strategies to prevent further disparity, and offer access via telehealth (TH). As a platform, TH has potential to address some of the needs of the population with ULL/D by bridging discrepancies in care. *Unlimbited Wellness* aligns with the efforts of the

Healthy People 2020 program which demands health care and public health professionals to address the needs of populations and prevent further disparities (Healthy People 2020, n.d.).

Community Experiential

Prior to the start of this Doctoral Experiential project, students participated in the professional education mini-course, “Upper Limb Prosthetic Rehabilitation for Occupational Therapists”. This course consisted of 5 modules which were then followed with a terminology sheet and a quiz after each module was reviewed.

As the Unlimbited Wellness program started, there were weekly protocols that were created towards facilitating each session. Furthermore, after each session, tip sheets were created based on each module. The five modules that were created consisted of Overuse Conditions: Part 1, Overuse Conditions: Part 2, Preparing for a Medical Consult, Awkward Social Situations, and Intimate Relationships. The empty tip sheets were given to the participants prior to each session and were filled out after each session then emailed to the participants with all the included information.

The Unlimbited Wellness Resource Guide was developed to further educate, support, and empower individuals with upper limb absence(s). The resource guide includes adaptive equipment recommendations, general resources, exercises and stretches, breathing exercises, ergonomic sitting suggestions, and the compiled tip sheets. This guide is for educational purposes only and is owned by Single-Handed Solutions, LLC.

Scholarly Component

Prior to the 14-week experiential component, we began writing an Internal Review Board (IRB) proposal draft under the advisement of Dr. Debra Latour, OTD, M. Ed, OTR/L. Over the course of 14 weeks, we will establish the WNEU Telehealth Center in the basement of the

Bellamy House to conduct research and provide support to limb loss organizations. The IRB application is required for data collection and analysis of that data from the *Unlimbited* Wellness program. The IRB application was submitted at Western New England University review board.. A requirement that needed to be completed prior to submitting the IRB consisted of the CITI Program: Social and Behavior Research Basic Course. Upon completion, a certificate was given to each group member. Once the IRB was approved, the *Unlimbited* Wellness program was implemented. The IRB application can be found in Appendix B.

Program Surveys

Pre-program, post-program, and weekly post-session surveys were developed prior to the start of the program. These surveys were formed to determine participant acceptance, analyze participant satisfaction rate and feedback for the conducted session. After participation in all five sessions, participants were asked to give their overall opinion of the program on a Likert scale.

Call for Papers MAOT

Our group submitted a Call for Papers for the fall 2021 Massachusetts Annual Occupational Therapy (MAOT) Conference. The purpose for our submission was to present our findings of the *Unlimbited* Wellness program at the MAOT conference. In the submission, we completed an abstract and developed a learning objectives to describe our program, the participants and the results. The application can be found in Appendix C

Literature Review

Upper extremities (UEs) are fundamental for activities of daily living, instrumental activities of daily living, communication, expression, and affection (Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011). When an UE is missing due to congenital or acquired factors, it is evident that an individual's livelihood is greatly affected. Direct effects and the needs of

individuals with upper-limb loss or congenital differences (ULL/D) are apparent; however, individuals with ULL/D also have needs surrounding secondary physical and psychological complications (Latour, 2019; Stevens, 2011; Østlie et al., 2011). Physically, there are increasing demands on the remaining limb resulting from overuse injuries including pain in the back, neck, or shoulder of the remaining limb (Stevens, 2011). This may in turn may result in secondary psychosocial conditions including increased social stigma, decreased self-image, and poor body image (Stevens, 2011; Østlie et al., 2011).

The experiences individuals with ULL/D encounter require unique and specialized services. Because of this individuals with ULL/D may feel unsupported in their rehabilitation; they report a lack of access to care and peer support networks, and feel as though their provider lacks education or experience regarding their limb difference (Latour, 2019). As a result, insufficient support from peers and professionals can lead to lower self-reported quality of life and lower life satisfaction scores (Stevens, 2011; Østlie et al., 2011).

Recently in the United States, there has been a shift in the use of telehealth (TH) as a service delivery model in healthcare. As a health service modality, TH has many benefits which include: flexibility and accessibility to high-quality care, especially for individuals living in remote areas or areas with provider shortages; time efficiency for home, work, and travel; reinforced communication between providers and patients; decreased healthcare costs for both the provider and patient; and improved self-awareness through patient education and empowerment, in regard to managing their chronic conditions (Donelan et al., 2019; Kruse et al., 2017). The many benefits of TH, such as supporting quality of care and overcoming barriers to accessing care, support the Triple Aim initiative to improve population health outcomes (Nash, Fabius, Skoufalos, Clarke, & Horowitz, 2016). Complete literature review can be found in

Appendix D.

Purpose

According to Khan, et al, (2016), It is determined that individuals with ULL/D between the ages of 5 and 12 years old are at a greater risk for developing secondary physical and psychosocial conditions. As a result, there is a need to address self-image, social acceptance, participation and transitions for this population. All of these factors may lead to lower quality of life and satisfaction for children with ULL/D. This gap in care reflects unmet needs that can be addressed via TH. Currently, organizations such as Handspring, is looking to incorporate TH into their practices to address ULL/D needs. Both Handspring and *Unlimbited* Wellness, focus on providing resources and a holistic approach for patients who require specialized care in upper limb prosthetic rehabilitation as well as needing resources to combat secondary conditions to be able to engage in activities of daily living.

Handspring, and *Unlimbited* Wellness (Latour, 2019) provide resources, outreach opportunities, and increase connections within the ULL/D community to improve quality of life. The implementation of a TH center at WNEU has the potential to connect these organizations and programs to benefit children between the ages 5 and 12 years old with ULL/D. Through the TH center, individuals in this age group could access resources relevant to their unique needs and connect with a peer support group to develop skills for preventing and improving physical overuse, social isolation, and advocacy skills.

Methodology

Program Goal

The overarching goal of this project is to connect, educate, and empower individuals with upper limb absence(s) (ULA) through virtual community engagement with a focus on expanding the program to include varying ages, levels of ULA, and etiology.

Target population and sampling

Participants were recruited from Handspring Clinical Services using convenience sampling. Participant inclusion criteria were adults 18 years or older with ULA and parents/guardians of children with ULA between the ages of five and 17. Exclusion criteria included intellectual disabilities such as dementia, literacy rates below an 8th grade level, or an inability to communicate verbally, and an inability to access necessary technologies such as WiFi, videoconferencing capabilities, or appropriate bandwidth.

Handspring Clinical Services afforded resources required for this program expansion. Support included access to client databases, a HIPAA-compliant platform, Microsoft Teams, access to social media pages, and a clinical consultant. There were no additional costs to run this program, as the program occurred virtually. Program facilitators prepared and coordinated all sessions, and participants attended the sessions free of charge.

