Current Topics in Upper Limb Loss and Difference: Unlimbited Wellness and Secondary Conditions

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- [Fawn] Again, our topic today is, Current Topics in Upper Limb Loss and Difference: Unlimited Wellness and Secondary Conditions. Our presenter is Dr. Deborah Latour. She is a registered occupational therapist and owner of Single-Handed Solutions, providing clinical educational and research consulting services to manufacturers, providers and individuals with upper limb loss and difference. She offers clinical interventions through her affiliation with Handspring Clinical Service. Debbie graduated with a bachelor's from Tufts University and earned her master's from Springfield College and post professional OTD at A.T. Still University. She's a full time academic faculty member at Western New England University. She is active with the Amputee Coalition and is a member of the ACPOC, AAOP, ATA and AOTA. Debbie has a congenital upper limb difference, is an active prosthesis user and shares her experiences and tips through her blog at www.single-handedsolutionsblogspot.com. She's the inventor of Record of Patented Prosthetic Technology and has authored published articles and chapters in occupational therapy and textbooks as well as copyrighted educational materials distributed by ContinueD and MedBridge. She has consulted with scholastic books as a sensitivity reader for diverse publications. Was mentioned in the book "Inventology" by Pagan Kennedy and is a subject in the We Design exhibit of Design Museum that open October 3rd in Boston, Massachusetts. Welcome back Debbie, so glad to have you.

- [Debra] Good afternoon, everyone. It's nice to be here and I wanna thank Fawn Carson for inviting me back. And I certainly wanna also thank the list of presenters who happened to be my colleagues but also my friends. It's a real honor to be presenting to ContinueD again. So I thank all of you for joining in this particular series, I hope you attend every single one. So just to review, you probably have been able to look at your course materials and it's my hope that at the end of this particular session today that you as the participant will be able to better understand the factors that contribute to health behavior change. You'll be able to describe the benefits and challenges of using telehealth as a health care delivery platform and also to be able to access consultation from specialty providers. So I feel very confident that you could contact any of the presenters this week, after having taken their courses and speak with them about the possibility of consulting to any challenging cases that you might have. It's important that you'd be able to describe the issues that are relevant and important to the population itself and what of these issues impact care. And then it's also my goal that you'll be able to identify secondary conditions in each category. It's very obvious to us we can oftentimes, list the physical overuse conditions that seem to affect people but we tend to forget and not even talk about those psycho-social implications and then also that you'd be able to better understand the strategies to be able to mitigate and/or prevent these particular problems.

Just a few disclosures. I know that Fawn mentioned quite a bit there, in her introduction, I apologize for that. But just so that you do know I have, over 63 years living lived experience with a congenital upper limb difference and over 62 of these have been using prosthetic technologies. Different kinds for different periods of times in my life and for different activities. And over 41 of these, over 63 years have been as a practicing occupational therapist. I am a full time faculty member at Western New England University and I am the owner of Single-Handed solutions. And the reason that I mentioned is because some of the groups that I mention Handspring for one, I do have a business relationship with them in the past and currently and I think that it's prudent to mention that. All the materials in this presentation are copyrighted and owned by me. If you would like to be able to access the specific copyrighted forms, some of these are offered today as an example. I would be happy to send them to you but please know that they're copyrighted. I do not sell them but I do use them to promote these particular the problems that people have and help them to better advocate for themselves.

Just a little bit of background, about the population itself. Now, just a precursor to this is that I tend to have a population health perspective. I think it's important when we're talking about, different groups of people to be able to better understand who they are, what kinds of issues they experience and consider what they think are important for solutions or essential factors for how we might attack some of the problems that they experience and develop strategies. So to better understand this population, let's just take a peek at the numbers. There are 2 million Americans who live with limb loss and its projected that within 50 years by the year 2050 in fact, that's 30 years away that there will be another 28 million Americans who experience limb loss. Now if we look at the population of people who have experienced either acquired limb loss or congenital limb difference, there are about one in four of those who are impacted by upper limb loss. So most of the people with limb loss it affects their lower limbs, about one in four it impacts their upper limbs. There are about 2,000 Americans every year, okay, think about this, every year who experience loss of their upper limb proximal to the wrist. So every year we see 2,000 new people who have limb loss.

