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CONTINU ED



Current Topics in Upper Limb Loss and Difference Virtual Conference

Guest Editor: Debra Latour, OTD, MEd, OTR/L

continueD

Current Topics in Upper Limb Loss and Difference:

Un*limb*ited Wellness and Secondary Conditions

Debra Latour, OTD, M.ED., OTR/L



Learning Outcomes

- As a result of this course, participants will be able to:
 - list 3 factors that contribute to health behavior change
 - describe the benefits and challenges of using telehealth as a health care delivery platform
 - describe the issues that are important to the population and that impact care
 - list and describe 3 secondary conditions related to each category (physical and psycho-social) and strategies to mitigate and/or prevent these problems

continued

Disclosures



- 63+:Congenital UL difference
- 62+:Lifelong prosthesis user
- 41+:Occupational Therapist



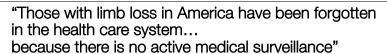
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Background

- 2,000,000 Americans *
- +28,000,000 Americans *
- 1:4 ULL : LLL
- ~2,000 Americans at, proximal to wrist**
- 0 Information!!!



Sheehan and Gondo, 2014



Review of the Literature: Evidence and Themes

- Need for Collaborative Care
- Secondary Conditions
- Including Psychosocial Impact
- Need for Prosthetic Training
- Access to Care and Telehealth (TH)







Needs Assessment 1

- QuickDASH
- McGann Client Feedback Form
- Focus Group Questions

Focus Group Question

Please consider the following topics and questions in preparation for our focus group discussion activity on April 22, 2017 at 9 AM.

- 1. How do you perceive your prosthesis? Some examples for discussion include
 - a. As a tool that you use purely for function
 - c. As an extension or a part of your body or self-identif
- As a combination of any, an or other purposes
 Do you ever feel that the prosthesis is an extension or a part of your be
- If you could design your perfect prosthesis, what would it look like.
- What is your actual prosthesis wear schedule and use?
- . What are your perceptions about the prosthetic training that you received?
- a. Was it enough?
- c. Was it relevant to your lifestyle, goals, and/or values?
- Please share with us your experiences of pain in your opposite arm, neck or back, if at
 Please be prepared to tell us, if at all, how you became informed, of the likelihood of
- evenoping overuse syndrome.

 8. Please share with us your experiences, if any, with seeing others with upper limb
- 9. What experiences do you have of isolation because of your congenital difference?
- 10. What experiences do you have of participation in peer support group activities?
- What is your access to specialized care relevant to your congenital limb difference, or prosthesis?
- 13. Can you describe some awkward social experiences related to your congenital limb difference and/or your prosthesis and how you handled them? Some examples for
 - discussion include:

 a. Describe what happens when you meet someone for the first time or must shak
 - Describe how you feel when you drop items in public, such as to manage currency at a cash register
- 14. Please share with us what strategies you use, if any, to prevent others from seeing ye residual limb or prosthesis when in public.

continued

Needs Assessment 1 Results

Emerging Themes

- Overuse, trauma to 'sound' limbs, other anatomy
- Lack of prior information
- Difficulty to obtain specialized services
- Social isolation
- Past experiences of being bullied, excluded
- Concern for others

Changes in Scores

Individual Participant Data 🗸 🗸								$\hat{\Gamma}$
Client	Age	Sex	Side	Prosthesis	Pre-FG Q-DASH GDI	Post FG Q-DASH GDI	Pre-FG MCFF- M	Post-FG MCFF- M
1	70.9	м	L	Passive Aesthetic	29.5	25	70.8%	78.3%
2	64.6	F	R	Passive Aesthetic Activity-specific	18.18	15.15	66.67%	75.2%
3	62.5	м	L	External-power Activity-specific	13.64	11.4	76.9%	85%
4	59.8	м	L	External-power	38.63	38.63	64.2%	70.6%
5	52.1	м	R	External-power	56.8	45.1	65.38%	83.2%

If nominal beneficial change can be detected following one strategic interaction,

then how much greater might be the impact of several planned interactions?