Program Activities and Management

The program was held in one hour weekly sessions over the course of five weeks. Each week covered a different topic to facilitate discussion. Figure 1 describes the timeline of activities. Prior to each session, participants received an email reminder, meeting invitation, and an incomplete tip sheet template relevant to the specific topic. Partially completed tip sheets and group protocols served as framework for the sessions. The tip sheets served as preparatory worksheets, springboards for discussion, and resources for participant use in their final state. After each session, participants filled out a GoogleForm questionnaire for researchers' to gather

feedback on the sessions. Attendance for each session varied. Figure 2 details participant weekly attendance.

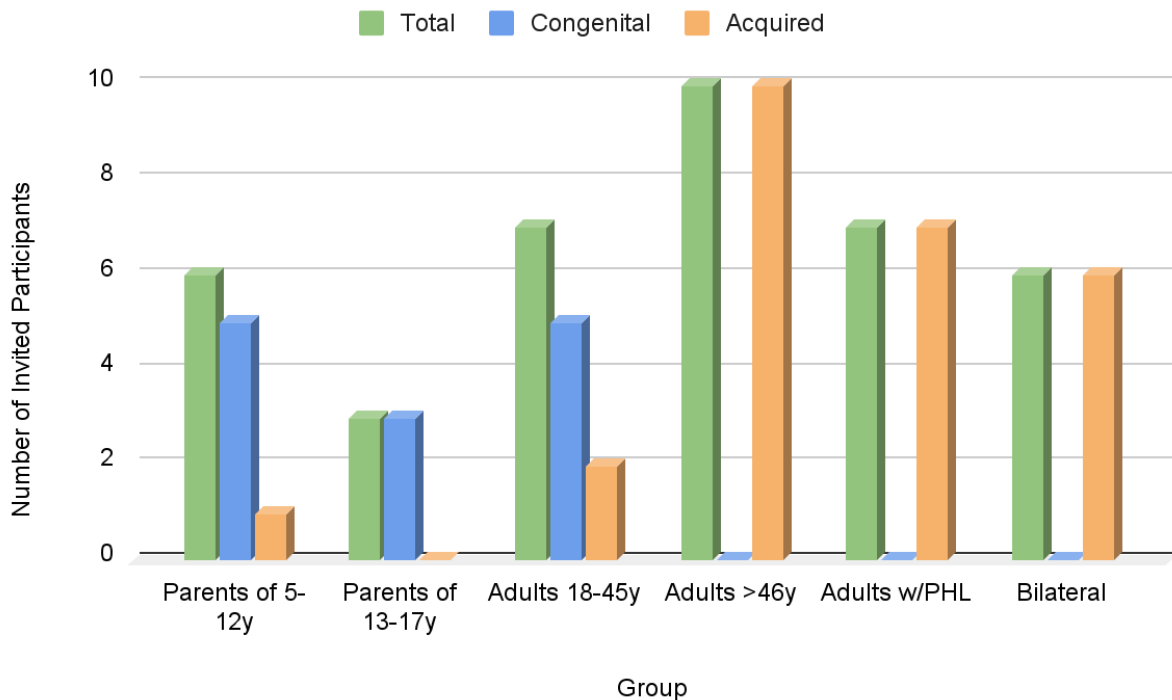
Results

A total of 39 adults affected by ULA were invited to participate in the *Unlimbited* Wellness program. Figure 3 summarizes participant demographics from the community partner's client database. Nine individuals provided consent to participate in the program and filled out the pre-survey. A total of four participants completed this post-survey ($n = 4$).

Of the 17 items, participants' responses on 10 items reflect positive changes, with question 11 having the greatest positive percent change (+ 16.0%). Responses on seven items reflect negative changes, with question 16 having the greatest negative percent change (- 26.6%). Table 1 details the survey questions, pre and post-program average scores, and percent change averages. One-hundred percent of participants ($n=4$) reported that they would attend another *Unlimbited* Wellness session. The following figure describes participants' self-reported gains from attending the program. Complete program evaluation report and results can be located in Appendix E.

Figure

Invited Participant Demographics



Mini Project

As part of the DEx requirements, I volunteered to work with Handsmart for my mini project. Handsmart's mission is to support and empower people world-wide by creating and updating an open access, easily understandable consensus resource based on evidence, for those engaged in upper limb loss/difference rehabilitation (Handsamrt n.d.). The Handsmart team consists of 16 independent international experts consisting of 15 therapists (4 physical and 11 occupational therapists) and 1 prosthetist, from different regions of the world. The clinicians are all either independent practitioners or working with a company and specialized in upper limb absence rehabilitation, either in clinical or research settings.

I got involved working with Handsmart which is a group of international clinicians focusing on upper limb absence rehabilitation. I have currently proposed the global expansion of a virtual support group to handsmart by attempting to expand the *Unlimbited* Wellness program

on a global scale. The proposed ideas consisted of increasing web traffic for handsmart, expand the *Unlimbited* Wellness program, link individuals with upper limb absence(s) worldwide, find partnering organizations and generate revenues by offering continuing education units (CEUs). Furthermore, I plan to move forward with this project by linking with different individuals who are experienced with program expansion, and partnering organizations to move this project forward. More information can be located in Appendix F.

Discussion

Individuals with ULA require specialized services; yet, there are limited resources available (Maduri & Akhondi, 2021; Kannenberg, 2017). Individuals with ULA are at increased risk for developing secondary physical and psychosocial conditions (Latour, 2019; Braza & Yacub Martin, 2020; Østlie et al., 2011).

The results of this program suggest that a virtual support group is effective in connecting and educating participants of varying ages, levels of absence, and etiology. The program survey was designed to gather group members' perceptions on their health and wellness pre- and post-program participation. Data from Likert-scale items and data from self-reported program gains indicate participants learned from each other, learned about secondary health conditions, learned preventative strategies, and increased access to resources. However, study limitations exist and influence the interpretation of data results. The survey used lacked validation and reliability; therefore, the data should be interpreted with caution.

Learning Outcomes

Although attendance fluctuated, a core group of participants attended most sessions. This enhanced rapport between program facilitators and participants, and supported engagement and participation in in-depth weekly discussions. At the end of the program, all participants reported

that they would attend future *Unlimbited* Wellness sessions, suggesting this program's appropriateness in reaching all members of the ULA population. The following table identifies the strengths, weaknesses, opportunities, and threats (SWOT analysis) of *Unlimbited* Wellness.