Now what's a common denominator amongst all of these people? Is that they report that they have received little to no information about their medical care, about what they can expect or about what they can do to prevent any of the problems. In 2014, two writers on Dr. Sheehan from, both of these writers are from Amputee Coalition. Dr. Sheehan and George Gondo and they wrote a book that stated that individuals with limb loss in America have been forgotten, in our healthcare system and that's because there is no active medical surveillance. That's a really telling sentence and it's a bold statement to make. In order to investigate that of course, I had to look at what does the literature say about that? Are we really overlooked? I have to say as a consumer of prosthetic technology and an individual who lives with upper limb difference there are many times that I have felt that care for people like me has been overlooked. But what does the evidence tell us? So in conducting a review of the literature I found some very interesting themes. One theme reported over and over and you can look at my list of references, is pretty exhaustive and quite frankly, some of it was exhausting to read, I will tell you and you can laugh at that, I hope you will. But one of the themes that was overarching was the need for, inter-professional collaborative care. And that means essential communication. If we think about our current medical environment, our healthcare environment, we're often operating out of separate silos and there's few to any opportunities to really collaborate unless we tend to be under the same roof as some of these other providers.

Another theme that emerged was the prevalence of secondary conditions and most of the literature initially points to the obvious physical secondary conditions. But more and more authors, particularly Murray out of the UK, was talking about the psycho-social impact that people with limb loss and limb difference, often experience. I'm gonna talk more about each of these bullet points but I wanna mention them now. Another facet that was explored by the literature repetitively, was the need for prosthetic training and the essential element of occupational therapists as being providers of such training and being able to work. Let's go back to the first bullet point, to be able to work in an interprofessional, perspective collaboratively with other healthcare providers. And then the last theme was the ability of the population of individuals with upper limb loss or difference to be able to access care. And the fact that many times they cannot access, the specialized care needed to be able to learn to work and learn to use their prosthesis.

So how do they do that? Well, they often go to see an occupational therapist or other provider who's a generalist and those people don't have access to the specialist providers who can consult with them. So the emerging theme of this literature review was that telehealth because it's provided to most commonly people in rural atmospheres and environment that it would be able to be essential to help this particular population to access health care. I do wanna tell you that this particular project is dear to me. It was an idea that I had about 2012 and it wasn't until I was able to go return to school for my doctorate that I found a way to learn how to enact this program. In order to enact the program I had to perform a needs assessment. So I chose a community partner in a practice, in Upstate New York that has offices all over the country called Handspring. So they were able to allow me to access their current client list and their past client list, over the past four years via chart review so that I could develop an opportunity to invite people to a focus group. The data that I was able to access included verification of the individual's congenital limb difference and level because my first round of this program was for people with congenital limb difference. Their prosthetic technology and use, any co-morbidities they already had and identified as well as secondary conditions and pain.

So I used this to form a focus group of individuals with the common presentations and to be able to invite them to participate. As the OT I had to maintain ethics and integrity of my data collection throughout the process that included initial and follow up interviews as well as the focus group transcripts. I did receive approval, IRB approval of non-jurisdiction because this was exempt but I did go through that process so that I could access the records and report on them. So my target group ended up being five clients age 50 years and over who presented with congenital transradial difference and all of them voluntarily participated, in a semi-structured focus group. The focus group was held via teleconference platform, on a secure setting. So initially the individual preliminary and follow up interviews with each participant occurred on a one-to-one basis, during which time each participant completed two inventories and then I compared the results to see if there would be differences, in their self-perceptions of ability, quality of life and prosthesis satisfaction.