Needs Assessment 2



Practitione	r Surv	ey Res	ults		
Please rate the following statements:	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I have basic knowledge about treatment strategies for individuals with ULL/D.	27.8%	44%	16.7%	11.1%	
I feel competent treating the individual with unilateral ULL/D.	16.7%	33.3%	27.8%	16.7%	5.6%
I feel competent training an individual to use a body-powered prosthesis toward functional independence.	5.6%	11.1%	16.7%	44.4%	22.2%
I feel competent training an individual to use an externally- powered prosthesis toward functional independence.		16.7%	16.7%	38.9%	27.8%
I have basic knowledge about telehealth as it pertains to OT intervention.		38.9%	50%	11.1%	
I would consider consultations via telehealth if they were available.	50%	44.4%	5.6%		



Gaps

Healthy People 2020

- Multi-faceted Challenges
- Access to Specialized Care
- Specialized training, consults for practitioner

National Prevention Strategy

- Create healthy environments
- Promote physical, mental health
- Prevent further disparity
- Priority areas:
 - Active living
 - Injury and violence-free living
 - Mental, emotional well-being
- Affects all population levels:
 - Individuals with ULL/D
 - Community Practitioners
 - Administrative, Funding and Policy-makers





Program Goals

Overarching Goal:

to use TH to improve understanding of secondary conditions, learn strategies for self-advocacy, and access peer support.

- Specific objectives for Participants to:
 - Identify 3 strategies to prevent/protect from further physical disparities
 - Successfully use teleconferencing to access peer support
 - Identify 3 strategies to manage awkward social situations
 - Identify 3 strategies to self-advocate in medical and social situations



Program Description

- Pre-program interview
- 10 sessions/12 weeks
- Peer-Interactive, Participatory
- 3 distinct modules
 - Physical Conditions, Strategies
 - Health Care Visits
 - Psycho-Social Conditions, Strategies
- Post Program Interview

Session	Leader	Topic	Activities			
1	Program Manager	What is overuse?	Information Sheet Pre-program survey QOL survey Group Discussion			
2	Peer to Peer	What compensation strategies do we use?	Create Tips and Tricks sheet Group Discussion			
3	Program Manager	Other physical disparities	Information Sheet Group Discussion			
4	Peer to Peer	How do we self-advocate to health care providers?	Create Tips and Tricks sheet Group Discussion			

1	Program Manager	Guided group discussion: Visiting the Doctor, An All or Nothing Experience Survey program satisfaction, TH experience
2	Peer to Peer	Guided group discussion: Experiences Using Tip Sheet and Practitioner Visit Guide at MD Visit

1	1	Program Manager	Greetings and Disclosures	0	How do we greet people? Do we disclose our limb difference, conceal it, or? Group Discussion
[2	Peer to Peer	Sharing social stories	0 0	Create Tips and Tricks sheet Group Discussion
1	3	Program Manager	Help!	0	How do we feel when strangers stare, or point? How do we request or refuse help? From family? From strangers? Group Discussion
4	4	Peer to Peer	How do we self- advocate?	0 0 0	Create Tips and Tricks sheet Survey program satisfaction, TH experience, QOL Survey Group Discussion



Program Materials

Module 1: Sessions 1-4

- Introduce participants
- Problems experienced with anatomy other than limb loss/difference
- Interventions
- Prevention
- Talking to Our Providers

	What it is	Causes	Symptoms	Treatments	Prevention
SHOULDER					
Rotator Cuff Tendonitis	Impingement of cuff structures on overlying bone	Prevalent in work- related disorders	Weakness and pain that may radiate down the arm; limited shoulder motion (abd, £R)	Rest the shoulder; Acold overhead activities x1-3 wks; Limit raining, arms; Avoid immobilization; Medis: NSAIDs, steroidal injections; Gendle ROM; Surgery	Orient objects and tasks in front of body Reduce weight of objects Hold objects close to body Use step-stools Ask for help!
ELBOW			•		
The state of the s					
WRIST					
HAND					
NECK					
SPINE					
HIPS					
KNEES					
ANKLES					
FEET					
	1				

Session 1 Tip Sheet: Common Overuse Conditions

continueD

Program Materials

Module 2: Sessions 5-6

- What do our Providers do?
- What do we wish our Providers would do?
- What do we wish our Providers would do?
- What do we our Providers need to know?
- Preparing for a Provider Visit Use