Table
SWOT Analysis of Unlimbited Wellness

<p>Strengths</p> <ul style="list-style-type: none"> • Program expanded to various ages, levels of limb absence, and etiology • Increased access to resources (+16%) • Connected individuals with ULA (50% self-reported) • Participants learned from each other (75% self-reported) • Learned about secondary health conditions (50% self-reported) • Learned strategies for preventing secondary health conditions (75% of participants; +13.56 increase from pre-to post-) • Overall satisfaction rating from five sessions: 4.4 • Intraprofessional collaboration • Support from Handspring • Program facilitators learned from participants • Weekly feedback to guide program • Covered varying topics in short duration • Intimate group size • Consistent participation after session 1 • Developed resource guide 	<p>Weaknesses</p> <ul style="list-style-type: none"> • Study duration • Inconsistent participation • Non-standardized assessments • Newly developed surveys • No pre-study interviews to determine participant appropriateness • Small sample size <ul style="list-style-type: none"> ◦ No in-depth data analysis • No direct communication with participants • Contradictory data • Differing needs between participants
<p>Opportunities</p> <ul style="list-style-type: none"> • Interprofessional collaboration • Connect members of ULA population nationally • Virtual support groups easily accessible • Specialized knowledge in niche area: inform future OT practice • Additional virtual programming 	<p>Threats</p> <ul style="list-style-type: none"> • Participant drop-out • Varying time zones • Inclement weather affecting internet connection • IRB limitations • Small target population

The results of this program are encouraging and demand further investigation. Future research related to the expansion of the *Unlimbited* Wellness program should aim to include the use of standardized assessment tools to measure program effectiveness. Performing more in-depth statistical analyses is suggested to improve study reliability and validity. Additionally, increasing the sample size, lengthening study duration, and administering one-on-one interviews with participants will produce results generalizable to the greater ULA population.

References

- Braza, D. W., & Yacub Martin, J. N. (2020). Upper limb amputations. In Frontera W. R., Silver J. K., & Rizzo T. D. (Eds.). *Essentials of physical medicine and rehabilitation: musculoskeletal disorders, pain, and rehabilitation (4th ed.)*. Elsevier.
- Colver, A. (2006). What are we trying to do for disabled children? *Current Paediatrics*, 16: 501–505. <https://doi.org/10.1016/j.cupe.2006.08.014>
- Dantona, R., Tessler, B. (1967) Architectural barriers for the handicapped. A Survey of the Law in the United States. pp. 34–43.
- Deans, S., Burns, D., McGarry, A., Murray, K. and Mutrie, N. (2012). Motivations and barriers to prosthesis users participation in physical activity, exercise and sport: a review of the literature. Retrieved from <https://journals.sagepub.com/doi/pdf/10.1177/0309364612437905>
- Donelan, K., Barreto, E.A., Sossong, S., Michael, C., Estrada, J.J., Cohen, A.B., Wozniak, J., & Schwamm, L.H. (2019). Patient and clinician experiences with telehealth for patient follow-up care. *The American Journal of Managed Care*, 25(1), 40-44.
- Glanz K, Rimer B, Viswanath K. (2008). Health behavior and health education: Theory, research, and practice. 4th ed. Jossey-Bass.
- Golchin, M., Attarchi, M., Mirzamohammadi, E., Ghaffari, M., & Mohammadi, S. (2014). Assessment of the relationship between Quality of Life and Upper Extremity Impairment Due to Occupational Injuries. *Medical journal of the Islamic Republic of Iran*, 28, 15
- Handspring. (n.d.). Holistic care for patients needing upper limb prosthetic & orthoses. <https://myhandspring.com/>
- Khan, M. A., Javed, A. A., Rao, D. J., Corner, J. A., & Rosenfield, P. (2016). Pediatric

- Traumatic Limb Amputation: The Principles of Management and Optimal Residual Limb Lengths. *World journal of plastic surgery*, 5(1), 7–14.
- McCawley P. (n.d.). The logic model for program planning and evaluation. University of Idaho Extension. [https:// www.cals.uidaho.edu/edcomm/pdf/cis/cis1097.pdf](https://www.cals.uidaho.edu/edcomm/pdf/cis/cis1097.pdf).
- Michielsen, A., Van Wijk, I., & Ketelaar, M. (2010). Participation and Quality of Life in Children and Adolescents with Congenital Limb Deficiencies: A Narrative Review. *Prosthetics and Orthotics International*, 34(4), 351–361
<https://doi.org/10.3109/03093646.2010.495371>
- Nash, D.B., Fabius, R.J., Skoufalos, A., Clarke, J.L., & Horowitz, M.R. (2016). *Populationhealth: Creating a culture of wellness*. Burlington, MA: Jones & Bartlett Learning.
- Østlie, K., Magnus, P., Skjeldal, O.H., Garfelt, B., & Tambs, K. (2011). Mental health and satisfaction with life among upper limb amputees: a Norwegian population-based survey comparing adult acquired major upper limb amputees with a control group. *Disability and Rehabilitation*, 33(17–18), 1594–1607. doi: 10.3109/09638288.2010.540293
- Stevens, P. (2011). Losses Beyond the Limb: an analysis of the co-morbidities and challenges associated with upper-limb loss. *The O&P Edge*, December Issue. Retrieved from https://opedge.com/Articles/ViewArticle/2011-12_01

Appendix A

Needs Assessment

Identification of Problem or Unmet Needs

Adolescents and children with congenital limb deficits and upper limb loss are physically and noticeably different from their friends, classmates, siblings, and other peers. Sociology of childhood highlights the importance of the child's environment to population and the significance of quality of life. Children with congenital limb deficits often present boundaries and limitations in social participation and activities. Quality of life and engagement are two critical elements in current pediatric research and are known to be essential in explaining the health status of a child with upper limb loss (Colver, 2006). Their involvement in daily activities is dependent on the severity of their deficiency and the lack of resources. As a result of their differences, they are at a higher risk for lower engagement in leisure and social activities in school and home, mainly due to body image related to self-esteem (Deans et al., 2012). This may very well lead to a negative perception of their quality of life and may negatively influence their engagement with peers. Psychosocial functioning and participation can be analogous to a healthier lifestyle. I will be focusing on lack of education with prosthetic use, negative self-image, decreased social participation, and decreased overall quality of life in individuals with limb deficiencies and upper-limb loss (Michielsen, Van Wijk, & Ketelaar, 2010).

Identification of Target Population

The target population that I will focus on for this needs assessment is children ages 5 and 13 with upper limb loss and congenital limb deficiencies in the United States. Furthermore, this population consists of children who may or may not use prosthetics throughout the day. The Center for Disease Control Prevention (CDC) estimates that each year, 2250 babies are born with

congenital limb deficiencies (CDC, 2014). Severe disability, as in upper limb loss, can alter the child's position and social role among peers, mainly in the early period of his or her life (Dantona, Tessler, 1967). The environment consistent with this population is primarily at their school, home, social gatherings, and events within the community. Due to lack of available data, it's important to address problems such as education, self image, social participation and overall quality of life within this population.

