Expanded sense of possibilities: qualitative findings from a virtual self-management training for amputees

R Cooper[1], S L Winkler[2], M Schlesinger[3], A Krueger[4], A Ludwig[5]

[1]Conflict Resolution Studies Department, Nova Southeastern University,
Fort Lauderdale, Florida, USA

[2]Center of Innovation on Disability and Rehabilitation Research, James A Haley VA Hospital,
Tampa, Florida, USA

[3]Occupational Therapy Department, Nova Southeastern University,
Fort Lauderdale, Florida, USA

[4,5]Virtual Ability, Inc.
Aurora, CO, USA

[1]robicoop@nova.edu, [2]sandra.winkler@va.gov, [3]ms3429@nova.edu,
[4]akrueger@virtualability.org, [5]emecapalini@gmail.com

[1]www.nova.edu, [2]www.cindrr.research.va.gov, [5,6]www.virtualability.org

ABSTRACT

This paper presents the procedures and results of a qualitative study that was part of a larger study comparing two methods of accessing a self-management training for amputees: e-learning and a virtual world. Interviews were conducted in Second Life (SL) with ten subjects who completed the training in the virtual world and seven subjects who completed e-learning training. Interpretative Phenomenological Analysis (IPA) was used for qualitative data analysis, leading to the identification of 14 themes within five major categories. An overarching theme of the SL experience resulting from analysis was that of an expanded sense of possibilities**.**

1. INTRODUCTION

In 2004, the Department of Veterans Affairs (VA) convened a traumatic amputation QUERI (Quality Enhancement Research Initiative) workshop to develop best practices for the new generation of war-wounded service members arriving with major limb amputations from the wars in Iraq and Afghanistan. The problem was community reintegration: when the service members returned to their hometowns and local VA medical centers, they did not fit the treatment profile of the typical amputees with amputation(s) resulting from deconditioning diseases. An additional challenge was there were few of Iraq and Afghanistan amputees, which meant geographically they were far apart. The distance limited peer interactions and clinician specialty skills. It became apparent at the amputation QUERI workshop that peer support for this cohort of amputees was going to have to e over the Internet. Tele-rehabilitation was an option for specialized regional amputee rehabilitation centers to provide training for more rural clinicians. The virtual world was an option for peer-to-peer interaction and self-management training. The US Department of Defense had built two virtual worlds: one for post-traumatic stress disorder (PTSD) (T2 Virtual PTSD Experience) and the Amputee Virtual Environment Support Space (AVESS). The T2 PTSD virtual remains active. When the AVESS project lost funding, Dr. Winkler's research team, which included some of the original AVESS team members, built "Virtual Health Adventures" with virtual meeting spaces and self-management education for amputees. It is intended that "Virtual Health Adventures" would be expanded to provide similar experiences for individuals with other disabilities and their families, for example, diabetic foot ulcers and caregivers of individuals with traumatic brain injury.

A virtual world is a synchronous, computer-based simulated environment, populated by a persistent network of people represented by personalized avatars that simultaneously and independently explore the virtual world, participate in its activities and communicate with others (Aichner & Jacob, 2015; Bartle, 2003; Bell, 2008). Users, through their avatars, are able to socialize, communicate, collaborate and learn with other avatar participants in a three-dimensional environment (Ducheneaut, Wen, Yee, & Wadley, 2009). Second Life® (SL) is the largest of many virtual worlds. Conceptualized by Philip Rosedale who founded Linden Lab, SL offers a

persistent, open, unlimited, highly customizable space. The content of SL is created by its users who rent virtual land (islands). The result is a shared space that provides a sense of "being with others," seeing physical representations of each other, and communicating and acting in that shared space (Thomas & Brown, 2009).

Amputation is a life-long condition. Increased prosthetic use is significantly associated with better psychological ($P<.05$) and social health ($P<.001$) (Gallagher & Maclachlan, 2004), but prostheses and prosthetic needs change over time so that acquiring current and evolving prosthetic and health-related information is an on going process. In addition, social and physical function, and support from others have been identified as important factors in the amputation adjustment process (Gallagher & Maclachlan, 2001). To address these issues, a self-management program was developed. Self-management programs provide patients with the knowledge, skills, and confidence to deal with disease-related problems, e.g. to help patients with managing life roles, negative emotions, comorbidity and secondary conditions (K. R. Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The question for this project was how do amputees view engaging in a self-management training program as an avatar. For example, how to amputees view themselves as an avatar performing conditioning and balance activities? The research presented here was part of a larger study that compared two methods of accessing a self-management training for amputees: e-learning using Articulate® software (www.articulate.com) and the SL virtual world. We hypothesized that the virtual world cohort would have better health-related outcomes that the less-immersed e-learning group. The purpose of this paper is to present the findings of the qualitative arm of the study aimed at understanding how amputee subjects experienced SL. The research question asked, "How do participants experience the SL virtual world?"