Timing	Situation Topic	Issue	How I Feel	What I Do	What Else Could I Do
Preparing for	Disclosure	Should I prepare practitioner			
the Visit		in advance regarding my			
		ULL/D?			
	Explaining Medical	How much information			
	History	should I provide?			
	Organizing	Medical information is			
		disorganized			
The Visit	Greetings	Practitioner extends hand to			
	1	shake my (absent) hand			
	Labels	Practitioner uses any of the			
		following or similar:			
		"Amputee", "Different",			
		"Special", "Disabled",			
		"Handicapped"			
	Disclosures	Should I wait for the			
		practitioner to ask about my			
		absent limb?			
	Explaining Medical	Repetitive questions about			
	History	ULL/D			
	Disinterested or	Practitioner does really seem			
	Dismissive	to be interested in my			
		concerns.			
	Impromptu "Rounds"	After practitioner greets me,			
	1 1	leaves and returns with			
		colleague(s) to 'meet' me			
	Lack of Holistic	Practitioner focuses on side			
	Approach	of ULL/D			
	Incorrect terminology	Practitioner uses terms that			
		are not used currently or			
		uses incorrectly			
New Provider	Choice	Should I assume provider is			
		familiar with diverse needs of			
		individual with ULL/D?			
		Should I prepare practitioner			
		in advance regarding my			
		ULL/D?			
	Referral	Should I prepare practitioner			
		in advance regarding my	I	1	l
		ULL/D?	1		
	Explaining Medical	*Repetitive questions about			
	History	ULL/D	I	1	l





Program Materials

Module 3: Sessions 7-10

- Common Awkward Social Situations
- Family, Friends, Strangers
- Home, Community, Work
- How it feels
- What we do
- What we could do instead

Topic and Event	Who is Involved	How I Feel	What I Do	What Could I Do?
Being Different:	Family			
*Person uses any of the following or				
similar: "Amputee", "Different",				
"Special", "Disabled", "Handicapped"				
Or offensive words				
	Friends			
	Strangers			
	Children			
Stares and/or Points	Family			
	Friends			
	Strangers			
	Children			
Greetings:	Family			
Side-hug or Person extends hand to				
shake my (absent) hand; Business				
situations; Questions that emerge;				
Fist bump; "Shitty" handshake (limp or				
attempting to mimic)				
	Friends			
	Strangers			
	Children			
Disclosures:	Family			
Advance Preparation or				
Repetitive questions				
	Friends			
	Strangers			
	Children			
Regarding Help:	Family			
Insists on helping; Minimizes need				
	Friends			
	Strangers			
	Children	1		

continued

Theoretical Frameworks

- Supporting evidence: Literature Review
 - Uninformed: secondary conditions likelihood
 - Experienced isolation and social stigma
- Precaution-Adoption Process Model (PAPM)
 - Linear, systematic progression of steps toward change
 - Choice of "no change"
 - Dynamic, progressive stages
 - May revert to prior stage; may move forward from decision not to act (Stage 3)
 - Educate; once educated, choice to accept or reject action
 - May maintain new behavior(s)

The intrapersonal processes of meeting with peers provides positive impetus for behavior change, social identity, and support.





Program And Evaluation Design

Logic Model

- Uses measures
- Offers comparative perceptions
- Pre-/post-group experiences
- Links between participants/ resources/outcomes to identify performance measures
- Sequential "if/then" deduction
- Each step builds upon next
- Accountability to facilitate stakeholder buy-in

Resources (Inputs)	Activities (Outputs)	Participation (Outputs)	Short-term Outcomes	Intermediate-term Outcomes	Long-term Outcomes
Program	1:1 interviews	Participation	Increased	Continued	Improved
Manager		in program	awareness and	application of	physical and
Time	Baseline	discussion and	knowledge	techniques to	mental health
	surveys	activities	about	manage secondary	
Research for			secondary	conditions relating	Improved
Activity	Technology	Active	conditions	to health	perception of
Materials	tutorial	engagement			wellness
		with peers	Increased	Improved	
Skype for	Strategies to		awareness of	perception of ability	Improved
Business	apply	Attendance to	protective,		awareness and
	information to	7 of 10	preventive	Development of	access to peers
Support from	daily life	sessions	techniques	peer support	
Handspring			and daily		Improved
leadership	Mid-point	Shared	application	Improved use of	awareness and
	survey	experiences to		telehealth	access to
		apply	Understanding	technology	telehealth
	End-point	strategies	of telehealth		
	survevs				
77	77	77	77	17	77
		Extern	al Influences:		
Time	. technology is:	ues. long term	financial sustai	nability funding lim	itations

continued

Program Measures

- Comparative perceptions to pre- and post-group experiences
- On-line customized survey
- Independent MCFF-M completion
- 1:1 interview
 - PHWA
 - Participant Goals
- Post-group interview: telephone or TH interview?

