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Amputee Perspectives of Virtual Patient Education

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Abstract

Amputees have expressed the need for more information on the recovery path that follows amputation. Inclusion of education in the amputation rehabilitation process empowers amputees to make decisions about their options and form realistic expectations. Virtual worlds are effective as healthcare support communities because they provide both synchronous and asynchrous communication, voice enabled technology, file sharing and more, enhanced by immersion in a visually stimulating and interactive 3-D environment. The objective of this research was to discover how a virtual world could be used to address amputees' educational needs. A focus group of three lower limb amputees ages ranging from 39 to 82 was convened. Data were analyzed qualitatively using the thematic analysis procedure. Four themes emerged: Challenges amputees face, Getting out and doing things, Becoming empowered, and What's next for the virtual world. The challenges voiced set an important context. While we anticipated that amputees would want both education and support in a virtual world environment, we learned that support is not only part of education but that both are empowering. Participation in the virtual world facilitated getting out and about and getting moving.

Keywords

Amputee, Amputation, Virtual World, Avatar, Prosthesis, Prosthetics, Focus Group, Thematic Analysis

Amputee Perspectives of Virtual Patient Education

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Amputees have expressed the need for more information on the recovery path that follows amputation. Inclusion of education in the amputation rehabilitation process empowers amputees to make decisions about their options and form realistic expectations. Virtual worlds are effective as healthcare support communities because they provide both synchronous and asynchrous communication, voice enabled technology, file sharing and more, enhanced by immersion in a visually stimulating and interactive 3-D environment. The objective of this research was to discover how a virtual world could be used to address amputees' educational needs. A focus group of three lower limb amputees ages ranging from 39 to 82 was convened. Data were analyzed qualitatively using the thematic analysis procedure. Four themes emerged: Challenges amputees face, Getting out and doing things, Becoming empowered, and What's next for the virtual world. The challenges voiced set an important context. While we anticipated that amputees would want both education and support in a virtual world environment, we learned that support is not only part of education but that both are empowering. Participation in the virtual world facilitated getting out and about and getting moving. Keywords: Amputee, Amputation, Virtual World, Avatar, Prosthesis, Prosthetics, Focus Group, Thematic Analysis

Amputees have expressed the need for more information on the recovery path that follows amputation. Ultimately, they feel it is they who bear the responsibility for their care (Klute et al., 2009). Inclusion of education in the amputation rehabilitation process empowers amputees to make decisions about their options and form realistic expectations (Meier & Heckman, 2014). In comparison to amputees who participate in support groups, amputees who received self-management training in addition to participation in support groups demonstrated a significant reduction in the likelihood of being depressed and "bothersomeness" of functional limitations, and improved self-efficacy and positive/negative state of mind at six-month follow-up (Wegener, Mackenzie, Ephraim, Ehde, & Williams, 2009). A systematic review of self-management education after amputation (Pantera, Pourtier-Piotte, Bensoussan, & Coudeyre, 2014) found the following educational needs expressed by amputees across studies: pain management, prosthetic hygiene, socioemotional adjustment, managing depression, information on prosthetics, professional life and transportation, falls prevention, and possible sports and physical activities.

This manuscript presents amputees' perspectives of using a virtual world for patient education. Virtual worlds are effective as healthcare support communities because they provide both synchronous and asynchrous communication via text messaging, voice enabled technology, file sharing and more, enhanced by immersion in a visually stimulating and interactive 3-D environment (Davis & Calitz, 2014). Synchronous communication in the

virtual world occurs when all avatars involved in the communication are participating at the same and waiting for replies from each other either by using voice or chat. Asynchronous communication occurs when one or more of the individuals/avatars is offline. The online individual can type communication into the chat feature that will be delivered to the offline individual/avatar when they log in. Alternatively, the virtual world has a setting that will deliver chat communication to the offline users' email.

Our project used the Second Life® (SL) virtual world to build two islands that we named "Virtual Health Adventures" (VHA). Ours is one of many health-related activities that occur in SL. Beard, Wilson, Morra, & Keelan, (2009) identified five distinct types of health-related activities in SL: education and awareness, support, training, marketing and promotion of health services, and research. In 2009, there were 152 healthcare support groups in SL (Norris, 2009): 16% of them have at least one hundred members and 33% have less than a dozen; 49% of the groups were for health issues (e.g., cancer 13%), 20% for disabilities, 15% for mental health (e.g., suicide, depression) and 5% for addictions.