So I used the 11 question version of the dash so that was the QuickDASH. I used the self-report instrument of perceptions about the prosthesis use as well as the impact of secondary conditions. This is something that was developed collaboratively with prostatitis at the Handspring. It's also copyrighted and it's used around the country now by many facilities. And then I developed a list of focus group questions that offered an insight into the kinds of experiences that people had. So these questions had to do with their lived experiences such as being able to access prosthetic training and resources, prevent secondary conditions, handle social challenges and develop self advocacy skills. One of my authors from my lit review, a gentlemen, Dr. Craig Murray used interviews with prosthesis users to discover common experiences and themes that are important to the population. His research suggested that the valued personal identities and the self-management of patients ability status should be a priority for all of us as healthcare professionals who are involved in prosthesis users medical care and personal development.

Some of the emerging themes that developed from this particular group discussion, were actually anticipated by the lit review. The difference in the pre-focus group and post-focus group abilities using the QuickDASH and McGann Feedback Form reveals an upward trend, in their perceptions of ability and satisfaction following this one peer interactions. So some of those emerging themes include overuse and trauma to their sound limbs, a lack of having been informed, difficulty to obtain specialized services, a feeling of social isolation because people had never seen any one like themselves. And all of the participants recounted past experiences of being bullied or excluded by people who should have been leaders or important in their lives like coaches and teachers and employers. And all of the people who participated in this expressed a concern for others, particularly younger groups of people so that they could be be able to anticipate what problems they might experience. So what struck me about this focus group experience was that if this one opportunity, this one hour and a half long focus group session, could offer insight to the potential impact of peer input and influence during a multi-layered kind of program. So it posed the question to me that if nominal beneficial change could have been detected, following this one interaction, how much greater might be the impact of several planned interactions? So that really got me going.

When I spoke with my advisors at A.T. Still University they suggested that I query occupational therapist. So I then had to go through another round of IRB and query occupational therapy practitioners, via an online survey. So there were about 23 questions as well as just some basic information, about the participants. Most of the respondents were OTRs or Certified Hand Therapists. Most were employed full time and most were staff practitioners. Most of them had not treated any persons with upper limb loss or difference in the past year and the rest of them reported that they had treated no more than five people with upper limb loss in the same amount of time. So this particular survey informs the needs assessment, about the gap in care particularly the perceived, OT generalist practitioner knowledge and competency to be able to provide treatment to this population, the need for specialist consultation and the use of telehealth to provide information, education and support because some of the questions actually had to do with access to telehealth.

So some of the gaps in care that were identified actually correlate with important documents in our country right now. The "Healthy People 2020" document talks about, health care providers addressing population needs and preventing further disparities and then the National Prevention Strategy, also talks about including problems that relate to being able to create healthy environments for people and promoting health, both physically and mentally. Emotional and behavioral health. Being able to prevent further disparity. All of this moves toward the idea of enhancing quality of life for a population and it affects all of the population levels. The people themselves with upper limb loss or difference, community practitioners like you and me as well as administrative funding and policymakers.

So I set out to create this program where the overarching goal was to be able to use telehealth to improve the understanding of secondary conditions. In essence, telehealth was going to be the bridge to help people to be able to get connected with people like themselves, to inform and empower them to be able to maintain or improve a healthy lifestyle that would support their independence, their safety and their well being. This philosophy correlates with how we aim to change health care behaviors. So the ways that we do that are by educating our population, informing them to necessary information and then engaging with them. In some kind of way that the learning becomes active and lively to them and thus the end result with health behavior change is that we then empower people to make those particular changes. So this program was designed to link members of the target population as peers and inform them to the different kinds of secondary conditions that they might experience and help them to share strategies with each other, okay?

All of these areas coincided with the gaps in care that I previously stated. There were, each module was held over a period of about four weeks so there were 10 sessions in all that lasted over a period of time 12 weeks. It was peer interactive and participatory and the three modules included distinct areas. The first one was focused on physical conditions and strategies and then health care visits. And then the, I'm sorry, that was the second one was the health care visits and that was really interesting time in this group. I'll talk more about that in a moment. And then the last session was on psychosocial conditions and strategies followed by a post program interview. During program module one which was sessions one to four, the participants were able to be introduced to each other via telehealth. Everyone had to sign in, people could choose to reveal themselves and open their camera or not but their mic had to be on. People talked about the kinds of experiences that they had with anatomy other than their limb loss or difference and what interventions were taken to help them, what they might do to prevent them and then the sessions ended with talking to our providers.

