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Utilization and Perception of Peer-Support After Lower Limb Loss in the United States: Potential Benefits on Mobility Outcomes

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UTILIZATION AND PERCEPTION OF PEER-SUPPORT AFTER LOWER LIMB LOSS IN THE UNITED STATES: POTENTIAL BENEFITS ON MOBILITY OUTCOMES

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Abstract

Introduction Limb loss is a life-changing event that significantly impacts patients' functioning as well as psychosocial well-being. Psychosocial support in the form of amputee peer-support is widely recognized as beneficial to individuals after lower limb loss (LLL). However, there is currently a lack of research on the utilization of peer-support after LLL and its perceived benefits to function. The purpose of this cross-sectional study was to examine and quantify participants' experiences with peer-support after LLL, and how peer-support experience is associated with mobility outcomes. We hypothesized that participants with LLL would express generally positive experiences with peer-support and that it would have a positive impact on their outlook on life and functioning during activities of daily living (ADL). We also hypothesized that individuals who have received peer-support would exhibit higher levels of mobility compared to those without such experiences.

Methods A 32-item survey was developed to examine respondents' amputation history, experiences in peer-support activities, and their mobility (measured using Prosthetic Limb Users Survey of Mobility, PLUS-M). The items were developed and validated by 2 experienced amputee peer-support group organizers, prosthetic clinicians (physical therapists and prosthetists), and 5 persons with LLL. The online survey was distributed nationally to 169 peer-support groups and limb loss care facilities in 44 U.S. states, as well as social media-based support groups from March 2021 through February 2022. Individuals both with and without peer-support experience were included. Descriptive statistics were used to analyze the patterns of peer-support utilization and participants' perception. Independent t-tests were conducted to examine the effects of peer-support experience on mobility outcomes.

Results 82 completed responses were extracted for data analysis (53% female, 54% over 55 years of age, 65% with transtibial amputation). Sixty-eight % of the respondents received peer-support after amputation, among them 75% reported that peer-support had a positive impact on their outlook on life, and 78% reported that information gained during their peer-support experience was helpful to their ADL. Companionship afforded by peer-support was one of the most enjoyable experiences. Respondents who received peer-support exhibited a trend of higher mobility than those who did not (55 vs. 36 percentile on PLUS-M; p=0.055), despite their comparable ages (56.7 vs. 54.4 years; p=0.211).

Conclusion Individuals with LLL reported generally positive experiences regarding their engagement in peer-support activities. Peer-support groups are viewed as a helpful source for both information and emotional support, benefiting functional and psychological recovery after amputation. Furthermore, individuals who have received peer-support exhibited greater mobility. Future research should explore how peer-support may be incorporated to improve the effectiveness and patient experience of rehabilitation after LLL.

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Introduction

Despite advancements in medicine, the prevalence of limb loss in developed countries such as the United States remains high, as one in every 190 Americans are living with the loss of a limb.[1] According to a recent research study, non-traumatic lower limb loss (LLL) decreased between 2000-2009, but began to increase again in the younger and middle-age population in recent years. This worrying trend is driven in large part by the resurgence of type II diabetes and is likely to worsen in the coming years.[2]

Post-LLL rehabilitation typically begins with wound healing and pain management, followed by therapy focused on improving mobility including safe transfer, prosthetic fitting, gait, and fall prevention training.[3-5] However, there is limited knowledge regarding the psychosocial aspects of limb loss during the rehabilitation and recovery process. This is an important issue to consider, as limb loss has been demonstrated to significantly impact patients' mental health, with anxiety and depression being common short- and long-term concerns.[6,7] A common strategy to address the psycho-behavioral adjustments after limb loss is amputee peer-support, however its utilization and the potential benefits to a patient's physical and psychological functioning have not been empirically investigated.[8]

Peer-support in other medical disciplines has been shown to be beneficial for individuals with various medical conditions, as it helps to provide a sense of understanding for the patient from someone who has experienced a similar condition and its coping/recovery process.[9] For example, peer-support has been considered as a powerful contributor in the recovery from psychiatric illness. It promotes an individual to be oneself, help others, share with others his/her experiences, and embrace life roles as an individual receiving support while also being a peer for someone else.[10] Providing peer-support has been shown to lead to positive outcomes after trauma such as

brain injury,[11,12] and burn injury.[13] Burn survivors who participated in a support group displayed higher and better social interaction, as well as activity participation including work and employment.[13]

Current evidence regarding the benefits of peer-support for individuals with LLL is limited. The general consensus is to recommend patients to seek peer-support due to its low cost and risk of harm.[9] Evidence from a military hospital setting showed that learning from other individuals with personal experiences of recovery from LLL can lead to more successful adjustment for a new patient with LLL, in regards to work, family, and community living.[14] In a recent study, Nathan et al. showed that many patients had an early goal of joining a peer support group with the intention to regain mobility and functionality to be better able to restore their way of living.[15] However, the current body of knowledge on peer-support after limb loss lacks information from patients' perspectives pertaining these perceived benefits.

Therefore, the purpose of this study was to quantify personal experiences with peer-support after LLL. Specifically, we examined the utilization and both the positive and negative perceptions of peer-support in a national sample of individuals with LLL. Furthermore, we analyzed how peer-support experience is associated with mobility outcomes after amputation. Our hypothesis was that participants would express a generally positive experience with peer-support, and peer-support would have a favorable effect on their outlook on life. A second hypothesis was that individuals who have received peer-support would exhibit higher levels of mobility function compared to those without such experiences.

Methods

Participants A list of amputee support groups with representations from most states of the United States were assembled for this study. This list was designed to facilitate a comprehensive recruitment of participants for our survey. The support groups were identified through a nationwide search. The "Support Groups & Peer-support" resource page on the Amputee Coalition website was screened.[16] Extensive searches were conducted to identify contacts to amputee care facilities in Veterans Affairs Health Clinics and Medical Center facilities, civilian rehabilitation facilities, prosthetic clinics, and amputee-related social media pages/profiles on Instagram and Facebook. These pages/profiles included established amputee support groups, prosthetic and orthotic organizations and businesses, and physical therapy programs with a description of amputation rehabilitation focus. The assembled contact list contains organizations from 44 of the 50 states (Appendix A). Six states were not included because we could not identify the contact information of any established limb loss related groups or organizations within these states. In total, 139 groups were invited through email to distribute the survey to their group members and/or patients. The participants did not have to report which support group or organization they belong to. The inclusion criteria were that the participant had to be at least 18 years of age, willing to participate in the survey study, and have a major amputation to the lower limb, defined as loss of at least the ankle joint.

Procedure

The survey was developed to quantitatively and qualitatively explore the role of peer-support after amputation. The items were designed based on the aims and objectives of this research project, which includes the patients' responses to their demographic and medical

history, personal experiences and perceptions of peer-support after their limb loss, and a limb loss specific mobility outcome measures (detailed below).