2. METHODS

Following Institutional Review Board approval, two islands in SL were rented from Linden Lab on which a self-management training, based on Alberto Esquenazi's Stages of Rehabilitation for Amputees (Esquenazi, 2004), was created. Development of the 17-station self-management training area and virtual world community management were performed by Virtual Ability, Inc.

2.1 Subjects and Recruitment

Participation in a semi-structured interview was included in the informed consent document for the larger study. Because the interviews were held in SL for the purpose of anonymity and confidentiality, the first ten amputee subjects randomized to the virtual world group who completed the study were invited to participate in the interviews. Amputee subjects who chose to experience the virtual world intervention as an avatar after completing the study as a subject randomized to the control e-learning group were also invited to participate in the interview. Seven amputee subjects from this group participated in interviews for a total of 17 interviews included for analysis in this paper. No subjects declined the interview. See Table 1 for a description of subjects who participated in the semi-structured interviews.

2.2 Theoretical Approach

The methodology employed for the qualitative component of this study was that of Interpretative Phenomenological Analysis (IPA) (Smith, 2009). With its focus on lived experience and interpretation of meaning, IPA has broad applicability across the social, health and human sciences. In particular, phenomenology is increasingly being used by occupational therapists and occupational scientists as an approach to understand the individual's unique experience within the context of his or her environment (Clarke, 2008). With its focus on understanding experience and meaning, this approach is well suited to evaluating participants' experiences with the virtual environment space. The IPA approach is inductive and iterative in nature, allowing ideas and themes to emerge from the participants' personal accounts rather than imposing a predetermined theory. However, the theoretical framework for the methodology itself is one that draws upon and links phenomenology, hermeneutics, and idiography, as the approach focuses on lived experience, emphasizes the role of interpretation, and acknowledges the significance of individual experience (Cooper, 2014).

2.3 Procedure

Subjects were invited to participate in the semi-structured interviews by PI Winkler upon completion of post-training data collection. Interviews were performed in SL by Al Hall, as part of his doctoral research. PI Winkler met subjects in SL then invited them to the virtual conference room where they were introduced to Al, through his avatar. Interviews were performed using the text chat feature. The text served as the interview transcript.

Table 1. *Description of sample.*

		SL n=13	e-learning n=4
Age		52	62
Race/ethnicity	White	13	3
	Black	0	1
Gender	Male	10	2
	Female	3	2
Amputation	Unilateral UL	2	0
	Unilateral LL	10	3
	Bilateral LL	1	1
	Unilateral UL & Bilateral LL	0	0
Years since first amputation	0-5	9	3
	6-10	1	1
	11-15	1	1
	16-20	1	0
	>25	1	0
Etiology	Trauma	4	0
	Dysvascular	3	0
	Disease	6	4
Prosthetic use	Daily	9	3
	Weekly	0	1
	Did not use prosthesis	4	0
On computer	Hours per week	29	29
Prior experience with VW		1	0

2.4 Analysis

Co-I Cooper conducted the qualitative data analysis. Data analysis in IPA includes the following steps: a) reading and re-reading of the transcript; b) initial noting and coding of the data; c) developing emergent themes; d) searching for connections across emergent themes; e) moving to the next case; f) looking for patterns across cases; g) developing a theoretical structural description of the experience (Smith, 2009). Initial noting includes three stages of coding in which the researcher notes descriptive, linguistic, and conceptual comments throughout the transcript. Each stage of noting has its own purpose and focus: descriptive comments capture what the participant has experienced; linguistic comments convey the participant's meaning-making process through linguistic indicators such as metaphors, repetition, or capitalization for emphasis; and conceptual comments identify initial possible themes and patterns in a tentative manner, subject to further analysis and interpretation. The themes developed through IPA analysis reflect the focus on experience and meaning, as illustrated below in the results section.

3. RESULTS

Analysis of the qualitative data collected through interviews in SL resulted in the development of 14 themes within 5 major categories. The 5 major categories were: 1) General Experience of Second Life; 2) Experience of Using Avatar; 3) Experience of Training Format; 4) Perceptions of Training Content; and 5) Perceptions of Training Needs of Friends and Family. Between 2 and 4 themes were grouped under each of these categories. In presenting these themes below, words in quotation marks are taken directly from participants in order to retain their voice, in keeping with standards of qualitative reporting.