Now, if you take a look at this template, this is really kind of a washed template but it's meant to give you an idea. The participants were presented with a template filled out in, about the first four columns of this. And if you're interested in the templates themselves, I'd be happy to share them with you. The idea was that the templates that were, the sections that were completed were meant to inform the the participants. And then the areas that were not complete which were the last two columns what kinds of interventions people experienced and what we could be doing to prevent these problems from arising. People collaborated together during the sessions and we filled them in together so that by the end of session four everyone who participated in the group had a completed version of the template that they had contributed to formulating. What was interesting about this was that I as a practitioner knew what the likely conditions were. But in talking with and in leading this group, people started talking about other areas that are not commonly researched.

So for example, many people with unilateral congenital upper limb difference, oftentimes experience overuse in their feet as well as their knees. Now one might say, oh, well, that's, it's not uncommon for everyone to have knee osteoarthritis. But in further discussion, pretty much all the participants acknowledged that they use their foot on the same side of their limb loss to be able to retrieve objects and it was interesting for me as the facilitator because I would let myself kind of move to the background of the conversation and let the group lead it. They were the ones bringing some of these new areas up so it was informative to me as well. In module two, this is where it got really interesting because people started to talk about what happens when we go to our medical providers? What happens when we go to see our PCP? What do they ask us? What do we wish they would tell us or ask us? What we feel that as consumers of health care that our providers need to know? And that led to developing a form to help people better prepare for a provider visit use.

Now this was also a pivotal time in the program because people had been meeting for four weeks already, they had gotten to know each other, everyone by this time was opening up their camera to share it so that it was very, it appeared very personal. And some of the themes that came up were how our care providers are so focused on limb different side that they fail to talk to us about the other aspects that are prevalent to our care. What that physical overuse is, what kinds of problems we might be having, in our opposite upper limb? What kinds of other problems we were having? What some of the vascular implications might be? So that's actually another relatively little known area of secondary conditions for many particularly with congenital limb difference is that we often have vascular issues in our other anatomy. That may include things like vascular disease, fibromuscular dysplasia which is a form of a vascular disease. And as these illnesses and conditions are becoming better known we're looking at what is the correlation with people with limb loss or congenital difference. This was also a time that became pivotal with group members because they started to talk more personally to each other about what they feel like when they go to a practitioner. And the practitioner sees that they have this congenital anomaly and instead of sitting and talking to them about it the provider often goes and gets several other colleagues so that they can view us as specimens. Almost like we're feeling like we're in a zoo or something. So people really talked about that.

Another aspect of this particular element part of the program was that it was purely facilitated by participants at this point. So they were again presented with this semi filled out, semi completed template and they drove the discussion to complete all sessions so that by the end of session six they once again had a completed template and that led me to then create a form for them to use with medical providers. And they all went and used that, many of them had end of the year annual visits with their providers so they brought that and used the form to help organize their own materials but also because there were references they were able to inform their providers which spoke toward that empowerment piece. So here we are employing all aspects of health behavior change, we're informing the participants, engaging them in an activity in which they collaborated with each other and then proceed to empowerment. One of the goal was empowerment. I'll let you hear what their end results were. Module three we talked about those awkward, social situations and this was strategic on my part and that's because we are more willing to talk about the physical aspects, they seem a little less personal. It was easy to talk about the medical providers because it was how we perceived we're being treated and how it makes us feel. But to talk about those awkward social situations, is a little more sensitive. It meant revealing more about ourselves in a venue that think about it, people might think of telehealth as being very impersonal but it became very personal.

So we talked about these awkward social situations that occur not just out in public but even with our own family and our friends, our inner circle as well as with strangers. And then we delineated, does it matter if the stranger is an adult or a child? Do we respond differently? And what are the different environments that these awkward social situations might occur? Well, quite frankly, they occur in all environments, the home, the community work, even the places where we worship. So then we talked about when these things occur, how does it feel? And how do we handle it? What do we do? And most people talked about how they respond in a negative way that they then feel badly about. So we talked about what we could do instead. And all of those aspects were elements that, my goodness, I'm having trouble speaking here. But these were all elements that the participants completed and filled in so that again, by the end of session 10, they had a completed template that was theirs. It was a tool that they could use.