Health	Topic	Pre-	Pre-Grou	p Post-Group	Post-Group	Comments
		Group	Mean		Mean	
Social		A:7	7.8	A: 8	8.7	+1
		B:6		B: 8		+2 hearing peer input offe
		C:10		C: 10		=
Physica	al	A:5	5.3	A:7	7	+2
		B:6		B:7		+1 started w/personal trai
		C:5		C:7		+2
Family		A:8	8.7	A:10	9.3	+2
		B:8		B:8		=
		C:10		C:10		=
Occupational		A:9	8.7	A:10	9	+1
		B: 7		B: 7		=
		C:10		C:10		=
Mental	/Emotional	A:5	8	A:9	9	+4
		B:8		B:8		=: Getting ready for baby i
		C:10		C:10		=
Spiritui	al	A:9	8.3	A:10	9.3	+1 "Felt differently out in staring; feeling embolden- five someone in public. The thought I would always fe
		B:6		B:8		+2 "Learning new txs and others by sharing ideas.
		C:10		C:10		= "I think I rated myself to than 10 on most of these item, I would."

Subject Pre-Group Post Group Comments



Results

- Promoted health, wellness and well-being
- Education
- Meaningful Occupation
- Social Participation

"Unlimbited Wellness made a difference in my confidence to speak about my limb difference and my prosthesis especially in public with strangers; the program gave backbone."

- I learned strategies to deal with situations in public.
- I feel much more approachable, comfortable, and confident: less self-conscious.
- Contributing to group projects made me feel like I was doing something important and I was learning by doing.
- I felt invested in this group even though we were far apart from each other. I was not alone and being a part of something with like-peers gave me a different perspective.
- Even things that were uncomfortable became comfortable because of the context of familiarity with anonymity.
- I am less likely to sound angry and I want to make a difference for the next person.



Discussion

Would stakeholders perceive value in the Unlimbited Wellness program?

- Program evaluation:
 - dynamic changes in health behavior, perceptions of well-being, and that access to peer interaction and information makes a difference
- Surveys at stages of the group process:
 - behavior changes individually and collectively
- Addressed the challenge initially posed, to address and meet the physical and psychosocial needs of America's forgotten,
 - individuals with diminished disparity empowering to self-advocacy



Implications: Population

- Information for prevention and empowerment
- Self-Advocacy
- Improved health, wellness and well-being
- TH as connected health:
 - Delivery of services
 - Access to peers
- Potential policy changes

continued

Implications: OT Practitioners

- Access to specialized training, consults, support
- Access to patient/client population
- Population, cultural awareness
- Measures, tools to address QOL, health, well-being
- Interventions to prevent further disparity





Next Steps

- New groups forming!
 - Shorter duration, more frequent
 - Expanded, separate groups:
 - Children
 - · Parents of children,
 - Individuals with acquired loss
 - Individuals with bilateral loss
 - Professional practitioner group!
- Future study
 - Differences amongst groups relating to secondary conditions and strategies to prevent and/or manage them
 - Effectiveness of groups to determine
 - Impact of participation
 - · Extent secondary conditions are mitigated and
 - If a refresher or additional programming would be beneficial



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I am a member of the international



Sharing Resources of Upper Limb Absence Worldwide

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Questions?

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Current Topics in Upper Limb Loss and continued Difference Virtual Conference Mon 11/11 Unlimbited Wellness and Secondary Conditions Debra Latour, OTD, MEd, OTR/L Tues 11/12 Problem Solving Complex Issues with Pediatric Upper Limb Loss Difference Vivian Yip, OTD, MA, OTR/L Wed 11/13 OT for Targeted Muscle Reinnervation and Pattern Recognition Control Kristi Turner, DHSc, OTR/L Thurs 11/14 Bilateral Upper Limb Loss Shawn Swanson Johnson, OTR/L Fri 11/15 Electronic Multi-Articulating Hands and Digits, Toe-to-Hand Transfers, and Hand Transplantations Diane J. Atkins, OTR/L, FISPO

