

People with Disabilities in Virtual Worlds: Who, How, Why, and What's Next?

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Abstract

People with disabilities are proportionately over-represented in virtual worlds, with probably one in five people in a virtual world having one or more disabilities—physical, mental, emotional, or sensory. They enter virtual worlds using a variety of assistive technologies, and participate in all the varied activities available therein. Recent research has shown significant social/emotional benefits for people with disabilities who participate in Second Life, both casually and in treatment groups. Peer support groups are available as well. Challenges exist for all virtual world participants, including addiction, frustration, increased isolation, and lack of confidentiality. No challenge is limited to persons with disabilities. Research about people with disabilities in virtual worlds has been limited. Several potential research topics are suggested.

Keywords

people with disabilities; Second Life; virtual worlds

Introduction to People with Disabilities in Virtual Worlds

Why do people with disabilities enter virtual worlds? What does their presence in virtual worlds tell us about virtual identities? How do people with disabilities use virtual worlds in unexpected ways?

Although there are no measures within virtual worlds such as Second Life, people with disabilities make up about 20% of people in online casual games (Popcap, 2008), which may be a comparable population. People with more severe levels of disability seem to be over-represented in these environments.

Some types of significant disability, such as leg amputation or lower body paralysis, do not affect an individual's ability to use virtual worlds. Four types of impairments do impact ability to function in a virtual world: keyboard/mouse; print; hearing/speech; and cognitive (Krueger & Stineman, 2011). Individuals with these disabling conditions use a wide variety of assistive technology to access virtual worlds, including alternative keyboards and other input devices, textual user interfaces, voice-to-text software, and eye gaze detection systems. Human transcriptionists provide text of voiced events for deaf individuals, speak text aloud for dyslexic individuals, and describe images for blind individuals. Special limited user interfaces, controlled by their guardians, allow persons with low intellectual capacity to use virtual worlds safely. Coaches and mentors assist developmentally delayed individuals to participate independently.

For all the same reasons anyone else does: taking a class, listening to or performing live music, being creative, having a job, socializing, or just plain having fun (Babbis, 2009; Stendal, Balandin, & Molka-Danielsen, 2011; Stewart, Hansen, & Carey, 2010). The general benefits to people with disabilities of being in a virtual world are the same as for others. However, specific benefits accrue to people with disabilities from being in virtual worlds.

Benefits to People with Disabilities of Participation in Virtual Worlds

Recent preliminary research (Gilbert, Murphy, Krueger, Ludwig, & Efron, in press; Novek, et al., 2011) has shown social/emotional benefits from Second Life participation, including lowered depression, anxiety, and loneliness; and increased positive affect, self-esteem, and general life satisfaction. Specific medical benefits of virtual world usage have been documented for populations including burn patients (Patterson, Hoflund, Espey, Sharar, & Nursing Committee, n.d.), children with mobility disorders (Inman, Loge, & Leavens, 1995) or communication deficits (Tartaro & Cassell, 2008), and adults with intellectual disabilities (Hall, Congoy-Hill, & Taylor, 2011). We do not yet know if there are different benefits for people with mental vs physical disabilities. Nor do we know the long term effects of participation in virtual worlds for this population.

While it is unlikely that anyone comes into Second Life or other open access virtual worlds to find peer support, over 120 inworld peer support groups for various chronic illnesses and disabling conditions have been documented there. People with very low incidence disabilities have stated, "I had never met anyone with my disability until I came into Second Life." Sometimes a virtual world is the only place to meet someone like yourself. Participants in Second Life peer support groups are more likely to seek social supports than people using other forms of online support such as chat rooms or forums (Green-Hamann, 2010).

Challenges to People with Disabilities of Participation in Virtual Worlds

While there are clearly many potential benefits of virtual worlds for people with disabilities that require further research, we also need to expand our knowledge of challenges and barriers to appropriation. Concerns related to participation in virtual worlds include addiction (Davidow, 2012), emotional harm (Saunders, 2011), frustration at not being as capable or as good-looking as your avatar, and increased social isolation from sitting in front of a computer all night (Turkle, 2011). Confidentiality of personal information remains an issue in virtual worlds (Ford, 2001). None of these challenges apply solely to persons with disabilities.