Now, this whole model, this whole project, supported the evidence that was found in the literature review. People stated that they were uninformed about the likelihood of secondary conditions, particularly the element of the psychosocial secondary conditions. And they all stated that they experienced isolation and social stigma. The model that I used to develop this program, is called the Precaution-Adoption Process Model. It's a model of health behavior change, it's linear and it's systematic and it's progressive. It's also incredibly dynamic and one of the things I liked about it and why I chose it is because it offers the the choice to the participant of no change. So people can hear about a concept new medical information, they can choose to accept it or not. They can move forward through the stages of health behavior change and even revert to a prior stage or they can stay where they are and then move forward later to be able to make a health behavior change. The bottom line is that the goal of a program like this was to educate and using this model once educated, a person could choose to accept or reject action but they could never go back to being uninformed. So the idea of being able to inform our clients for whom we are in charge of their care is highly important, especially in this day and age. There's all kinds of information on the internet but how much of it is valid? And how much of it is truly relevant to our clients? So this is a way to help.

The interpersonal processes of being able to meet with peers provided a positive impetus, for behavior change social identity and support. Now to evaluate this program, I used something called the Logic Model. The Logic Model uses measures that the program designer chooses him or herself. It offered a comparative perception. It took a peek at both the pre and post group experiences. It showed links between the participants, their resources and what kinds of outcomes that might impact the performance measures and it offered a sequential if/then deduction. And what I liked about using this model is that it shows that each step builds upon the next and there's accountability and that facilitates better stakeholder buy in and if we think about it, the participants themselves are the key stakeholders.

One of the interesting things that I didn't take into consideration ahead of time but that became one of these external factors along the bottom area here. I'm gonna use the cursor to show that I know how to use technology, this bottom bar are the external influences. And one of the external influences, I didn't take into account was a power outage. And during one of our meetings, everyone lost power, the whole East Coast and even across the country because I had some participants who were in other areas, the Midwest and the Mountain states. These were people who didn't know each other, it was really pretty interesting but everybody experienced a power outage at the same time. And that was an external influence that I didn't count on but it certainly impacted the group. But what was interesting is that even though everyone, no one could participate that particular time, they facilitated a next meeting time. So that was pretty exciting.

This particular slide shows you those, comparative perceptions to their pre and post group experiences. Now these were assessed using an online customized survey. I reused some of that, those other forms I had use before, including the McGann feedback form as well as the QuickDASH and then I completed a one to one interview with people in which I also used the Pizzi Holistic Wellness Assessment. Which I would strongly recommend that people take a look at and even consider contacting the author Dr. Michael Pizzi. But what was important about this is that people got to really see for themselves where they experienced change, they had to make comments about what kind of an impact this situation of experiencing unlimited wellness had on them. And at the end one of my queries to each participant in their interview was, would you like to do your, I'm sorry, in preparation for their interview was, would you like to meet by telephone or telehealth using the teleconference platform? And they all chose a telehealth interview which is pretty interesting.

So the bottom line results were that this program promoted health, wellness and well being to all of the participants. They all perceived that they had been informed or educated. They all stated that they participated in a meaningful occupation of creating their own resource templates. And the element of social participation was a key factor because even though it was something in which they could engage in with strangers they did not feel, like they were among strangers. They felt that they had made friends. One person called it familiarity with anonymity. If you look at the second to the last bullet point, even things that were uncomfortable became comfortable because of the context of familiarity with anonymity. People also learned life lessons. They stated that they were by thinking about what they, how they typically respond and how they could respond. Instead, it gave them new tools in their own tool kit to be able to demonstrate out in public. Most people said that it made a difference in their ability to speak about their limb difference and their confidence in doing so. It made a difference in their confidence and their competence to speak about their prosthetic technology, particularly with strangers. And all of the participants stated that it gave them backbone because it built them, it empowered them.