Literature Review of Existing Data

Due to technological advancement and the positive influence of social media, the current research on this population is minimal. Evidence from the literature suggests that children with disabilities, such as upper limb loss, are at a higher risk for lower quality of life and psychosocial maladjustment compared to children without disabilities (Wallander, Varni, 1938). Moreover, several studies suggested that the participation of children with disabilities is correlated with a higher quality of life and decreased social and health problems. One article completed a survey to determine the quality of life among children with congenital deficiencies who use prosthetics compared to the general population. The purpose of this study was to compare the health problems that are associated with quality of life among prosthesis wearers compared to non-wearers. The result of this study indicated that quality of life with regards to school participation and functioning were higher among children who wore prosthetics. Another study demonstrated emotional and behavioral problems and lower social competence in children with limb deficiency. (Michielsen, Van Wijk, & Ketelaar, 2010). This intervention could be

effective for target population by increasing their functioning in school and overall quality of life.

Another study was done to evaluate functionality through education in acquired and congenital upper limb deficiency among children. The purpose of this study was to determine the functional level among children with congenital and acquired limb loss after a rehabilitation program such as education and proper usage. This study included 40 children ages 8 -17 with upper limb loss. The children were educated with prosthetic fitting, rehabilitation, and prosthetic training. This study compared children with and without prosthetics over six months. The results showed significant differences between the two groups. The children who underwent training showed higher scores in the Child Amputee Prosthetics Project - Functional Status Inventory (CAPP-FSI) and in Prosthetic Upper Extremity Functional Index (PUFI). The results showed that daily prosthetic usage through training and education leads to higher participation in activities (Soyer, Unver, Tamer, Ulger, 2016). This intervention could be effective for children with congenital limb deficiency and upper-limb loss by increasing participation in daily activities.

Another intervention that can be beneficial to empower individuals with upper-limb loss and to improve health behavior change is the use of telehealth. Individuals with upper limb loss are often struggling with being independent and require specialized services. Furthermore, they may come across secondary conditions such as pain, perception, overuse, isolation, and social stigma (Latour, 2019). Telehealth was developed to help these individuals prevent or overcome these secondary conditions. In a study done by Latour (2019), three individuals over the ages of

37 participated in the Unlimbted Wellness program for three months. The Unlimbted Wellness program is designed to use telehealth to help individuals interact with other peers and facilitators through telehealth to learn about psychosocial and physical health conditions and to share strategies to manage any secondary conditions related to upper limb loss (Latour, 2019). The results of this study showed that the program implementation was successful by comparing the pre-post group scores done by the Pizzi Health and Wellness Assessment (PHWA). The PHWA was used to measure pre and post changes in the social, physical, occupational, family, spiritual, and emotional components of the participants after the use of telehealth. The overall purpose of this study was to determine if this intervention can help individuals who come across secondary conditions, and after the duration of this program, the participants expressed feeling empowered and demonstrated changes in health behavior. Telehealth is often used for interventions across all ages and all conditions. This intervention could be effective for this target population by empowering individuals to overcome and manage secondary conditions.

Resource Availability and Barriers of Identified Problem

RESOURCES:

AMPOWER

AMPOWER Online Community is a safe, free online community for individuals with limb loss or their families to discuss and connect topics related to what it's like to be an amputee with each other. Their mission is to empower and strengthen those affected by limb differences through education, communication, and peer mentorship. To engage in a conversation with another individual with limb loss who may have shared the same experience as you can be very

motivating. Furthermore, one can help others with resources or access to information (AMPOWER, 2019).

New England Amputee Association

New England Amputee Association's (NEAA) mission is to reach out to people with limb loss and provide a supportive environment where information and experiences are shared, and friendships are formed (NEAA, 2019). The NEAA helps children with limb loss by providing funds from equipment and raises donations to send children to camps.

Amputee Coalition

The Amputee Coalition (AC) founded in 1986, is the nation's leading organization on limb loss for all ages. Their main goals are to improve patient care, enhance the quality of life, and prevent limb loss. They have served thousands of individuals with limb loss along with their families by educating and offering support as well as empowering each individual through their journey. Their mission is to reach out to individuals with limb loss and provide education, advocacy, and support (Amputee Coalition, 2019). The AC offers families with fact sheets to better educate them with the needs and resources required for an individual with limb loss. Furthermore, they provide information for grants through a variety of nonprofit and charity organizations such as Ability Found, Amputee Blade Runner, Help Hope Live, and others. The AC also offer support groups that provide a safe and supportive environment. The purpose of the support group is to connect with others who have faced challenges and were able to overcome them. This organization has been more involved with children with upper limb loss, and since 2000, they have provided a safe environment for children to learn more about living with limb

differences. They offer traditional six-day summer camps for kids with limb loss and limb differences from age 10-17 at no cost. Campers are challenged to develop skills to be more independent and built new friendships.

LIMB for LIFE

Limb for life foundation provides payment for prosthetics for amputees U.S citizens through donation. They currently have a variety of different locations across all states and are working with a company that offers prosthetics in West Springfield. This foundation is beneficial for this population because it can provide them with funding for prosthetics that they might not be able to afford.

BARRIERS:

Access to healthcare

A significant number of amputees reported barriers that were related to physical and emotional healthcare and environmental. One in 10 amputees did not receive medical care when they needed the most due to financial problems, and nearly half of the people with depressive symptoms reported a lack of support within their community (Amputee-coalition, 2005). Barriers to healthcare can affect children with congenital limb deficiency and upper-limb loss by limiting their access to equipment which can lead to a variety of different secondary conditions.

Self-perception

Adolescents are extremely cautious and careful about their self-image and may avoid any social interactions if they feel undermined or ridiculed. Research on adolescents and children with Limb loss indicates several participation restrictions. These restrictions are linked with a variety of personal limitations such as balance confidence, social discomfort, and emotional impact of amputation or satisfaction with a prosthesis. Furthermore, they also experience environmental restrictions such as lack of accessibility, living in rural areas, climate, and transportation issues (Gallagher et al., 2011). This barrier affects this target population by negatively affecting their self-image, social participation and environmental restrictions due to self-perception.

Appendix B

IRB Application

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)

1. Responsible
Project Investigator:

Phone No.:

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

E-mail:

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

Phone No.:

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

E-mail:

3. Title of Project:

4. Nature of the
Research and
Expected Benefit:

5. Anticipated Duration of the Project

From MM/YYYY:

To MM/YYYY:

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 Yes No
renewal?

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 #)

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

<input type="checkbox"/> Unpaid classroom volunteer	<input type="checkbox"/> Paid classroom volunteer
<input type="checkbox"/> Unpaid nonclassroom volunteer	<input type="checkbox"/> Paid nonclassroom volunteer
<input type="checkbox"/> Other (Please specify)	

9. Expected participant duration and compensation.

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

Expected participant compensation (Check all that apply.)