Survey development

The online survey was developed by the investigators including a rehabilitation researcher and physical therapist with 6 years of experience in organizing a local amputee support group (Las Vegas Amputee Support Group). After the initial draft of the survey was developed, it was further reviewed by another experienced amputee peer-support group organizer with 20 years of experience (Lively Limbs! Amputee Support Group) who is also a certified prosthetists, a physical therapist experienced in treating patients with LLL, and five persons with LLL to establish relevance and validity. Further testing was done to ensure the flow and readability of the questions, and whether or not the survey would function properly on a range of devices (computer, tablet, and smartphone). The finalized questionnaire (Appendix B) and survey procedure were approved by the University of Nevada, Las Vegas Biomedical IRB, then hosted on the Qualtrics online survey platform (Qualtrics International Inc., USA).

The self-reported survey consists of 32 questions regarding respondents' amputation including the timing, cause, and level of amputation. The next portion of the survey focused on the respondent's experience and perception regarding peer-support after their amputation. This includes questions about their personal experiences and opinions, and how likely they would recommend others with LLL to join a peer-support group, and ends with open-ended questions regarding their positive experience and how aspects of peer-support could be improved. The third part of the survey focused on LLL-specific mobility outcome measures. Specifically, the 7-item short form Prosthetic Limb Users Survey of Mobility (PLUS-M) questionnaire was used. PLUS-M is a self-reported questionnaire designed specifically to assess functional mobility in

individuals with limb loss.[17,18] The survey concludes with questions regarding basic characteristics of the participant, with questions regarding their age, gender, ethnicity, etc.[19]

Survey Distribution

The online survey link was sent in emails to the identified contacts of the amputee service organizations (Appendix A). An introductory email that included a request to have the survey link forwarded to individuals in their organization who may fit our inclusion criteria. The study was also advertised on the identified limb loss-related social media pages and profiles through posts on Instagram and Facebook. A follow-up reminder email was sent to organizations who did not respond to the first email. The data collection spanned a 12-month period (March 2021-February 2022).

Data Analysis

For quality control, once the survey was closed, we reviewed all responses from respondents to confirm that they met the inclusion criteria and that the survey was completed properly. Respondent characteristics, including their age, gender, ethnicity, race, cause and level of amputation, as well as time since amputation were categorically described. Respondents' experiences with peer-support, including timing of receiving support, how they learned about it, meeting frequency, preferred meeting format, and barriers to accessing peer-support were analyzed.

For the open-ended question regarding how the respondents feel about their peer-support experiences (i.e. question 19), a thematic analysis was conducted. Each response was assigned a theme, and these themes were then evaluated to determine how they overlapped. We classified related themes to develop overarching themes that represent the responses of our survey

participants. For instance, we classified "companionship" responses that indicated the need for validation, relatedness, and belonging. The responses that primarily reflected a desire in assisting other amputees and acquiring information to cope with life after amputation were classified as such, despite the fact that same responses occasionally also indicated a need for validation and belonging.

To test hypothesis 1, we descriptively examined the respondents' perceptions regarding the different aspects of potential benefits of peer-support after LLL. To test hypothesis 2, we compared the reported outcomes (e.g. PLUS-M scores) between individuals who received and did not receive peer-support (yes vs. no response to question 11: "*After your amputation, have you participated in any organized amputee peer-support group activities [including interactions on the internet]?*") using independent t-tests. The PLUS-M raw score was converted to T-score for statistical analysis.[17] Further comparison of the two groups (peer-support vs. no peer-support) regarding potential confounding factors such as age, time since amputation, cause (traumatic vs. non-traumatic), and level of amputation (above vs. below the knee; knee disarticulation was categorized as above-the-knee) were conducted using independent sample t-tests and Chi-square tests as appropriate.

Results

The survey was distributed electronically to 169 identified contacts for distribution to potential participants (Appendix A). The survey was also advertised on 17 profiles and platforms on Facebook and Instagram. One hundred and sixty-nine participants started the survey with 131 responses recorded. The response rate to individual questions varied and of the 131 recorded responses, 100 (76%) completed all the survey questions. Of them, 82 (82%) were included in our analysis. Responses excluded were from individuals who did not have a major amputation to the lower limb or with responses that could not be interpreted.

Respondent Characteristics

The mean age of the respondents was 56.4±10.9 (range 29-78) years, with about equal number of male and female (47 vs. 53%, respectively). Additional details of the respondents' characteristics are summarized in Table 1. The most common reported cause of amputation was dysvascular (32.9%), which included diabetes and other vascular diseases. Among the respondents, the most common level of amputation was transtibial (65%), and 50% of respondents are fewer than 5 years from their amputation. Ninety-three percent of the respondents have been fitted with a prosthesis and used it regularly.

Table 1. Respondent Characteristics

Category	Percent of Respondents (%)
Age	
35 years and younger	4%
36 - 45	6%
46- 55	34%
56 - 65	31%
66 +	23%
Gender	
Male	47%
Female	53%
Ethnicity	
Hispanic	3.6%
Non-Hispanic	91.6%
Decline to State	4.8%
Race	
Caucasian	80.7%
African American	7.2%
Asian	1.2%
Native Hawaiian or other Pacific Islander	1.2%
Other	7.2%
Cause of Amputation	
Dysvascular Disease	32.9%

Cancer	6.1%
Trauma	30.5%
Congenital	3.7%
Infection	9.8%
Other	17.1%
Level of Amputation	
Transfemoral (including knee disarticulation)	28.9%
Transtibial	65%
Ankle disarticulation	4.8%
Other (did not state)	1.3%
Time Since Amputation	
5 years or less	49.4%
6 - 20 years	34.5%
21 - 40 years	7.4%
41+	8.6%

Peer-Support Experience

Among respondents, 68.7% have participated in amputee peer-support group activities. The duration of involvement ranged from a few months (16%) to more than 5 years (27%). Most respondents participated in monthly meetings (50%; Table 2). The majority of the respondents prefer group meetings being conducted in an open discussion format (65%), followed by lectures (34%), one-on-one meetings or visits (31%), and online interactions (28%). When asked about

who first told them about amputee peer-support, the responses varied, with healthcare staff during their post-amputation hospital stay and rehabilitation being the most common (22 and 21%, respectively; Figure 1). When asked about when peer-support would be most helpful to them, the respondents indicated that receiving support after amputation and during rehabilitation would be most helpful (94%).