One of the things that happened right around that week seven time period as people were starting to discuss these awkward social moments, one of the participants stated that she was really excited, she had not been a prosthesis user and she was going to be traveling from her area of the company to New York to be able to get a prosthesis. And one of the other participants said, "Oh, my goodness, well, that's great, I live in New York, "where are you going for your prosthesis?" And she told him, she mentioned the name of the practice which happens to be my community partner in this project. And he said, well, I go there so it was interesting to me that none of the participants realized that they were all people in my client circle. And that became obviously apparent through this conversation. But the other thing that happened was that she said she really hoped that having a prosthesis for the first time in her life at age 50 something, it would make a difference for her that she really hoped that she'd be able to learn to play golf. And these two people made a plan to meet at the practice at the prosthetic practice so that one participant could show the other how he golfs and what he does. So not only was it empowerment for self, for oneself but it became empowerment for each other, building upon that interpersonal perspective and connection.

So points to talk about. One of the factors that was most important to me was, would stakeholders perceive value, in the Unlimited Wellness Program? Well, by the program evaluation there appeared to be dynamic changes in the participants health behaviors, their perceptions of well-being and their ability to access peer interaction and information that made a difference for them. Surveys that were held at different points in the group process, showed behavior changes on an individual level but also collectively which was very interesting. And lastly, by the program evaluation, it appeared to address that challenge that Sheehan and Gondo initially posed to be able to address and meet the physical and psychosocial needs of America's forgotten. These individuals who participated in a program like this, all reported that they experienced diminished physical, psychosocial and even spiritual disparity and felt empowered to greater self-empowerment, self-advocacy.

So what does that tell us? It tells us that for the population, people like me with congenital limb difference and even people with acquired loss at all ages should and can have information to be able to prevent further disparity and feel empowered over their destiny and over their quality of life. It provided tools for self-advocacy and offered a pathway for improved health, wellness and well-being and it showed all of them that telehealth could be a connected health platform, both in delivery of services and access to peers. When we change a population by informing them and helping them to take on actively engaged with their own health care needs this is what leads to potential policy changes because individuals then become larger groups of communities and it is only through communities that we can affect change. Now what about the implications for OT practitioners? People like you and I? Well, this platform shows us that practitioners who are generalists can access specialized training, consults and support. That we as practitioners can access a patient or client population that otherwise would be elusive to us. That we wouldn't be able to reach. It gives us a greater awareness of the population and that's cultural as well. It helps as clinicians to understand what is important to this particular population? What needs have they identified, the opportunity to fit in. The ability to do things, to be able to cut their own food or perform tasks as independently as possible. This kind of program offers us measures and tools that will help us to address quality of life, health and well-being for our constituencies, the clients that we serve. And it provides us with another intervention pathway to help to prevent further disparity.

Now, my next steps are really in process now as we speak. One of the things I should have mentioned, for OT practitioners is that it also helps us to mentor the novices, the new groups coming up. And this is why I mentioned it now because as I am forming new groups, I have a group of four students at Western New England University who will be in their third and final year next year and they will be completing, their doctoral experiential residency. And on their own they happened upon, the Unlimited Wellness Program, in their own literature review and they have taken on helping to expand this program to include children, parents of children, individuals with acquired loss and individuals with bilateral loss. My focus is to develop a professional practitioner group, almost like a journal club but online.

So if you're interested in any of these things, when we get to my last slide, I hope that you'll take down my address, my email address and contact me because this is going to be a really exciting opportunity for my students but also for people across the country. I'm hoping to engage in future studies that will help to determine or find answers or answer the questions of whether or not there are differences amongst the different groups that relate to secondary conditions and the strategies that are used to prevent or manage them. And how effective continually we should be looking at program evaluation. What is the impact of participating in a group like this? To what extent are the secondary conditions mitigated? Most of the people from my first round, are asking for a follow up group. I'm going to be doing that and I think it's wonderful that the people who have already tasted the experience of telehealth are looking for more and they've also tasted the opportunity of meeting with peers from around the country. And then of course, wondering whether a refresher or additional programming would be beneficial. Judging by the response I've had, from the original participants, my guess is a yes because they're asking for the program. Now the next few slides are a list of the references that I used to develop this particular program. I'm happy to share my templates if you contact me. This has been published also, this entire article has been published by the "Journal of Prosthetics and Orthotics" in October of 2019 in its entirety so you can see some additional information there.