<input type="checkbox"/> No compensation	<input type="checkbox"/> \$\$ compensation
<input type="checkbox"/> Other (Please specify)	

If applicable, please
specify \$\$ rate

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

<input type="checkbox"/> On-campus	<input type="checkbox"/> On-Line	<input type="checkbox"/> Off-Campus
------------------------------------	----------------------------------	-------------------------------------

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

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?

<input type="checkbox"/> Yes	<input type="checkbox"/> 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.

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.

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).

19. Are you applying Yes No
for an exemption?

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.)

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:

Date

2. Investigator's
Signature, If Different:

Date

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

Appendix C
MAOT Application

Massachusetts Association for Occupational Therapy, Inc.
CALL FOR PAPERS CONFERENCE 2021
Papers must be mailed or received via email by June 1st

Title: *Unlimbited Wellness:Virtual Support for Upper Limb Absence*

Presenter #1: Dr. Debra Latour, PP-OTD, M. Ed., OTR/L

Job Title & Affiliation: Assistant Professor of Occupational Therapy, Western New England University__

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 413-782-1449

Fax: N/A _____ *Email:* debra.latour@wne.edu

Presenter #2: Maccabee Gabay, OT/s _____

Job Title & Affiliation: Doctor of Occupational Therapy Student, Western New England University_____

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 818-428-0070

Fax: _____ *Email:* Maccabee.gabay@wne.edu

Presenter #3: Alison L. Johnson, OT/s _____

Job Title & Affiliation: Doctor of Occupational Therapy Student, Western New England University_____

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 413-522-8160

Fax: N/A _____ *Email:* alison.johnson@wne.edu

Presenter #4: Sarah E. Kelly, OT/s

Job Title & Affiliation: Doctor of Occupational Therapy Student, Western New England University_____

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 617-291-8511

Fax: N/A _____ *Email:* sarah.kelly1@wne.edu

Presenter #5: Samantha A. Pagano, OT/s _____

Job Title & Affiliation: Doctor of Occupational Therapy Student, Western New England University_____

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 847-682-0464

Fax: N/A _____ *Email:* samantha.pagano@wne.edu

Presenter #6: Maura E. Pitluck, OT/s

Job Title & Affiliation: Doctor of Occupational Therapy Student, Western New England University_____

Notification Address: 1215 Wilbraham Road, Blake Law Center, Room 202, Springfield, MA 01119

Home Phone: N/A _____ *Work Phone:* 860-885-4263

Fax: N/A _____ *Email:* maura.pitluck@wne.edu

If you are promoting a product within your presentation please check here: ☐

Educational Level of Presentation: Refer to *Tip Sheet* for descriptions of each level.

☐ Student ☒ Introductory ☐ Intermediate ☐ Advanced

Presentation Length: ☐ Full Day (*Annual Conference Only*) ☐ 1.5 hour ☐ 1 Hour

☐ 30 Minutes (first time presenters & students only)

☐ Poster Presentation (*Annual Conference Only*)

Content Area (please circle):

Administration

Assistive Technology

Developmental Disabilities

Education

General Issues

Gerontology

Mental Health

Pediatrics

Physical Disabilities

Prevention/Wellness

Professional Development

Research

School Based Practice

Sensory Integration

Work Practice

Other _____

Abstract (75 word limit):

Unlimbited Wellness is a virtual support program aimed at empowering, educating, and engaging adults affected by upper limb absence(s) (ULA) (Latour, 2019). The purpose of this program is to promote health and well-being through community support. *Unlimbited* Wellness is a program developed and piloted by Dr. Debra Latour PP-OTD, M. Ed., OTR/L. Students at Western New England University have expanded this program and determined its effectiveness as part of their doctoral experiential capstone.

Learning Objectives

1. Participants will recognize virtual platforms as effective tools for facilitating support groups.
2. Participants will understand the unique needs of the ULA population.
3. Participants will learn about community program development and evaluation.

Reference:

Latour, D. (2019). *UnLimbited* Wellness: Telehealth for adults with upper-limb difference. *Journal of Prosthetics and Orthotics*, 31(4), 246-256. <https://doi.org/10.1097/JPO.0000000000000263>

Appendix D

Literature Review

Review of the Literature

Upper extremities (UEs) are fundamental for activities of daily living, instrumental activities of daily living, communication, expression, and affection (Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011). When an UE is missing due to congenital or acquired factors, it is evident that an individual's livelihood is greatly affected. Direct effects and the needs of individuals with upper-limb loss or congenital differences (ULL/D) are apparent; however, individuals with ULL/D also have needs surrounding secondary physical and psychological complications (Latour, 2019; Stevens, 2011; Østlie et al., 2011). Physically, there are increasing demands on the remaining limb resulting from overuse injuries including pain in the back, neck, or shoulder of the remaining limb (Stevens, 2011). This may in turn may result in secondary psychosocial conditions including increased social stigma, decreased self-image, and poor body image (Stevens, 2011; Østlie et al., 2011). The experiences individuals with ULL/D encounter require unique and specialized services. Because of this individuals with ULL/D may feel unsupported in their rehabilitation; they report a lack of access to care and peer support networks, and feel as though their provider lacks education or experience regarding their limb difference (Latour, 2019). As a result, insufficient support from peers and professionals can lead to lower self-reported quality of life and lower life satisfaction scores (Stevens, 2011; Østlie et al., 2011).

Recently in the United States, there has been a shift in the use of telehealth (TH) as a service delivery model in healthcare. As a health service modality, TH has many benefits which include: flexibility and accessibility to high-quality care, especially for individuals living in remote areas or areas with provider shortages; time efficiency for home, work, and travel; reinforced communication between providers and patients; decreased healthcare costs for both the provider and patient; and improved self-awareness through patient education and

empowerment, in regard to managing their chronic conditions (Donelan et al., 2019; Kruse et al., 2017). The many benefits of TH, such as supporting quality of care and overcoming barriers to accessing care, support the Triple Aim initiative to improve population health outcomes (Nash, Fabius, Skoufalos, Clarke, & Horowitz, 2016).

The variety of TH modalities in healthcare calls for additional research to indicate its best practices and applications (Shigekawa, Fix, Corbett, Roby, & Coffman, 2018). According to Donelan et al. (2019), patients reported no difference in their quality of care between virtual and office visits and no difference in personal connections with providers during appointments. Furthermore, there is strong evidence supporting TH for mental health interventions and improving health-related quality of life in adults, children, and families (Shigekawa et al., 2018; Brook, Kindler, & Marsac, 2019). Several studies synthesized by Shigekawa et al. (2018) indicate that TH appears to be equivalent to in-person care.