Table 2.
Frequency of participation in peer-support activities

	Frequency	Percent
Multiple times a week	5	6.1%
Once a week	5	6.1%
Once a month	41	50%
Once every 2-6 mo.	4	4.9%
Once every 6-12 mo.	2	2.4%
Once a year or longer	5	6.1%

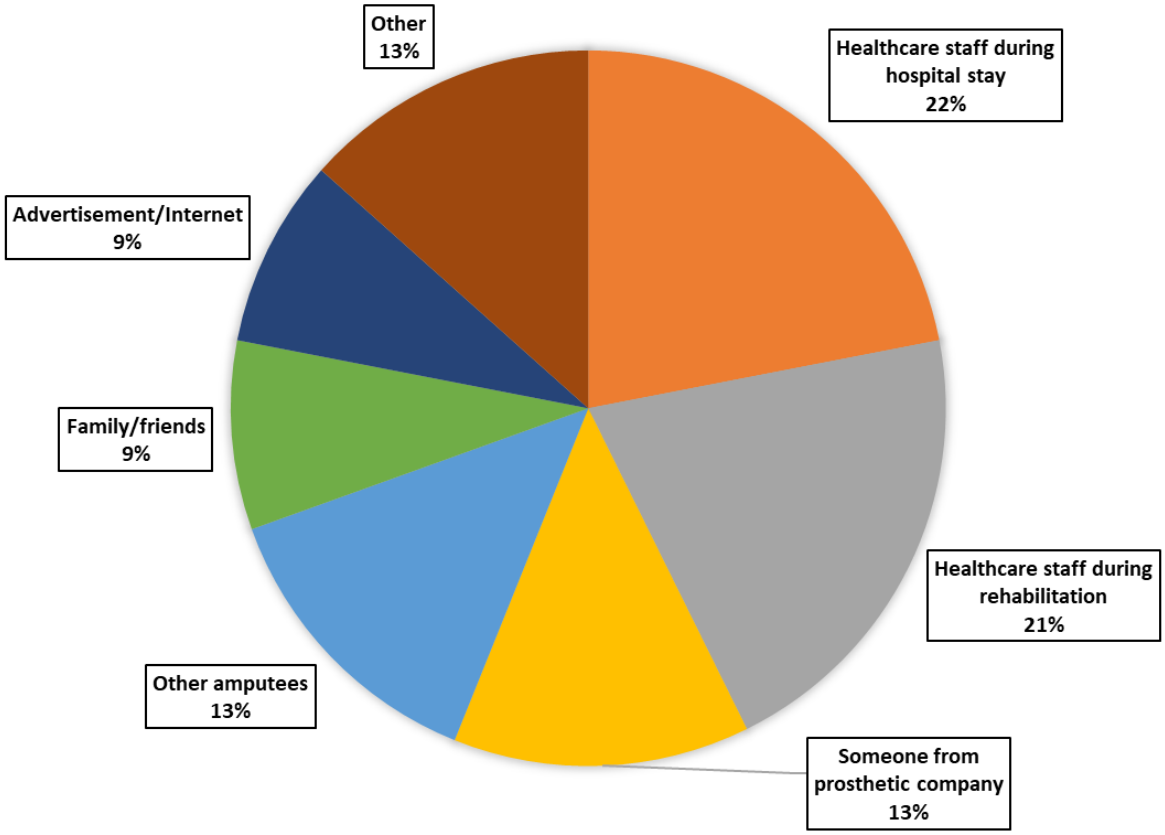

Figure 1. Sources from which respondents first learned about Amputee Peer-Support

The top two barriers to peer-support participation were issues related to COVID-19 (34%), and scheduling conflicts (21%). Lack of transportation, lack of a local peer-support group, and lack of meeting information from the local peer-support group combined for 27% of participants' barriers (Figure 2).

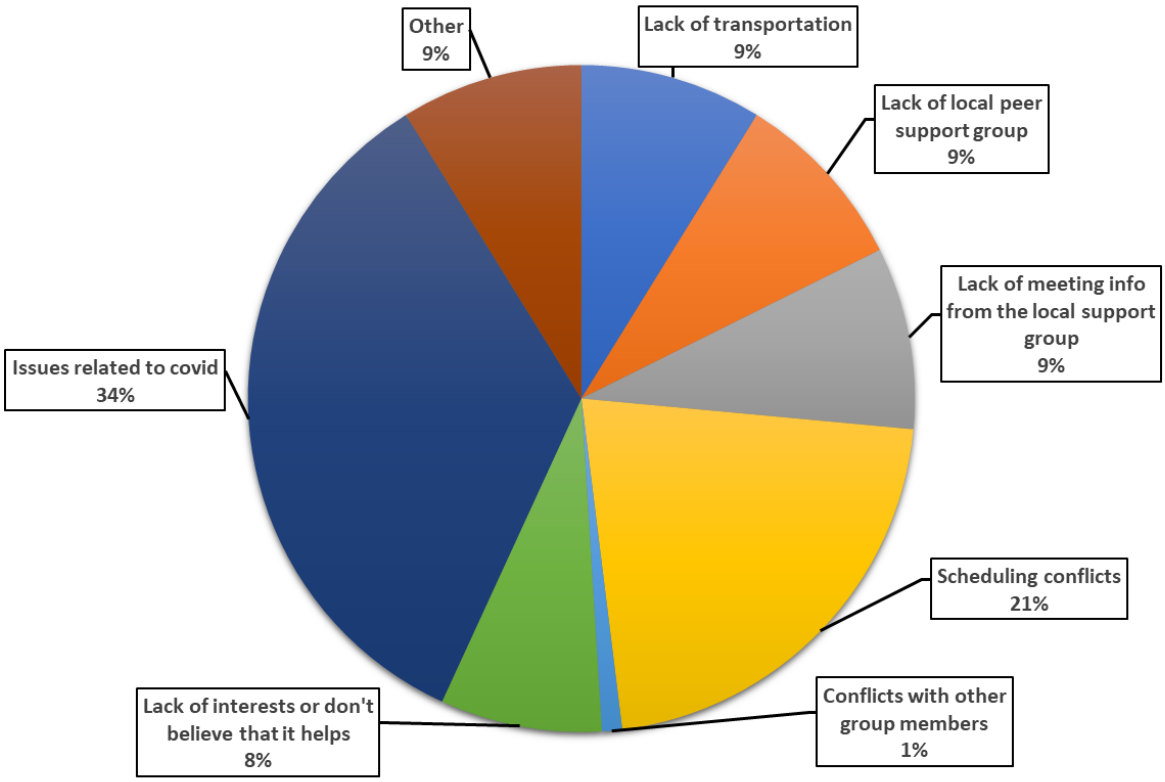

Figure 2. Barriers to Peer-Support Participation

Perception of Peer-Support Benefits and Altruism

On average, respondents generally agreed that peer-support is useful and beneficial to multiple different aspects of their lives (range = 56 to 88 %; Figure 3). The two specific questions about altruism yielded the highest level of agreeance (i.e. "*I try to help others in my support group, even if they do not help me*" and "*Peer-support group gave me an opportunity to help other amputees*"). Almost all respondents would recommend joining a peer-support group to someone with LLL who is currently not a member of one (94±14 %).