I do wanna give a shout out to the International Handsmart Group of which I belong and many of my presenters belong. And it's at this time that I'm happy to entertain questions and certainly you can contact me at my Single-Handed Solutions' email address as well as at Western New England University. So, I can see that there might be a few questions popping up, you can type in a question and I will read the question back to you as a group because if one person is asking the question, there might be more than one.

- [Fawn] Okay, the first one is how many participants were in your focus group and what was the ratio of congenital difference and traumatic loss?

- [Debra] Great questions. So in the focus group, there were seven initial participants and two dropped out so that there were five. All of them had congenital upper limb difference. This was a very, so one of the things that's important to understand is that adults with congenital upper limb difference, are really hard to find. We make up the smallest slice of the pie if one were to look at the constellation of adults with upper limb loss. Most adults with upper limb loss constitute almost 90%, acquired loss and the acquired loss is due to trauma primarily and then due to disease. The population of people with, of adults with congenital upper limb differences only about 10%. If we looked at the population of children with upper limb loss or difference, children with congenital limb difference makeup 90%. So as a child, I was part of the majority of kids who present with upper limb loss because I was among 90% even though very few, one in four of them might have had upper limb. But as an adult I'm surrounded by people with acquired loss because my population now has become the minority. So

I'm part of the minority. For the focus group, I was specifically targeting adults who were 50 and over. So I had to really search to find seven people across the country willing to participate and at the end of the day only five of them did. They all had unilateral congenital upper limb difference. For the program, I started with those same seven, opened it up to more. I had plenty of takers who, people with acquired loss who wanted to participate but for the purposes of my doctoral project I had to limit the numbers. And that was from my advisor and the program director. So there were ultimately five people who were part of the focus group. I'm sorry, the Unlimited Wellness Program and by session three, we were down to three. One of them had to drop out due to medical issues of his spouse and another one had to drop out due to medical issues of his own. So I hope that answers your question. This is why it's important to me to develop groups that are population oriented so that then next groups are going to focus toward parents of children and certainly people with, adults with acquired loss. I should say that in the program rendition, the participants ranged in age from 35 to 65. Okay, there's, another question.

- Okay, great. Yeah, I'll read it out loud for you. How did you handle the identities of participants and their ability to communicate with each other after the fact?

- [Debra] Great question, so during the program I, the way I handled the identities of participants was to make it their choice to open up their videos, their camera, no one had to and certainly no one had to disclose anything about themselves. And I didn't share anything about participants other than to introduce them by first name and that was after having had permission, from the participants. As far as them staying in touch after, I did nothing to promote that nor did I do anything to discourage it, that was between them. So when two of the participants chose to meet at the prosthetic practice in New York that was with permission of each other and they had the opportunity to share each other's information if they wanted to. So I hope that answers your question there.

- [Fawn] Okay, another one coming in, is can you talk a little bit more about the benefits of telehealth in your experiences?

- [Debra] Yes, yes, great question. I actually use telehealth a lot. I have multiple licenses and in states so that I can use this platform. I would say that it allows me reach, it allows me which sounds kind of funny being a person who's missing their right forearm but telehealth offers me access to people and likewise, it offers them access to me. The other thing that it offers is access to their community providers. So I can't tell you how many times the community practitioners, OTs in hospitals, outpatient clinics, home health, have contacted me with the client using a telehealth platform and asked for guidance in the person's care. Suggestions to further the plan of care. Information about what might be expected, troubleshooting problems with prosthetic technology or even strategies to be able to accomplish different tasks. And that's both with and without prosthetic technology. Also being able to guide those community practitioners, toward helping the person, prevent further disparity physically looking at joint protection and energy conservation and other strategies to be able to prevent overuse. Considering assistive devices or adaptive strategies that will allow this opportunity but yet not put another part of the body at risk. And then another aspect that often practitioners feel uncomfortable talking about, are those psycho-social implications like how do you feel when someone stares at you? So oftentimes, I can be that culture broker and buffer in that realm so I use telehealth to help accomplish all of this for the client, him or herself as well as the practitioner.