While TH can be used to enhance preventative, habilitative, and even rehabilitative care, the appropriateness of TH should be on a case-by-case basis. Practitioners wishing to use TH as a modality for their practice should use clinical and ethical reasoning to ensure that the TH method is safe, effective, and appropriate for their client (American Occupational Therapy Association [AOTA], 2013). Debra Latour, OTD, M. Ed., OTR/L, used TH to address the unmet needs for adults over 35 years old with congenital unilateral upper-limb difference in her program, *Unlimbited Wellness* (2019). Program participants reported improvements in their physical, mental, emotional, and spiritual health. Additionally, the program manager and community partner indicated positive outcomes. *Unlimbited Wellness* successfully used TH tailored to the specific needs of individuals with upper-limb differences to better their quality of

life and empower them (Latour, 2019). Children, adolescents, young adults, and aging adults with ULL/D, along with their caregivers, could benefit from an expansion of this program.

Appendix E

Evaluation Report

Unlimbited Wellness Program Evaluation Report

Methodology

Program Goal

The overarching goal of this project is to connect, educate, and empower individuals with upper limb absence(s) (ULA) through virtual community engagement with a focus on expanding the program to include varying ages, levels of ULA, and etiology.

Target population and sampling

Participants were recruited from Handspring Clinical Services using convenience sampling. Participant inclusion criteria were adults 18 years or older with ULA and parents/guardians of children with ULA between the ages of five and 17. Exclusion criteria included intellectual disabilities such as dementia, literacy rates below an 8th grade level, or an inability to communicate verbally, and an inability to access necessary technologies such as WiFi, videoconferencing capabilities, or appropriate bandwidth.

Handspring Clinical Services afforded resources required for this program expansion. Support included access to client databases, a HIPAA-compliant platform, Microsoft Teams, access to social media pages, and a clinical consultant. There were no additional costs to run this program, as the program occurred virtually. Program facilitators prepared and coordinated all sessions, and participants attended the sessions free of charge.

Program Activities and Management

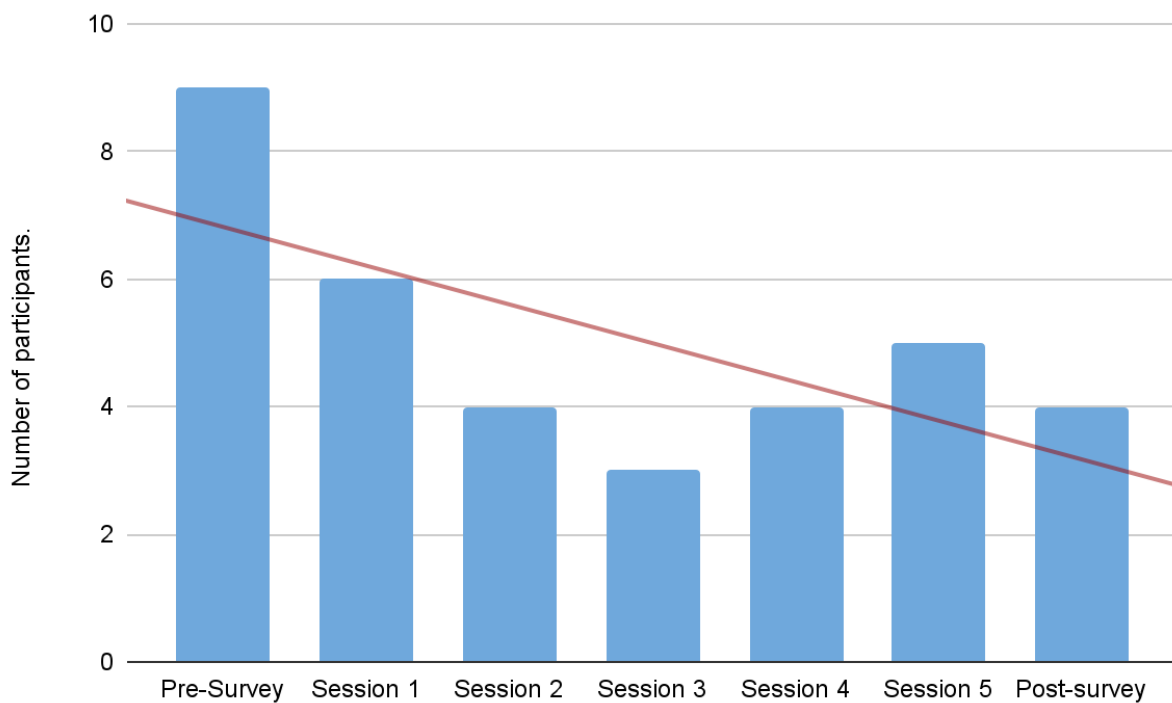
The program was held in one hour weekly sessions over the course of five weeks. Each week covered a different topic to facilitate discussion. Figure 1 describes the timeline of activities. Prior to each session, participants received an email reminder, meeting invitation, and an incomplete tip sheet template relevant to the specific topic. Partially completed tip sheets and group protocols served as framework for the sessions. The tip sheets served as preparatory worksheets, springboards for discussion, and resources for participant use in their final state.

After each session, participants filled out a GoogleForm questionnaire for researchers' to gather feedback on the sessions. Attendance for each session varied. Figure 2 details participant weekly attendance.

Figure 1
Activity and Module Timeline



Figure 2
Participant Attendance from Pre-survey to Post-survey



Custom Surveys

A mixture of qualitative and quantitative data were collected via GoogleForms. Program facilitators developed two surveys. The first survey measured change in participants' health and wellness perceptions related to their ULA before and after program participation. The second survey gathered weekly session feedback from participants to guide program development. All

survey information was de-identified and stored securely with two-factor authentication. Seventeen items on the pre- and post-survey related to participants' beliefs about secondary conditions, isolation, social issues, and virtual support groups. Participants rated these items on a five-point Likert scale ranging from strongly disagree to strongly agree. The specific survey items from which data were obtained to measure participants' change are summarized in Table 1. Additional demographic data regarding participant age, relationship to ULA, and ULA level was also collected. The questionnaires and study methodology were approved by the institutional review board at Western New England University.

Table 1
Pre- and post-item ratings.