For our VHA project, 59 amputees from four countries and more than thirty of the United States were enrolled to complete a 17-station self-management training that followed the principles of rehabilitation from pre-amputation to community reintegration (Cooper et al., 2018; Esquenazi, 2004; Winkler et al., 2018). The second island provided amputee participants, via their avatars, with opportunities to interact with each other and project staff. Several participants who completed the study, expressed an interest in continuing in the virtual world beyond their participation in the study and thus, supporting the sustainability of our virtual world. Online community success, member participation, and retention resides in the ability to develop activities that foster interpersonal relationship and attachment (Davis & Calitz, 2014; Preece, 2000; Ren et al., 2012). Because amputee participants wanted to sustain the virtual world beyond the research period, , we launched a secondary study that used a focus group to understand how a virtual world could better address the education needs of the global amputee community Our research question was what do amputees seek in a virtual world environment.9

Reflexivity

Consistent with all qualitative methods, the themes do not reside in the data but rather, emerge from the researchers' thoughts when interacting with the data (Ely, Vinz, Downing, & Anzul, 1997). The analysts were occupational therapists: the primary analyst a research health scientist at the Department of Veterans Affairs and the secondary analyst pursuing a master's degree in occupational therapy. The primary analyst was principal investigator (PI) of the larger study however blinded to data collection. The secondary analyst, who assisted with the focus group, coded, and analyzed data, was also involved in the enrollment of subjects in the larger study. Both analysts viewed the data through the lens of healthcare professionals who valued the importance of self-management and who also interacted as avatars with participants of the larger study.

Methodology

This study was approved by the Institutional Review Board at Nova Southeastern University.

Approach to Inquiry. A phenomenological approach was used for this research (Creswell, 2013). Phenomenology, or the study of experiences, was chosen to capture the participants' lived experiences of the virtual world (the phenomenon). Explorations of phenomena may be done in groups as small as three or as large as 15 (Creswell, 2013). Using

a phenomenological approach, participants are asked, broadly, what they experienced and what contexts affected their experiences (Creswell, 2013; Moustakas, 1994). In the context of this study, participants shared their experiences and contexts that both positively and negatively affected the experience.

Participants. Three focus group participants were conveniently selected from participants engaged in a larger study that compared dissemination of self-management evidence-based information to individuals with amputations and limb differences under e-learning and avatar-based virtual world conditions (Cooper et al., 2018; Winkler et al., 2017; Winkler et al., 2018). The focus group study opportunity was posted to the participants randomized to the virtual world group via the group chat feature. Interested participants contacted the second author by phone or email for further information. Informed consent was done by mail.

The three focus group participants were white males ranging in age from 39 to 82. All three participants had lower limb amputations. One participant was 20 years post amputation for a tibial birth deformity. One participant had a below knee amputation and several years later became a bilateral below knee amputee both vascular related. The third participant had a below knee amputation resulting from a failed knee replacement.

Data Collection. The one-and-a-half-hour focus group was conducted in the SL virtual world conference room and led by two facilitators, i.e., the five avatars were seated together in a virtual meeting room while the facilitators and participants were at their own computers. See Figures 1 and 2.
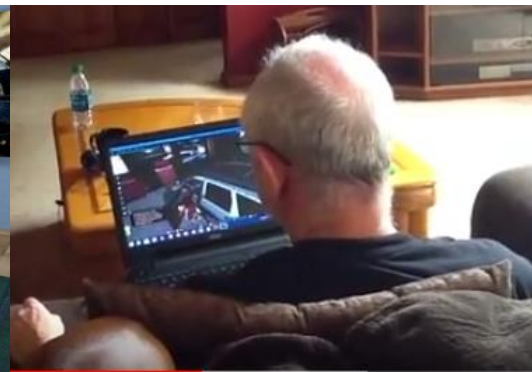
Figures 1 and 2. Show views of the avatars in the virtual conference room and of one the amputee participants logged into the virtual world on his home computer, getting ready to teleport to the virtual conference room to attend the focus group.