- [Fawn] Okay, another question is, are you still following up with these participants? Is there any plan for that or you're doing any longitudinal?

- [Debra] Yeah, so I follow up with all of them anyway just from the clinical perspective. They have all reached out to me multiple times and asked me when I'm starting up another group and I am just about to start up another one for them as a follow up and then certainly including, more people in that. So I don't have any specific longitudinal study plans, right this second but certainly with my doctoral experiential group we're going to be moving forward with developing more aspects to this program, more chapters to it and more small groups.

- [Fawn] Okay, another question is, the peer support network sounds great, have you seen other networks such as this in your years of practice?

- [Debra] I've not seen a network. I have certainly seen other OT practitioners providing, telehealth and in my years at Shriners Hospitals for children, we used telehealth to reach the children over in Europe and China and Asia. Places that were, they couldn't access specialized care but I never saw it as a network. This was, I don't know, something that I had in my head that if I could bring people together that perhaps it could help mitigate some of these problems. So I can't say that I've never ever seen another, network per se like this but that doesn't mean it doesn't exist. I'm sure that other people have thought of it. I just haven't seen it. Last thoughts to wrap up. I wanna make sure that I have covered everything that I said that I would. I'm hoping that you as participants if you have any last questions that you would ask them. I can see that there's one area maybe, I didn't talk in detail about but one of the things people talked about in terms of awkward social situations had to do with how they're greeted by other people. And let's face it, we live in a two-handed world, we often shake hands. Some of my participants talked about how people will offer a very limp handshake almost not sure which side to go for, especially if the person is missing a right hand. Should they touch a prosthesis? Should they acknowledge it? Being called names or labels, being referred to as disabled. Many people did not like that. They perceive themselves as abled, just differently abled. They didn't like labels of any sort, being pointed to, being left out or being called names which believe it or not, I hate to say does still occur. I'm gonna wrap up with one very sweet story about what we experience in life. I live a full life, I have a wonderful family and among my family are my two grandchildren who I just love dearly and enjoy spending just about every minute of the day with if I could. But one day I brought Bella and Rome who were at the time about eight and five, I brought them to the Science Museum. And I also brought the other grandmother with me and so she took my grandson and I had my granddaughter and then we switched off. But Bella and I came to this one exhibit that was a mannequin in the middle of the room and the mannequin had all of these prosthetic parts. And my granddaughter said to me grandma look, that robot, I mean, that doll that doll has a hand like you. And so we went over to it and we were talking about it and of course I had a prosthesis on and she was asking me questions about how the mannequin was able to make it work versus how I do and different things.

And before we knew it, there was a room, there was a circle around us of all strangers. And they started asking questions which of course, I answered. And at one point after about 15 minutes, Bella tugged on my my sleeve and said, "Grandma, can we go now? "Can we go see something else?" And people started apologizing because they thought I was part of the exhibit. So it's funny, but what a great platform to be able to ask questions and be open to answering them. I would like to encourage all of you to speak candidly with your clients who have upper limb loss or difference. I hope that you will get a lot out of not just this presentation but all of the presentations this week. And I would like to also remind you that this particular series is oriented to more of an intermediate level. If you're looking for some basic information, you can speak with Fawn or she can post the previous course series that was done in 2015 that offers a wonderful beginner platform of understanding the technology and everything else. So I'm going to close now. Thank you all for listening and for participating and be well.

- [Fawn] Thank you so much. Dr. Latour for a great talk. I'm going to close us out here but I do want to pop this up so everyone can see what we have coming up tomorrow and then throughout the week and I hope everyone can join us. Thanks again for a great talk. I hope everyone has a great rest of the day. You join us again on ContinueD and occupationaltherapy.com. Thank you.

- [Debra] Thank you.