#	Item	Pre (n=9)	Post (n=4)	Percent Change	% Change
1	I am comfortable talking with others about my (or my child's) experiences with upper limb loss/difference(s).	5.00	4.75	-0.05	-5.0%
2	It is important to me to connect with others who share my (or my child's) experiences with upper limb loss/difference(s).	4.78	4.00	-0.20	-20.0%
3	I feel confident sharing my experiences with upper limb loss/difference(s) in a group setting.	4.89	5.00	0.02*	2.0%
4	I am comfortable talking to friends or family about my experiences with upper limb loss/difference(s).	4.89	5.00	0.02*	2.0%
5	My experiences with upper limb loss/difference(s) affect my ability to socialize with others.	2.33	2.25	-0.04*	-4.0%
6	I reach out to family, friends, or professionals for support when needed.	4.33	4.25	-0.02	-2.0%
7	I accept my (or my child's) upper limb loss/difference(s).	4.78	4.25	-0.12	-12.0%
8	I am aware of health conditions commonly associated with upper loss/difference(s) such as anxiety, post-traumatic stress disorder, phantom pain and sensation, and overuse injuries.	4.22	4.50	0.06*	6.0%
9	I am familiar with preventative strategies for reducing physical health conditions such as prosthetic device use and regular exercise.	3.89	4.50	0.14*	14.0%
10	When talking to healthcare providers, I am comfortable advocating for my (or my child's) needs.	4.89	5.00	0.02*	2.0%
11	I know how to access upper limb loss/difference(s) resources (i.e. support groups, healthcare professionals, prosthetic device technologies, educational materials).	4.00	4.75	0.16*	16.0%

12	I feel successful in my daily roles (i.e. parent/guardian, partner, employee, student, etc.).	3.56	3.75	0.05*	5.0%
13	Virtual groups provide social connection opportunities.	4.56	4.25	-0.07	-7.0%
14	Virtual groups can be as beneficial as in person groups.	4.11	3.25	-0.26	-26.0%
15	I am comfortable relating to people virtually as I would in person.	4.56	4.25	-0.07	-7.0%
16	I behave like myself in a virtual group.	4.67	5.00	0.07*	7.0%
17	I am comfortable with using virtual meeting technology.	4.67	4.75	0.02*	2.0%

Note. Items were rated on the following likert-scale: 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree.

* Positive percent change between pre and post ratings.

Data Analysis/Program Evaluation.

Quantitative data were analyzed using statistical formulas within Google software. Pre- and post-survey item ratings were averaged and percent changes were calculated. Self-selected program gains were summated. Data may be used for future poster presentations or other scholarly works to better understand program evaluation and shape future *Unlimbited* Wellness programs.

Results

A total of 39 adults affected by ULA were invited to participate in the *Unlimbited* Wellness program. Figure 3 summarizes participant demographics from the community partner's client database. Nine individuals provided consent to participate in the program and filled out the pre-survey. A total of four participants completed this post-survey ($n = 4$).

Of the 17 items, participants' responses on 10 items reflect positive changes, with question 11 having the greatest positive percent change (+ 16.0%). Responses on seven items reflect negative changes, with question 16 having the greatest negative percent change (- 26.6%). Table 1 details the survey questions, pre and post-program average scores, and percent change averages. One-hundred percent of participants ($n=4$) reported that they would attend another

Unlimbited Wellness session. Table 2 describes participants' self-reported gains from attending the program.

Figure 3
Invited Participant Demographics

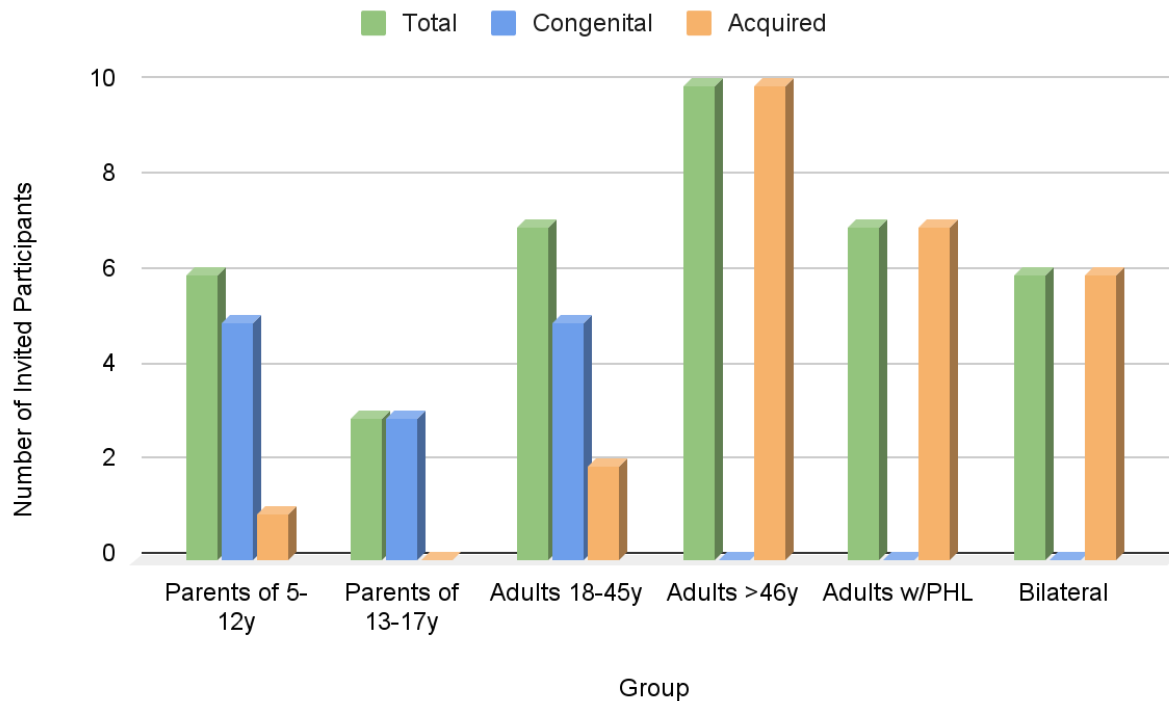


Table 2
Participant Self-Reported Outcomes

Gained from program	<i>n</i>	<i>n</i> /4*	%
Connect with others who are like me	2	0.50	50%
Learn about others' experiences	3	0.75	75%
Learn strategies for handling awkward social situations	1	0.25	25%
Learn about common ULA secondary health conditions	2	0.50	50%
Learn how to prevent secondary health conditions	3	0.75	75%
Learn about the benefits of prosthetic devices	1	0.25	25%
Learn how to access resources relating to upper limb loss/difference(s)	1	0.25	25%

*A total of four participants responded to the post-survey.

Discussion

Individuals with ULA require specialized services; yet, there are limited resources available (Maduri & Akhondi, 2021; Kannenberg, 2017). Individuals with ULA are at increased

risk for developing secondary physical and psychosocial conditions (Latour, 2019; Braza & Yacub Martin, 2020; Østlie et al., 2011).

The results of this program suggest that a virtual support group is effective in connecting and educating participants of varying ages, levels of absence, and etiology. The program survey was designed to gather group members' perceptions on their health and wellness pre- and post-program participation. Data from Likert-scale items and data from self-reported program gains indicate participants learned from each other, learned about secondary health conditions, learned preventative strategies, and increased access to resources. However, study limitations exist and influence the interpretation of data results. The survey used lacked validation and reliability; therefore, the data should be interpreted with caution.