The audio generated by the avatars speaking in the virtual world using the speak feature was recorded using Adobe® Connect™ Web Conferencing software. We followed the moderation guidelines for internet-based focus groups (e.g., SL virtual world environment) based on Krueger and Casey (2000). The following questions guided the focus group: (1) What did you as an amputee like about the Virtual Health Adventures (VHA) virtual world? (2) How can a virtual world meet the needs of amputees? Data consisted of the transcribed interviews and memoing notes taken by facilitators during the focus group.

Data Analysis. Thematic analysis procedure (Braun & Clark, 2006; Charmaz, 2014) was used to identify and analyze the focus group data. Thematic analysis (Braun & Clark, 2006) is a foundation qualitative analysis method that is free of theory and thus can be used flexibly e.g., in identifying themes. In the context of this study, thematic analysis was used as

a realist method to report the experience of the virtual world for each of the focus group participants. The analyst was not looking for anything beyond what a participant said (Braun & Clark, 2006). Rather, the intent was to use the explicit or surface meanings of the data to identify emergent themes that accurately reflected the participants' perceptions most relative to the research purpose which was to understand how a virtual world could better address the educational needs of the global amputee community; in fact, relevance to the research purpose was more important than a pattern repeating across participants.

The first phase of analysis was to become familiar with the data. This phase began during the focus groups by taking memoing notes, continued as the analysts transcribed the audio recording verbatim of all verbal utterances using Microsoft (MS) Word, then reading and rereading the transcribed data.

The second phase was to generate initial codes using line-by-line coding was performed to describe the content (Charmaz, 2014) using an inductive "bottom up" or data-driven approach giving equal attention to each line to limit researcher preconceptions. See Figure 3. The initial codes captured a few of the most semantically meaningful words per line in the first attempt to organize and condense the data. A list of the initial codes was compiled into a code book, Figure 4.

```
1 Q: would you like ahh from a virtual world?
2
3 S1. Umm anyways I'm an AK left amputee and the thing that I like about second life is actually I
4 have to stay away from it cause I find if I get in I spend too much if I get in I spend too much time      4 stay away or spend too much time
5 there but the I like the program and I like all the various for me the... going the going through the        5 like program
6 stations that were set up there assisted a lot in learning at looking at the phases for training and         6 stations assisted in learning,
7 also some exercises that I could be doing at home as opposed because of other issue I haven't               7 exercises at home
8 been doing much external physical therapy. So I'm trying to think eh exactly in what context are            8 not much external PT
9 you looking for, what type of an answer do you want?
```

Figure 3. Line by line initial coding.

```
3 stay away or spend too much time
4 like program
5 stations assisted in learning,
5-6 exercises at home

12 Liked stations
13 lot of information, amputation not planned
14 did not have benefit of knowing what I was getting into
15 problems with other leg
16 interact with people
17 My avatar has same conditions that I have, visualize myself as I hope to be
18 eventually getting out participating more
```

Figure 4. Code book of initial codes.

In the third phase, codes were sorted into potential themes. Themes were identified at the semantic or surface level without looking for a deeper meaning or underlying idea. Figure 5.

purpose Education is Eve	what amputees want	conditions Life as an Amputee	support groups
5 stations assisted in lea	246 education was every	13 amputation not planned	205 we gear support groups towards activitie:
5-6 exercises at home	247 I wanted to know cli	14 did not have benefit of knowing	206 hand bikes we takt to hospital
16 interact with people	248 what I could expect,	15 problems with other leg	207 adaptive sports
41 exercises don't practi	249 what's important, e>	19 stuck in house	208 rock climbing
42 exercises are crucial	250 deviations	23 no insurance find resources no	209 create positive atmosphere to push the er
55 Keep yourself educate	251 education paramou	34 amputee 20 years	210 get outside comfort zone, realizing their p
82 platform to transition	252 resources in one pla	35 elective amputation 1995 no Ir	211 everyday tasks, what ever would seem ea:
83 realize opportunities	253 find more informatii	36 figured it out myself	212 success engaging that way, find out goal
84 learn from someone e	261 education everythin	37 prosthesis on, walked out	213 miss the most, never do again

Figure 5. Organizing codes into potential themes.