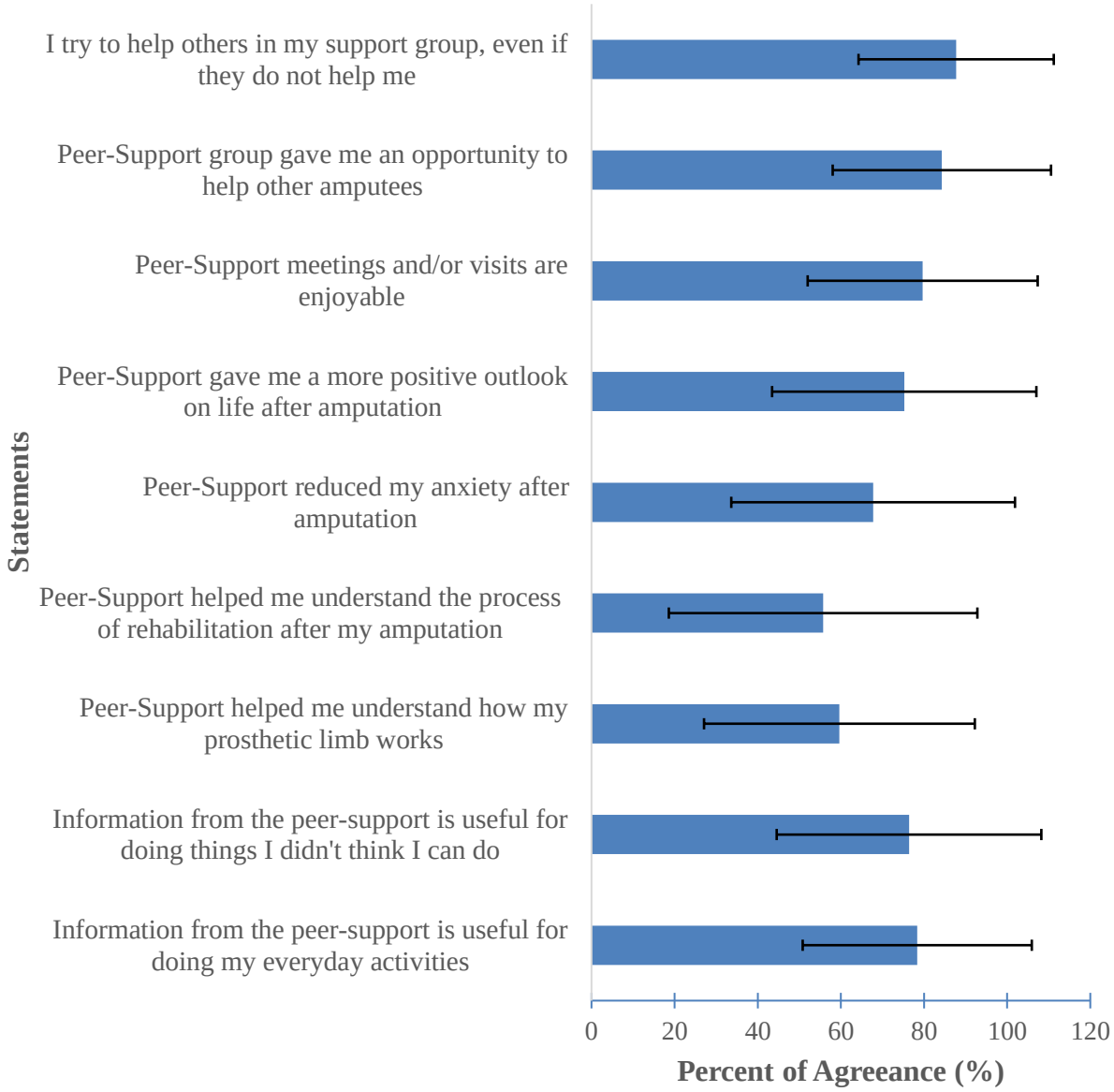

Figure 3. Perceptions of Peer-Support Benefits and Altruistic Behaviors

Qualitative analysis of the responses regarding what the respondents enjoy most in their peer-support experience revealed 3 main, sometimes overlapping themes. The respondents generally expressed a sense of compassion, altruistic love, belonging, relatedness, and validation as well as encouragement and empowerment; some even referred to their time spent in the peer-support group as "*definitely life changing*." The majority of them (44%) participated in peer

support group for companionship. Twenty-nine percent of the respondents sought out peer-support in order to assist others, while the remaining 27% sought out information about coping with post-amputation experience. They used peer support to "*connect with people who experience some of the things you do*", "*learn from each other and inspire one another*", "*bond with [like] others*", "*share stories, successes, and struggles*", receive "*support and information on how to live as best a life you can*", and "*gain knowledge that helps [your] understanding of what [you] are experiencing mentally and physically*". Their participation in support group activities enabled them to "*see other people like [me] and see how they solved issues*" and gave them "*a sense of comfort*" and "*emotional support from those experiencing similar challenges*". As a consequence, the peer-support helped reinforce the conviction that "*[I'm] not alone in my struggle(s)*" and their "*fight against depression and selfishness and pity*". Furthermore, they valued the opportunity to "*help others…navigate this new world and journey [they are] on*" and offer "*advice, support and empathy to the next new amputee*".

Effects of receiving peer-support on mobility function

Comparing the PLUS-M percentile scores between individuals who have received peer-support vs. those who have not, the peer-support group exhibited a trend of higher mobility score (PLUS-M T-score: 51.4±10.8 vs. 46.8±11.3; p=0.055; CI=-1.07-10.33). Further comparison of the two groups showed that they were of comparable ages (56.7±10.9 vs. 54.4±10.5 years; p=0.209), with no significant differences in cause, level, and time since amputation (p=0.484, 0.564, and 0.325, respectively).

Discussion

The journeys of recovery following LLL differ depending on many personal, familial, and societal factors. Support from a variety of sources is likely needed to facilitate recovery in different aspects of a patient's life. Our findings supported our hypothesis that individuals with LLL have a generally favorable experience with peer-support, including positive perceptions of peer-support's potential benefits to their recovery including both physical and psychological wellbeing. In addition to receiving knowledge and information that help them cope with life after amputation, a high percentage of peer-support participants demonstrated altruism toward their peers. Our findings also partially supported our second hypothesis that individuals who received peer-support would exhibit better mobility when compared to those who did not receive peer-support. Overall, our results provide preliminary evidence that receiving peer-support after LLL not only benefits the patients' emotional well-being, it may also have a positive impact on their recovery of function.

It has been reported that after amputation, patients typically learn their basic prosthetic skills (i.e. donning and doffing of prosthesis, transferring, and basic gait) from clinicians such as prosthetists and physical therapists,[20] while advanced mobility skills are more effectively learned from other people with similar amputations and other life experiences.[21] Our findings agreed with findings from Williams et al. that social support after amputation is significantly associated with improved mobility.[22] This phenomenon may be due to that amputee patients are more motivated when observing other individuals with limb loss who have successfully gone through the rehabilitation process including prosthetic skill and ADL learning.[23-25] There are preliminary evidence showing that learning from peers may prime the neurobehavioral system for more effective learning outcomes.[20,21] While the results from this cross-sectional study cannot imply

causality, given that implementing amputee peer-support presents minimal risk and cost to most patients, future research should focus on the potential of incorporating peer-support for facilitating post-LLL rehabilitation including prosthetic training.