3.1 General Experience of Second Life

Theme 1. "Learning Curve"

Participants found that it took some practice to become comfortable navigating within Second Life. For almost all participants, this was their first experience in a virtual world. Several noted that they found the Second Life technology somewhat difficult, whether logging in or finding locations. Participants noted that it became easier to maneuver within Second Life with practice.

Theme 2. "An Amazing Experience"

Participants expressed overwhelmingly positive emotions about their experiences in Second Life. In spite of the learning curve and technical difficulties referred to above, participants used very positive language to express their feelings about their experience in Second Life, including "fun," "thrilling," "intriguing," "amazing," "incredible," and "novel."

Theme 3. Second Life a Freeing Environment

In addition to finding Second Life fun and intriguing, participants spoke of it as an environment that provided a "release" from life in the real world. Several participants noted that spending time in Second Life was an "escape," and referred to wanting to visit more often. Participants noted that one can get "lost" in Second Life, both in terms of not being familiar with the sites they visited, and also in terms of becoming so absorbed in the virtual world that they lost track of how much time was passing. Several participants spoke about the ability to do things in Second Life that they could not do in real life, and the "freedom" they felt.

3.2 Experience of Using Avatar

Theme 4. An Enjoyable Challenge

Although some participants spoke of having difficulty maneuvering the avatar, they enjoyed using one. The challenges most frequently referred to were dressing the avatar and sitting down. Several participants spoke of enjoying doing things through the avatar that they could not do in real life, such as flying. Several participants noted that they liked the experience of going through the training as an avatar.

Theme 5. Identification with the Avatar

Participants found great significance in using an avatar. Several noted that they like the "idea of having an avatar." Participants expressed strong identification with their avatars. One stated, "I felt like the avatar was me." Several stated that seeing their avatar with all four limbs made them feel "normal" or "like a whole person." One participant referred to liking "seeing legs again."

Theme 6. Expanded Sense of Possibilities

In addition to identifying with the avatar, participants seemed to find inspiration from the avatar's actions. Participants felt less limited as a result of using the avatar. One noted that seeing the avatar "reinforced that I don't have limits." Another commented that he could be fearless as an avatar. Several participants observed that they wished they could do in real life what they could do as an avatar in Second Life. As one participant commented, "I liked being able to do things that I can't do in the real world." One participant perceived the avatar's mobility as transferable to real life, noting "The mobility of the avatar actually transfers to you if you allow it to."

3.3 Experience of Training Format

Theme 7. An Interactive Training Experience

Participants spoke repeatedly of how they appreciated the interactive format of the training in Second Life. Particular interactive aspects of the training that stood out to participants included teleporting to the stations and following the arrows to move through the training. Participants really enjoyed the activities included in the training; some of those mentioned included the car, the cane and the zip line. One participant commented that due to the interactive nature of the training, he felt as though he were really there, going through the course.

Theme 8. Mixed Experience with Training Videos

Participants had both positive and negative experiences related to the videos included in the training. While participants indicated they were glad there were videos in the training, several noted that the videos didn't load or were blurry. Several participants commented that they enjoyed listening to the amputees on the videos. One participant shared that he liked "sitting" as an avatar watching the videos on the big screen.

3.4 Perceptions of Training Content

Theme 9. Complete and Educational

Participants found the information in the training to be comprehensive. Participants noted that they found the training interesting, and were able to refer to specific examples of information they recalled that they had found useful or interesting. A majority of participants volunteered that they most enjoyed the information about the history of prosthetics.

Theme 10. Best for New Amputees

Participants indicated that they felt the training content was best suited for new amputees. Those who were new amputees expressed appreciated for gaining a better understanding of what to expect. Those who have been amputees for some years spoke of knowing much of the information but finding "reinforcement" in that information.

Theme 11. Positive Outcomes

Participants felt they benefited from the training content. Many noted that they had learned a lot; examples cited included ways to put on a prosthesis, ways to do leg exercises, and how to button a shirt with one hand. A few indicated that the training gave them "a good outlook." Several participants shared that the training gave them an expanded sense of options and possibilities.

Theme 12. A Transformational Experience

Within the category that summarized results pertaining to Perceptions of Training Content, a significant result was that several participants indicated that they found the training in Second Life to be a transformational experience. In referring to the sequence of training stations in SL, one participant commented, "It felt as though I left home and actually took on the course." Many noted that they had applied what they learned in real life. Examples cited included stump care and walking on an uneven surface. A participant noted that following this experience, "I see myself just meeting the challenge without hesitation and resolving any issues by breaking them down. It is easy to be aggressive and without fear in SL." Several noted that participating in the training gave them a sense of connection with other amputees. One participant stated that the training gave him the strength to look at his amputation incision for the first time.