Nine potential themes were refined to make sure that data within the themes was coherent, that there were clear distinctions between the themes but that that the themes also fit together to tell the story of the data (Braun & Clark, 2006). Development of Themes continued into the writing of the manuscript draft were renamed as the scope and diversity of each theme was described and supported with text (Charmaz, 2014; Patton, 1990).

Results

The initial themes were Like about the virtual world, Avatar, Education is everything, What amputees want, Life as an amputee, Support system, and Support Groups. As the themes were integrated into supporting text, the initial themes were condensed to four themes: Challenges amputees face, Getting out and doing things, Becoming empowered, and What's next.

Amputees Face Challenges. The topic most discussed was the challenges that participants face, which provided a context for the need for education, i.e., the life situations provoking their search for knowledge. Specific challenges included insurance coverage for prostheses and therapy to train conditioning and use of prostheses, functional limitations in performing daily activities, comorbidities and secondary conditions, trust in health care provision, and fear about what comes next. One participant who did not have insurance used online resources to "*find alternatives to heal.*" Another participant who had good insurance had to appeal multiple times and as a result waited a long time for his prosthesis. Associated with the wait were comorbidities such as problems with the both the residual limb and the intact limb and multiple infections, which in turn led to being sedentary and "*being stuck around the house.*" The loss of function and comorbidities led to lack of trust in medical care. Participants felt that they needed to get up and get their life going again but did not have enough knowledge to make an informed decision, leaving them with the feeling that they were giving their lives to "*someone else to run*" and the feeling that the first person to come into the hospital room with a leg was "*the one who is supposed to put me back together.*" In retrospect, participants agreed that had a training such as VHA been available to them while they were in the hospital, they would have learned how, or in participants' words, become empowered to take "*accountability for their care.*"

Getting Out and Doing Things. Overall, VHA was described as "*liked,*" "*awesome,*" "*unlimited platform,*" a "*good tool,*" and a "*cooperative environment*" with the "*greatest advantage for new amputees.*" One participant was unable to walk when he was enrolled in the study. As he navigated his avatar through the 17 self-management training stations and applied what he saw other amputees do, he walked independently for the first time since his second amputation.

> I can watch him [avatar] do things and it makes me feel like I can do those . . .
> just going through the stations and doing what I need to dare . . . umm you know
> I watched another amputee and saw what he did, and applied it to my life.

Further, through his avatar, one participant visualized an improved real life:

> . . . my avatar has the same conditions as I have. I set up one with a prosthetic
> left leg so it's allowing me to visual myself as I hope to be . . . it's allowing me
> to visualize an improved life, which is what I'm striving to get to . . .

All participants commented on how crucial the exercise simulations were - simulations in which the amputee could see himself, as an avatar, exercising. See Figures 6 and 7.

> The other thing I loved was the uh the uh exercises you know. That's the stuff that you forget about over years. You don't practice them and you begin to feel the effects of losing you're your umm muscle strength. You know if you don't do these exercises.

Figures 6 and 7. Amputees' avatars performing exercises while observing a peer perform the same exercise.

Becoming Empowered. Participants agreed that the peer support and knowledge provided in VHA made them feel empowered to move on and manage their lives post amputation: VHA provided a "*wealth of knowledge*" and "*offered me opportunities and resources*" from "*a global perspective,*" i.e., a virtual world users are international. Participants valued learning how other amputees have adapted. Similarly, participants expressed the need for education or "*resources to help you understand what you're going through and what are the possibilities*" in order to be "*proactive in your own care.*" Participants agreed that support should

> create a positive atmosphere so that people will… look for trying new things, doing things- pushing the envelope, getting outside of their comfort zone, and uhh realizing their own potential.

The virtual world was viewed differently than other social media in that the virtual world provides an opportunity to view yourself as an avatar performing desired health behaviors.

> . . . this [VHA] offers a different opportunity in that you actually get to see yourself doing things. I'm not just texting back and forth to someone sending a picture. I'm actually standing there in front of them talking to them.

We believe that the feeling of actually being there contributes to empowerment.

What's Next. Participants agreed that VHA could be an opportunity to extend support or empowerment to staff and caregivers:

> our lifestyle really does affect them . . . would be a… nice to see them to have a place to go and-and vent their frustrations or get advice or you know be able to talk amongst themselves you know.