Despite the many potential benefits, not all patients were informed about amputee peer-support after LLL. For example, Nathan et al. reported that the top reasons for individuals with LLL to not participating in an amputee support group were related to lack of information and fear.[15] Indeed, the various uncertainties facing patients after LLL are challenging and scary,[26] but this is precisely why early access to peer-support is important. These barriers may be alleviated by improving rehabilitation clinicians' awareness of both local and online peer-support resources, and by incorporating peer-support as a part of standard post-LLL care.[27] Findings from this study are in support of this premise that close to 70% of individuals who have participated in peer-support activities after their LLL received the support group information from healthcare staff, prosthetic companies, or other amputees. Furthermore, 94% of the respondents said that peer-support would be most helpful during the hospital stay or the rehabilitation process, which is consistent with the review findings from Reichmann et al.[9] In the U.S., the Amputee Coalition created the Certified Peer Visitor program, and recently incorporated the Hospital Partnership so that rehabilitation clinicians can have convenient access to trained amputee peer visitors in the inpatient setting.[28] Involvement of post-LLL rehabilitation clinicians in amputee peer-support activities may be useful for explaining and clarifying the progression of care, such as prosthetic prescription and fitting, to the patients.

Through the qualitative analysis of the open-ended responses in our survey, we sought to understand what individuals enjoyed the most about their peer-support experience. In addition to gaining pragmatic information, respondents reported that the most enjoyable aspect of peer-

support for them was the friendship and comfort they felt from other peers with similar experiences, allowing them to share and relate to each other's struggles and successes. Many enjoyed sharing stories about overcoming obstacles, and creating a community with others who are either just beginning to learn a new way of living or are many years into it. The desire to share also reflected in that most respondents prefer group meetings being conducted in an open discussion format when compared to lectures. Many individuals became leaders in their peer-support groups, as they felt the impact of the benefits for themselves and wanted to continue to encourage and connect with anyone who may be struggling. The relatedness and the altruistic desire to help other people experiencing similar hardship may be part of a beneficial coping mechanism to their own challenges. The bonds they created out of their participation in peer-support activities may offer them much-needed opportunities for meaningful and beneficial social attachments while they adjust to the life-altering event.[29] These relationships may provide people with both emotional and instrumental support, as well as sources of inspiration, empowerment, empathy, care, and understanding. This type of coping methods has been found to boost hopefulness, decrease loneliness, and reduce psychological symptoms such as depression and anxiety in individuals with disabilities including amputation.[30-33]

Based on our data, the top barriers to participating in peer-support after LLL were mostly environmental. They included restrictions related to COVID-19 (34%), scheduling conflicts (21%), and lack of communication (9%) and transportation (9%). Perception of lack of interest/benefit and conflict with group members together accounted for less than 10%. These findings are largely in agreement with previous studies on this topic.[15,34] Specific to the impact of COVID-19, a recent study showed that for persons with limb loss, physical activity and the ability to exercise and participate in support groups in the community were significantly

diminished.[35] Furthermore, many persons with limb loss reported that they experienced weight gain, decreased strength, and difficulty with mood regulation during the COVID-19 period of 2020-2021.[35] We believe the identified barriers to participating in peer-support should be interpreted as a positive opportunity, since most of the identified environmental barriers can be overcome with adequate resources. For example, scheduling conflicts and transportation issues may be overcome by offering meetings in different times of the month and in different areas of a city. Remote or virtual reality meeting options, while further development is still needed in this regard,[15] may also expand access of peer-support to more participants.

Peer-support for those in the limb loss community can come in a variety of forms, including meetings, limb loss educational programs, and limb loss specific activity and exercise programs. A recent survey, conducted by the Amputee Coalition revealed that physical and mental health priorities for individuals with limb loss are closely related.[36] Participants in the survey identified "strength and balance" and "ability to exercise" as top physical and mental health needs and priorities, noting how each intimately affects the other.[36] Individuals with LLL often do not have access to integrated physical and mental healthcare or to mental health providers who adequately understand the specific issues associated with LLL. Eliminating barriers to integrating physical and mental health care including peer-support in post-amputation rehabilitation, have the potential to drastically improve outcomes in this population. For example, psychological and social benefits of peer-based exercise programs through camaraderie and the inspiration offered when exercising with others in the limb loss community were significant in the perception of fitness and well-being, and are thus essential factors for creating positive effects on health-related quality of life.[35,37] Future research may focus on interventional

strategies to promote access and participation continuity to peer-based physical activity programs.

Limitations The main limitations of this study are related to sampling, which included that we only surveyed individuals with major lower limb amputation (i.e. excluding those with minor and upper extremity amputations) and that our study time frame being during the social distancing period of the COVID-19 pandemic. This likely led to our findings that 34% of respondents stated issues related to COVID-19 was a significant barrier to their access to peer-support.[38] The fact that more than 90% of the respondents were current prosthesis-users also indicates a potential sampling bias toward higher-functioning individuals.

Conclusion

Individuals with LLL reported generally positive experiences regarding their engagement in peer-support activities. Peer-support groups are viewed as a helpful source for both information and emotional support, benefiting functional and psychological recovery after amputation. Furthermore, individuals who have received peer-support exhibited a trend of having greater mobility. Future research should explore how peer-support can be incorporated for improving the effectiveness and patient experience of rehabilitation after LLL.

Appendix A

Name of Organization	State	Peer-support Group	Other (Rehab Facility, Prosthetic and Orthotic Org., PT Program)
CAST Ministries - Auburn	AL	X	
Amp Up North Alabama Amputee Support Group	AL	X	
AMP'D UP AZ	AZ	X	
Arise Prosthetics	AZ		X
Amputees Helping Amputees in Yuma	AZ	X	
Desert AMP Krew	AZ	X	
Honor Health Amputee Support Group	AZ	X	
Lively Limbs	AZ	X	
Tucson VA Limb Loss Support Group	AZ	X	
A.B.L.E Amputees Beyond Life's Expectations	AK	X	
Amputees of Arkansas	AK	X	
Jonesboro Amputee Support Group	AK	X	
Living with Limb Loss	OR/AK	X	
STAND Amputee Support Group	AK	X	
AMP'd UP	CA	X	
Amputee Support Group - CIL Berkeley	CA	X	
Amputee Support Group (Supported by the Functional Limb Service)	CA	X	
Central CA Amputee Education Group	CA	X	
Functional Amputee Support Team (FAST)	CA	X	
Gold Country Amputee Support Group	CA	X	
Mutual Amputee Aid Foundation	CA	X	
Sacramento Amputee Support Group	CA	X	
SCRAPPI	CA	X	

Taking the First Step	CA	X	
AMP IT UP! Quorum Prosthetics	CO	X	
ILP Amputee Support Group	CO	X	
Innovative Prosthetics Allstars	CO	X	
LIM359	CO	X	
UCH Amputee Support Group	CO	X	
Gaylord Amputee Support Group	CT	X	
Hospital for Special Care Amputee Support Group	CT	X	
Amputee Education and Support Group at Wilmington Hospital	DE	X	
Diamond State Amputees	DE	X	
Amputee Support Group Center for Rehab Medicine at St. Mary's	GA	X	
Northside Forsyth Amputee Support Group	GA	X	
UnLIMBited in the Bubble	GA	X	
Life Unlimbited	GA	X	
Southwest Idaho Amputee Support Group	ID	X	
Amputee Resource Network	IL	X	
Chicago Area Amputee Support Group	IL	X	
STEP UP	IL	X	
South Side Amputee Support Group	IL	X	
Unlimbited Potential Amputee Support	IL	X	
The Lifeline for Limb Loss	IN	X	
Central Iowa Amputee Support Group	IA	X	
Clarinda Regional Health Center Amputee Support Group	IA	X	
Northeast Iowa Amputee & Peer-support Group	IA	X	
Salina Amputee Support Group	KS	X	
The Amputee Experience	KS	X	
ACK (Amputees of Kentucky)	KY	X	
Lexington VA Amputee Support Group	KY	X	