3.5 Perceptions of Training Needs of Friends and Family

Theme 13. Understanding the Challenges of the Amputee

Participants indicated that friends and family need training that would provide a better understanding of the challenges amputees face, including how difficult it can be to function with a prosthetic device and issues of daily life. Friends and families need to understand all the stages a person with limb loss goes through. Participants noted that friends and family need training not only on the content in this training but also on the emotional needs of the amputee. One participant suggested it would be beneficial to have a site on Second Life where friends and family could learn together.

Theme 14. Knowing When and How to Help

A repeated observation of participants was that friends and family need to learn when and how to help the amputee. Participants indicated friends and family need to learn how to be more patient, and how to talk to the amputee. Participants also suggested practical training such as how to help an amputee who falls, or how to help an amputee up the stairs.

4. CONCLUSIONS

In this paper we have presented the results of the qualitative portion of a larger study that compared two methods of accessing a self-management training for amputees: e-learning using Articulate® software and the SL virtual world. The qualitative study consisted of 17 individual interviews in which participants responded to open-ended questions related to their experience of completing the training and the meaning they found in engaging in SL. Interpretative Phenomenological Analysis was selected as the appropriate methodology in order to focus on lived experience from an interpretive and idiographic perspective. Data analysis led to the identification of 14 themes, grouped within 5 major categories. In this paper, we presented five categories of themes which together shared the common superordinate category: Expanded Sense of Possibilities. These possibilities were not limited to the amputees themselves, but included family and friends as well.

Through the vivid words of participants as they described their experiences and shared their perceptions of completing the self-management training, it could be seen that they found SL to be a freeing environment, that they identified with their avatars and found that using the avatar gave them a sense of new possibilities, which led to the training being a transformational experience that impacted them in real life. We close with the following quote of one participant, which captures the spirit of the participants collectively in terms of the broader impacts of their experience of training in SL:

> *I looked at myself and realized I need to get active. That I need to acknowledge that this is not a novelty. It is very real and how am I going to make my life better. What am I going to implement to make my life work. For example, I have my old leg and liners, etc. just sitting around my room. That's not what I do with my other stuff. I need to get it organized. Also on a daily basis I need to not be afraid to walk without thinking that every step might mean I'm going to fall. I look at young people and they can do it. It's a mindset that I am working on adopting for myself as I move forward.*

Acknowledgements: We would like to thank all the participants in this study. This project is supported by the Agency for Healthcare Research and Quality Award # R24HS022021, PI Sandra Winkler, 2013-2017. We dedicate this paper to Al Hall, the PhD student who conducted the interviews as part of his doctoral research. Sadly, Al is no longer with us to witness the results of his work, but we are indebted to him for his contribution.

5. REFERENCES

Aichner, T., & Jacob, F., (2015), Measuring the degree of corporate social media use. *International Journal of Market Research,* **57**, *2*, pp. 257-275.

Bandura, A., (1977), *Self-efficacy: The exercise of control*, W.H.Freeman, NY.

Bartle, R., (2003), *Designing virtual worlds*, New Riders, San Francisco.

Bell, M., (2008), Toward a definition of virtual worlds, *Journal of Virtual Worlds Research,* **1,** *1*, pp. 1-5.

Creer, T., Renne, C., & Christian, W., (1976), Behaviorial contributions to rehabilitation and childhood asthma, *Rehabilitation Literature,* **37**, pp. 226-232.

Ducheneaut, N., Wen, M. H., Yee, N., & Wadley, G., (2009), *Body and mind: A study of avatar personalization in three virtual worlds,* Paper presented at the 27th International Conference on Human Factors in Computing Systems, Boston, MA.

Esquenazi, A., (2004), Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration, *Disabil Rehabil,* **26,** *14*, pp. 831-836.

Gallagher, P., & Maclachlan, M., (2001), Adjustment to an artificial limb: a qualitative perspective, *J Health Psychol,* **6,** *1*, pp. 85-100.

Gallagher, P., & Maclachlan, M., 2004, The Trinity Amputation and Prosthesis Experience Scales and quality of life in people with lower-limb amputation, *Arch Phys Med Rehabil,* **85,** *5*, pp. 730-736.

Lorig, K., & Holman, H. R., (2003), Self-management education: history, definition, outcomes, mechanisms, *Ann Behav Med,* **26,** *1*, pp. 1-7.

Lorig, K. R., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M., (2001), Effect of a self-management program on patients with chronic disease, *Eff Clin Pract,* **4,** pp. 56-62.

Patterson, B., (2001), The shifting perspective model of chronic illness. *Journal of Nursing Scholorship, 1st Quarter*, pp. 21-26.

Thomas, D., & Brown, J. S., (2009), Why virtual worlds can matter, *International Journal of Learning and Media,* **1,** *1*, pp. 37-49.