Other suggestions were to add a diary or logbook option for tracking progress because that "*keeps you working harder*" or even could be used to "*interact with your physical therapy.*"

The only reported negative comment was spending too much time in VHA. However, for amputees who are unable to drive due to their amputation, socializing could be considered a positive rather than a negative outcome.

Discussion

This study used qualitative methods to discover that what amputees seek in a virtual world. Based on the results, participants found both education about their condition and peer support to be most important in the virtual world experience. Initially, we thought of support and education, or knowledge, as separate subthemes, but it became apparent that support was a form of education, as have others, that social support is perceived as tangible, emotional and, informational (Davis & Calitz, 2014; Schaefer, Coyne, & Lazarus, 1981). Further, participants viewed support not only part of education but that both are empowering. "Empowerment group" was in fact suggested by participants as alternative terminology to "support group." Our findings are supported by those of (Beard et al., 2009) who also found that patient education and support the most common health purposes of virtual worlds. Direct treatment in a virtual world is limited in the US by licensure; at this time only mental healthcare providers' licensure allows for provision of treatment in a virtual environment. While VHA is the only known virtual world venue specifically designed to support the needs of amputees, SL is currently used for experiential learning, skill building, and socialization (Brewer et al., 2017) for other conditions such as cardiac rehabilitation (Brewer et al., 2017), weight loss (Behm-Morawitz, Lewallen, & Choi, 2016), and diabetes (Rosal et al., 2014; Ruggiero et al., 2014).

Brewer et al. (2017) conducted a virtual education series in the SL to foster healthy behavior change for patients with coronary artery disease. Their qualitative findings were in accordance with ours: the virtual simulations and range of environments intensified the emotional experience, thus enhancing the retention of heathy behavior knowledge. Participants reported an emotional attachment with their avatar that created a sense of being there and that interacting with peers made the educational material more relevant and impressive. Like participants in our study, participants identified next steps, including a desire to continue the community, simulations of procedures, and demonstrations of exercises, topics that we have explored in our virtual world.

(Behm-Morawitz et al., 2016) asked participants about their experience of using a virtual world training to affect the health and well-being, nutrition, physical activity, and body perception of overweight adults. Resulting themes were Virtual Embodiment, which referred to a strong, positive relationship with one's avatar and Health Self-efficacy which was similar to our empowerment. Similar to our findings, participants found the virtual world to motivate them to participate in health and weight loss activities in the real world.

Diabetes Island was created in SL by Ruggiero et al. (2014) to provide self-management education to large and diverse populations while minimizing barriers such as transportation and scheduling conflicts. While qualitative data were not collected, 94% of participants agreed that the virtual Diabetes Island training motivated them to take better care of their diabetes. All participants reported that they used things they learned in SL in their real lives. Motivation and application to real life are similar concepts to our empowerment theme.

There were limitations to our study. First there were only three focus group participants with similar racial, ethnic, and sex demographics. Second, the sample only represented vascular, congenital deformity, and surgical complication etiologies for amputation. Finally, all three participants completed the study therefore were more likely to express positive experiences in VHA.

Conclusion

Our avatar-based virtual world, created in Second Life, was valuable in empowering amputees to overcome their challenges and to get out and move again. Through both virtual self-management education and virtual peer supports, amputees learned how to become accountable for their own care and experience, via their avatar, how their real life could be improved.

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Michelle Schlesinger was an Occupational Therapy student at Nova Southeastern University while conducting this research. Ms. Schlesinger is currently an Occupational Therapist at the James A. Haley VA Hospital specializing in vision rehabilitation for Veterans with traumatic brain injury.

Alice Krueger is the founder of Virtual Ability. As a woman with Multiple Sclerosis, she found it increasingly difficult to participate in her real life community. No longer able to leave home to work, volunteer, or socialize with friends, she turned to virtual worlds to fulfill these basic human needs. Ms. Krueger's avatar in Second Life® is Gentle Heron. Gentle can stand and walk without crutches.

Ann Ludwig is Vice-President of Development at Virtual Ability, Inc. Ann conceptualized and built the virtual world environment for this project.

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