New Life Amputee Support Group	KY	X	
ATLAS (Amputees Together Learning and Supporting)	LA	X	
Baton Rouge Rehab Amputee Support Group	LA	X	
Limb Up	LA	X	
Making Believers	LA	X	
Aspired Amputees	ME	X	
Amputee Support Group	MD	X	
Johns Hopkins Amputee Support Group	MD	X	
Peer-support for Amputees	MD	X	
Sinai Rehabilitation Center Amputee Support Group	MD	X	
Western Mass Amputee Support Group	MA	X	
Charlevoix-Boyne Amputee Support Group	MI	X	
West Michigan Amputee Coalition (WMAC) - Holland	MI	X	
Amputee Care Specialties	MO	X	
No Limb-itations	MO	X	
Montana Amputee Group	MO	X	
Balance	MN	X	
Little Fins Limb Difference Family Support Group	MN	X	
Moving on in the Gathering Place	MN	X	
Madonna Amputee Networking Group	NE	X	
Advanced Prosthetics and Orthotics	NV		X
Las Vegas Amputee Support Group	NV	X	
Pop Prosthetics	NV		X
Ampovation Support Group	NJ	X	
Believe U - Can Amputee Support Group	NJ	X	
New Mexico Amputee Forum	NM	X	
Hope in Motion – Penfield	NY	X	
Upstate New York Amputees	NY	X	

Amputee Support Group of the Carolinas, Statesville Division	NC	X	
Life Beyond Amputation	NC	X	
Un-Limb-Ited Support Group of ND	ND	X	
Amps4ohio Inc. Amputee Group	OH	X	
Amputee Recreational Support Group of Central Ohio	OH	X	
CAST Ministries – Lime	OH	X	
Southwest Oklahoma Amputee Program SOAP	OK	X	
Jim Thorpe Rehab Courageous Amputees	OK	X	
Tulsa Amputee Group Support (TAGS)	OK	X	
American Amputee Foundation of Oregon, Inc.	OR	X	
Amputee Resource Meeting	OR	X	
Central OR League of Amputees	OR	X	
Living with Limb Loss	OR/AK	X	
SW Washington Amputee Support Group	OR	X	
Amputee Coalition Altoona Area	PA	X	
Amputees Must Move On	PA	X	
Western PA Amputees Unlimbited	PA	X	
New England Amputee Association - East Greenwich	RI	X	
Charleston Amputee Support Group Team (CAST)	SC	X	
Sumpter Amputee Prosthetic Support Group (SAPSG)	SC	X	
Tidelands Waccamaw Rehabilitation Hospital Amputee Support Group	SC	X	
Amputee Support Group of Knoxville	TN	X	
Amputee/Limb Loss/Difference Support Group of Tri-Cities	TN	X	
Lakeway Amputee Support Group	TN	X	

Sevierville Amputee Support Group	TN	X	
Skyline Amputee Support Group	TN	X	
AIM - Amputees in Motion	TX	X	
Amputee Alliance	TX	X	
Amputee Support Group of Arlington	TX	X	
Amputee Support of Humble	TX	X	
Amputees in Action of Houston	TX	X	
Austin Amputee Group	TX	X	
Denton Amputee Support Group	TX	X	
Ft. Worth Amputee Coalition	TX	X	
Get Your Limb on Support Group -Kyle	TX	X	
H.E.L.P. Amputee Support Group	TX	X	
Houston Amputee Alliance	TX	X	
New Life Brace and Limb Amputee Support Group	TX	X	
Northeast Houston Amputee Support Group	TX	X	
PALS (Prosthetic and Limb Deficiency Support Group)	TX	X	
Post Acute Medical Amputee Support Group	TX	X	
Round Rock Amputee Support Group	TX	X	
Tarran County Amputee Network/TCAN	TX	X	
Amputee & Chronic Pain Support Group	UT	X	
Fit-Well	UT		X
Mobility Prosthetics	UT		X
Sky's the Limb-It	UT	X	
Central Virginia Amputee Support Group	VA	X	
Tri-Cities Amputee Support Group	VA	X	
Harborview Amputee Support Group	WA	X	
Lewis County Amputee Support Group	WA	X	
St. Luke's Rehabilitation Institute Amputee Support Group	WA	X	
Tacoma Amputee Support Group	WA	X	

Out on a Limb	WV	X	
Prosthetic Users Group	WV	X	
Amputee Support Group	WI	X	
Amputee Support Group of Northeast WI	WI	X	
ProHealth Amputee Caregiver Support Group	WI	X	
Wheaton Franciscan - St. Joseph Amputee Support Group	WI	X	
North Platte Physical Therapy	WY	X	

Social Media Profiles
Adaptive Amputees
Amputation Foundation (UK)
Amputee Coalition
Amputee Parents and Support Group
Amputee Peer and Support Group
Amputee Support Group (Street signs profile pic)
Amputees
Amputees Helping Amputees
Arizona Amputees and Prosthetics Support Group
Arizona Support Group
AZ Amputee
Beautiful Amputees
Las Vegas Amputee Support
Nevada Prosthetics and Orthotics
Power On with Limb Loss
PT Day of Service
UTAH Amputees

Appendix B

1. Please select a response below	• I agree to participate in this research study • I do not agree to participate in this research study
2. Do you have a leg amputation?	• Yes • No • Decline to answer
3. What is the cause of your amputation?	• Dysvascular disease (diabetes, vascular disease, blood clots, infection, etc.) • Cancer • Trauma • Congenital • Other (please state):
4. What is the level of your amputation? (if you have amputations in both legs, please select the highest level)	• Hip disarticulation or higher • Transfemoral (above the knee) • Transtibial (below the knee) • Foot • Other (please state):
5. How long has it been since your amputation? (Please select 1 if it is less than a year)	• 1-50 (years)
6. How long have you been using a prosthesis? (Please select 1 if it is less than a year)	• 1-50 (years)
7. Do you ever have difficulty making ends meet (for example: paying your bills) at the end of the month?	• Yes • No • Decline to state