Although attendance fluctuated, a core group of participants attended most sessions. This enhanced rapport between program facilitators and participants, and supported engagement and participation in in-depth weekly discussions. At the end of the program, all participants reported that they would attend future *Unlimbited* Wellness sessions, suggesting this program's appropriateness in reaching all members of the ULA population. Table 3 identifies the strengths, weaknesses, opportunities, and threats (SWOT analysis) of *Unlimbited* Wellness.

Table 3
SWOT Analysis of Unlimbited Wellness

Strengths	Weaknesses
<ul style="list-style-type: none"> ● Program expanded to various ages, levels of limb absence, and etiology ● Increased access to resources (+16%) ● Connected individuals with ULA (50% self-reported) ● Participants learned from each other (75% self-reported) ● Learned about secondary health conditions (50% self-reported) ● Learned strategies for preventing secondary health conditions (75% of participants; +13.56 increase from pre- to post-) 	<ul style="list-style-type: none"> ● Study duration ● Inconsistent participation ● Non-standardized assessments ● Newly developed surveys ● No pre-study interviews to determine participant appropriateness ● Small sample size <ul style="list-style-type: none"> ○ No in-depth data analysis ● No direct communication with participants ● Contradictory data ● Differing needs between participants

<ul style="list-style-type: none"> ● Overall satisfaction rating from five sessions: 4.4 ● Intraprofessional collaboration ● Support from Handspring ● Program facilitators learned from participants ● Weekly feedback to guide program ● Covered varying topics in short duration ● Intimate group size ● Consistent participation after session 1 ● Developed resource guide 	
Opportunities <ul style="list-style-type: none"> ● Interprofessional collaboration ● Connect members of ULA population nationally ● Virtual support groups easily accessible ● Specialized knowledge in niche area: inform future OT practice ● Additional virtual programming 	Threats <ul style="list-style-type: none"> ● Participant drop-out ● Varying time zones ● Inclement weather affecting internet connection ● IRB limitations ● Small target population

Future Recommendations

The results of this program are encouraging and demand further investigation. Future research related to the expansion of the *Unlimbited* Wellness program should aim to include the use of standardized assessment tools to measure program effectiveness. Performing more in-depth statistical analyses is suggested to improve study reliability and validity. Additionally, increasing the sample size, lengthening study duration, and administering one-on-one interviews with participants will produce results generalizable to the greater ULA population.

References

- Braza, D. W., & Yacub Martin, J. N. (2020). Upper limb amputations. In Frontera W. R., Silver J. K., & Rizzo T. D. (Eds.). *Essentials of physical medicine and rehabilitation: musculoskeletal disorders, pain, and rehabilitation (4th ed.)*. Elsevier.
- Kannenbergh, A. (2017). Active upper-limb prostheses: The international perspective. *Journal of Prosthetics and Orthotics*, 29(4S), P57-P62. doi: 10.1097/JPO.0000000000000158
- Latour, D. (2019). Unlimbited Wellness: Telehealth for adults with upper-limb difference. *Journal of Prosthetics and Orthotics*, 31(4), 246-256.
<https://doi.org/10.1097/JPO.0000000000000263>
- Maduri, P., & Akhondi, H. (2021). Upper Limb Amputation. In *StatPearls*. StatPearls Publishing.
- Østlie, K., Magnus, P., Skjeldal, O. H., Garfelt, B., & Tambs, K. (2011). Mental health and satisfaction with life among upper limb amputees: A Norwegian population-based survey comparing adult acquired major upper limb amputees with a control group. *Disability and Rehabilitation*, 33(17–18), 1594–1607.
<https://doi.org/10.3109/09638288.2010.540293>

Appendix F

Mini Project



hand smart

By: Maccabee Gabay



PROPOSALS

- Generate Revenue
- Update Handsmart's website
- Create a social media account
- Potential partnership with organizations
- Develop a student program



International Society for Prosthetics and Orthotics
...moving beyond physical disability

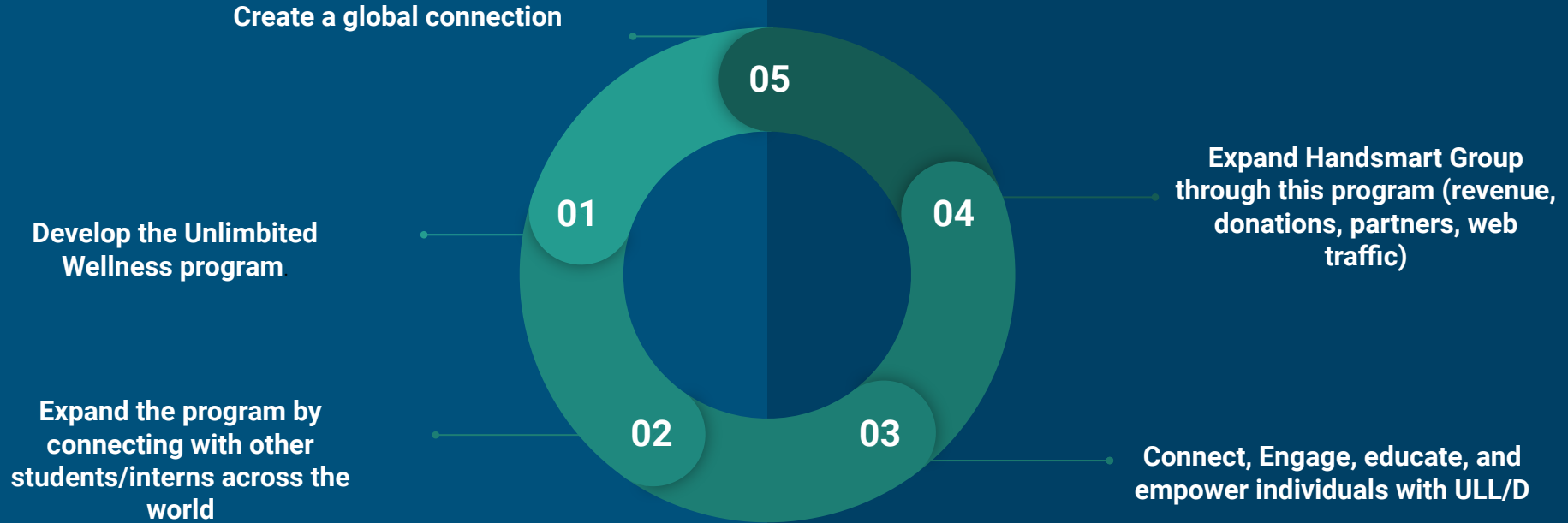
Generate Revenue

- **Develop a partnership with OT/PT programs**
- **Involve students**
- **Offer mentorships/internships/Reference letters**
- **Expand the *Unlimbited* Wellness program**
- **Donations can be considered as write offs**



WEBSITE/SOCIAL MEDIA

- Offer professional educational courses
- Provide list of resources and organizations that offer funds
- Yearly subscriptions
- Provide educational videos
- Articles for purchase
- Develop an instagram page



THANK YOU