8. On a scale of 0 (not worried at all) to 100 (worried all the time), have you ever worried about paying for your prosthesis or other health care you need after amputation?	• 0-100 (from not worried at all to worried all the time)
9. Did you receive any peer-support (talked to or visited by other amputees) before or after your amputation?	• Before • After • Both • None
10. If you have received peer-support, who <u>first told you</u> about amputee peer-support? Select all that apply.	• Healthcare staff (doctor, nurse, therapist, social worker…etc.) during the hospital stay for surgery • Healthcare staff (doctor, nurse, therapist, social worker…etc.) during the rehabilitation after amputation • Someone from a prosthetic company • Other amputees • Family or friends • Advertisement (website, magazine, or flyer) • Other (please state):
11. After your amputation, have you participated in any organized amputee peer-support group activities (including interactions on the internet)?	• Yes • No
12. If you have participated in	• Multiple times a week • Once a week

organized amputee peer-support, how often do you typically meet or interact with your peer-support group?	• Once a month • Once every 2-6 months • Once every 6-12 months • Once a year or longer
13. How long have you been a part of an organized amputee support group (including on the internet)?	• A few months • 1-2 years • 3-5 years • More than 5 years
14. If you have choices, what types of <u>peer-support meeting</u> would you prefer? (you can choose more than one)	• One-on-one meeting or visit • Group meeting or open discussion • Lecture on information related to amputees • Online interactions • Phone call or video meeting • Other:
15. On a scale from 0 (completely disagree) to 100 (completely agree), rate the following statements:	• 0-100 (from completely disagree to completely agree) o Information gained from the peer-support is useful for doing my everyday activities o Information gained from the peer-support is useful for doing things I didn't think I can do o Amputee peer-support helped me understand how my prosthetic limb works o Amputee peer-support helped me understand the process of rehabilitation (for example: physical therapy) after my amputation o Amputee peer-support reduced my anxiety after amputation o Amputee peer-support gave me a more positive outlook on life after amputation o Amputee peer-support meetings and/or visits are enjoyable o Amputee peer-support group gave me an opportunity to help other amputees

	○ I try to help others in my support group, even if they do not help me
16. On a scale of 0 (would not recommend at all) to 100 (would highly recommend), how much would you recommend a peer-support group for an amputee who is currently not part of one?	• 0-100 (from would not recommend at all to would highly recommend)
17. On a scale from 0 (completely disagree) to 100 (completely agree), at which time point do you think peer-support would be <u>most helpful to you</u> based on your experience?	• 0-100 (from completely disagree to completely agree) ○ Amputee peer-support would be helpful BEFORE my amputation ○ Amputee peer-support would be helpful AFTER my amputation while I was in the hospital ○ Amputee peer-support would be helpful AFTER my amputation and DURING rehabilitation such as physical therapy
18. What issues have prevented you from receiving as much peer-support as you'd like? (Can choose multiple responses)	• Lack of transportation • Lack of a local peer-support group • Lack of meeting information from the local peer-support group • Scheduling issues • Conflicts with other group members • Lack of interests or don't believe that it helps • Issues related to COVID-19 • Other:
19. Please tell us about what you enjoy most in your	• Free response (up to 2000 characters)

amputee peer-support experience.	
20. Please tell us what aspects of the amputee peer-support can be improved? How?	• Free response (up to 2000 characters)
21. Would you consider becoming a member of an amputee peer-support group?	• Yes • No (please state why not)
22. If you become a member of an amputee peer-support group, how often would you wish to meet/or interact with your support group?	• Multiple times a week • Once a week • Once a month • Once every 2-6 months • Once every 6-12 months • Once a year or longer • I do not wish to have any peer-support
23. What type of **peer-support meeting styles** would you prefer? (you can choose more than one)	• One-on-one meeting or visit • Group meeting or discussion • Lecture on information related to amputees • Online interactions • Phone call or video meeting • Other:
24. What issues have prevented you from receiving amputee peer-support? (Can	• Lack of transportation • Lack of a local peer-support group • Lack of meeting information from the local peer-support group • Scheduling issues • Conflicts with other group members • Lack of interests or don't believe that it helps

<table>
<tr><td>choose multiple responses)</td><td>• Issues related to COVID-19
• Other:</td></tr>
<tr><td>25. On a scale from 0 (completely disagree) to 100 (completely agree), at which time point do you think peer-support would be <u>most helpful to you</u>?</td><td>• 0-100 (from completely disagree to completely agree)
○ Amputee peer-support would be helpful BEFORE my amputation
○ Amputee peer-support would be helpful AFTER my amputation while I was in the hospital
○ Amputee peer-support would be helpful AFTER my amputation and DURING rehabilitation such as physical therapy</td></tr>
<tr><td>26. The following questions are about your mobility (from Plus-M)

Please respond to all questions as if you were wearing the prosthetic leg(s) you use most days. If you would normally use a cane, crutch, or walker to perform the task, please answer the questions as if you were using that device.

Please choose</td><td>
<table>
<tr><th></th><th>Without any difficulty</th><th>With a little difficulty</th><th>With some difficulty</th><th>With much difficulty</th><th>Unable to do</th></tr>
<tr><td>Are you able to walk a short distance in your home?</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Are you able to step up and down curbs?</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Are you able to walk while carrying a shopping basket in one hand?</td><td></td><td></td><td></td><td></td><td></td></tr>
</table>
</td></tr>
</table>

<table>
<tr><td>"unable to do" if you:
• Would need help from another person to complete the task,
• Would need a wheelchair or scooter to complete the task, or
• Feel the task may be unsafe for you</td><td><table>
<tr><td>Are you able to keep walking when people bump into you?</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Are you able to keep up with others when walking?</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Are you able to walk down a steep gravel driveway?</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Are you able to hike about 2 miles on uneven surfaces, including hills?</td><td></td><td></td><td></td><td></td><td></td></tr>
</table></td></tr>
<tr><td>27. What is your age?</td><td>0-100 (years)</td></tr>
<tr><td>28. What is your gender?</td><td>Male
Female
Non-binary
Decline to answer</td></tr>
<tr><td>29. What is your current weight (in pounds):</td><td>In pounds</td></tr>
<tr><td>30. What is your current height?</td><td>In feet and inches</td></tr>
<tr><td>31. Please select your ethnicity:</td><td>Hispanic
Non-Hispanic
Decline to state</td></tr>
</table>

32. Please select your race:	• Caucasian • African American • Asian • Native American • Native Hawaiian or other Pacific Islander • Other (state here if more than one race)

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Curriculum Vitae

Roopkiran Thind

Rthind97@gmail.com
Enthusiastic, dependable, and goal-oriented individual who excels in patient care environments.

Education

Doctorate of Physical Therapy
University of Nevada, Las Vegas
4504 S. Maryland Pkwy Las Vegas, NV 89154 | May 2023

Bachelor of Science Kinesiology
California State University, Sacramento
6000 J Street Sacramento, CA 95819 | May 2019

- Concentration in Exercise Science & Therapeutic Rehabilitation with a Biology minor
- Cum laude honors

High School Diploma
Mira Loma High School
4000 Edison Ave Sacramento, CA 95821 | 2015

- Golden State Seal Merit Diploma & International Baccalaureate Associates Diploma
- Salutatorian

Clinical Experience

The Johns Hopkins Hospital Graduate intern | 600 N. Wolfe Street Baltimore, MD 21287 | January 2023– March 2023
Valley Health Specialty Hospital Graduate intern | 8656 W. Patrick Lane Las Vegas, NV 89148 | September 2022– December 2022
Veteran Affairs Hospital Graduate intern | 6900 N. Pecos Road North Las Vegas, NV 89086 | July 2022– September 2022
Tim Soder Physical Therapy Graduate intern | 2779 W. Horizon Ridge Pkwy #100 Las Vegas, NV 89052 | June 2021– July 2021

Employment

Burger Physical Therapy Physical Therapist Aide & Clerk | 7200 S. Landpark Drive Sacramento, CA 95831 | June 2018 – February 2019

Additional Employment History

Golden 1 Credit Union Indirect Loan Processor | 8945 Cal Center Drive Sacramento, CA 95826 | June 2019– May 2020
Old Navy Brand Associate | 3581 N. Freeway Blvd Sacramento, CA 95835 | August 2014 – June 2019
Sierra View Country Club Event Associate | 105 Alta Vista Avenue Roseville, CA 95678 | April 2017 – July 2018

Service and Volunteer Activity

Parkinson's Rock Steady Boxing: Volunteer | *November 2021*
UNLV Fall Prevention Balance Screening: Volunteer | *September 2021*
Shriners Hospital: Volunteer | *March 2018 – May 2019*
Baudendistal Physical Therapy: Volunteer | *November 2017- June 2018*
UC Davis Medical Center: Volunteer | *March 2017 – September 2017*

Membership in Professional Activities

American Physical Therapy Association member *08/2020- current*

Certifications

CPR: American Heart Association, BLS for Healthcare Providers *05/2023-05/2025*

Research

Maluotoga M, Thind R. Patient Experience and Perception of Peer-support After Limb Loss: Implications for Post-Amputation Rehabilitation, *publication stage*; poster presentation at APTA CSM 2023 in San Diego

Moriah “Mo” Maluotoga

maluotogamo@gmail.com

Seeking an empathetic, patient-centered, and professional work environment with a culture for teamwork and quality care. Eager to learn, excellent communicator, avid team player, and quick learner. Passionate about health and wellness and helping others return to what makes them happy in life.

Education

UNIVERSITY of NEVADA - LAS VEGAS — ***LAS VEGAS, NV***
Doctor of Physical Therapy — *Graduation May 2023*
Master’s of Science, Kinesiology - Biomechanics — *August 2019 - May 2020*

UNIVERSITY of NEVADA - RENO — ***RENO, NV***
Bachelor’s of Science, Kinesiology — *May 2019*

Work and Clinical Experience

RENO VA MEDICAL CENTER (ACUTE CARE/OPPT) — ***RENO, NV***
Student Physical Therapist — *Jan 2023 - current*
Clinical Instructor: Kaylee Kimber, PT, DPT, GCS

- Evaluating and treating patients with various cardiovascular/neurological conditions, musculoskeletal pain, dysfunctions, mental illness, postoperative recoveries, and COVID-19
- Providing appropriate discharge recommendations/transitional care
- Collaborating with nursing staff and case management for quality patient care
- Regularly collaborating and co-treating with OTs;
- Collaborating with and delegating with PTAs
- Observed Amputee Clinic
- Will create and present in-service education on topic TBD

NEVADA PHYSICAL THERAPY - MIDTOWN (OPPT) — ***RENO, NV***
Student Physical Therapist — *Sept 2022 - Dec 2022*
Clinical Instructor: Jon Hodges, PT, DPT

- Evaluated patients with various musculoskeletal pain (acute and chronic), dysfunctions, and postoperative recoveries
- Developed and implemented individualized therapy programs
- Collaborated with therapy technicians for assistance with patient care and programs
- Provided patient education, encouragement, and personalized guidance
- Successfully directed 50% entry-level clinician caseload
- Created and presented 4-week strength/conditioning programs for various patients

NEURORESTORATIVE - RENO (SNF) — ***RENO, NV***
Student Physical Therapist — *July 2022 - Sept 2022*
Clinical Instructor: Michelle Sanders, PT, DPT

- Evaluated pediatric and geriatric patients with neurological and orthopedic conditions
- Developed, implemented, and progressed individualized therapy programs
- Traveled to/conducted home evaluations for safe discharge
- Provided family training for safe transfers and ambulation
- Successfully directed 100% entry-level clinician caseload
- Developed and presented in-service education on “Supernumerary Phantom Limb”

BOULDER CITY HOSPITAL (OPPT/WOUND CARE) ***BOULDER CITY, NV***
Student Physical Therapist *June 2021 - July 2021*
Clinical Instructor: Vince Dinglassan, PT, DPT

- Evaluated patients with various musculoskeletal pain (acute and chronic), dysfunctions, wounds, and postoperative recoveries
- Provided treatment for sacral wounds including implementation of wound vacs
- Collaborated with OTs for co-treatments

RENOWN REHABILITATION HOSPITAL (IP REHAB) ***RENO, NV***
Rehab Therapy Technician *June 2016 - June 2018*
Supervisor: Lisa Stiegman MS, CCC-SLP, MRMC

- Assisted PTs, OTs, and SLPs in evaluation of adult patients with neurological, musculoskeletal, and orthopedic conditions
- Assembled and repaired DME including walkers, canes, wheelchairs, and seat cushions
- Collaborated with rehab therapy staff, nursing staff, and food/nutrition for quality patient care
- Created a binder for "Extra Treatments with Rehab Techs," used by therapists
- Organized a system for use of RT300 with patients

Research

Utilization and Perception of Peer-Support After Limb Loss in the United States: Potential Benefits on Mobility Outcomes - Currently under process of Publication by end of 2023; Accepted to be presented at APTA CSM 2023. In collaboration with Roopkiran Thind, SPT | Under direct supervision of primary investigator Dr. Szu-Ping Lee, PT, PhD

Volunteer Experience

ROCK STEADY BOXING ***HENDERSON, NV***

- Supported and led exercises for clients with Parkinson's Disease (all stages) *Nov 2021 - Dec 2021*

FALL PREVENTION & SCREENING COMMUNITY EVENT ***LAS VEGAS, NV***

- Screened seniors for fall risk using STEADI protocol, MiniCog, and provided resources *Sept 2021*

Additional

OTHER EDUCATION/CERTIFICATIONS/RELEVANT EXPERIENCE:

- BLS
- OTAGO
- Surgery Observation (TKA, Achilles Tendon Repair)
- CSM 2023
- APTA Member since 2020

OTHER SKILLS:

- Proficient in Excel, Microsoft Word, Google Drive, Microsoft Teams, Outlook
- Personable, conversational, adaptable, reliable

EMR SYSTEMS FAMILIAR WITH:

- NetHealth, EPIC, CPRS

Personal Life

INTERESTS HIIT training, weightlifting, volleyball, outdoor activities, food, reading, Disney, Nevada sports
FUN FACTS Grew up with an older brother with Cerebral Palsy, ***n***ever seen Star Wars, ***s***ang the National Anthem at a volleyball tournament in the Reno Event Center when I was 13 y.o, ***s***tudent-athlete at UNR 2015-2019 (Women's Volleyball)

References

- **Kaylee Kimber, PT, DPT, GCS**
    - Acute Care PT at Reno VA Medical Center
    - C: 530-386-6828 | E: kaylee.kimber@va.gov
- **Lisa Stiegman MS, CCC-SLP, MRMC**
    - Manager of Rehab Therapy Services at Renown Rehab Hospital
    - C: 775-982-5003 | E: lstiegman@renowon.org