Perhaps the most common argument against the use of virtual worlds by persons with disabilities is that it gives them a false sense of reality, that it allows them to escape from the reality of their disabling condition. This fallacy derives from a common misunderstanding by able bodied people of what quality of life is like for a person with a disability, often stated as a "disability paradox" (Albrecht & Devileger, 1999). People with even quite severe disabilities, whom able bodied people might assume would have a low quality of life, often assert their quality of life to be high. People with disabilities do not typically go into virtual worlds to escape their disabilities. They don't believe they will become young and fit like their avatars any more than anyone else believes this.

Research opportunities

Little research in the use of virtual worlds by persons with disabilities has occurred until quite recently (Stendal, Balandin, & Molka-Danielsen, 2011). Some research has taken place in custom-designed virtual environments, but little in open access multi-user environments such as Second Life (Stendahl, 2012). Results of research done in other game-based virtual worlds (MMORPGs such as World of Warcraft and Everquest) may not apply in Second Life, which does not fit the characteristics of a game (Book, 2004).

Avatar appearance and veiled anonymity affect the user. The Proteus effect demonstrates that able bodied people with avatars more attractive than themselves have more self-confidence (Yee & Bailenson, 2007). Using a pseudonym in a less immersive online environment allowed people with mental health issues to more confidently discuss their concerns with others (Kummervold,

Gammon, Bergvik, Johnsen, Hasvold, & Rosenvinge, 2002). Might this explain some of Gilbert's results for people with disabilities in Second Life?

One of the unique affordances of virtual worlds is that individuals create their avatars in the manner they desire. This of course is directly opposite of the physical world, where it is very difficult to change many undesirable personal physical characteristics. Why do some people with disabilities in virtual worlds choose to embody their disability (e.g., using a wheelchair) (Harrigan, 2007), while others choose to appear able bodied? Are the positive results noted by Gilbert et al. similar for people who choose to embody their disability virtually and those who do not?

Idealized avatar appearance enhances the relationship of the individual to his virtual embodiment (Hobart, 2012; Jin, 2009, Nowak, et al., 2008). Attractive avatars are preferred by others for social interactions (Principe, & Langlois, 2013). How does this affect avatar choice by persons with visible disabilities?

Self perception theory (Bem, 1967) posits that we observe ourselves and use information from behavioral self-observation to infer our attitudes or moods, rather than our attitudes affecting our behavior. Will observing a positive-appearing and -behaving avatar bring health benefits to persons with disabilities? Perhaps positive results for people with disabilities of participating in a virtual world may transfer to physical world behaviors (Yee, Bailenson, & Ducheneaut, 2009).

The field is beginning to attract researchers from a variety of disciplines. Soon there may be more information available to document how and why people with disabilities use virtual worlds, and what benefits accrue to them and to the able-bodied people with whom they interact there.

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Exploring the Influence of Avatar Performance on Individuals with Parkinson's Disease

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Abstract

This study explores the potential use of virtual worlds as therapeutic environments for people diagnosed with Parkinson's disease. Using an ethnographic approach including participant since August, 2012, this research revealed insights into the power of virtual embodiment. Avatar performance appears to provide relief to Parkinson's symptoms including depression through the development of digital social capital. Likewise, initial results point to mediated effects that reveal potential application for physical rehabilitation. The implications of this preliminary study support an argument for further research to validate these findings that could have profound influence on the wellbeing of individuals with Parkinson's.

Keywords

Parkinson's; eHealth; embodiment; ethnography; virtual worlds

Introduction

In the past decade, greater recognition has been given to the power of communities that form online, especially those that provide social support within health related communities. Forums, chat rooms, blogs and websites open to comments, and Facebook groups are just a few examples of the avenues of support for individuals seeking information, interaction or simply someone to talk to about the challenges they face as a result of their illnesses or conditions. Numerous studies have identified the value of these groups for providing mutual aid and self-help for individuals who may not have access to or the motivation to attend face-to-face groups. They are often isolated geographically or emotionally, suffer from depression, and/or may have limited mobility.

This study investigated the effects of an online support group for individuals who have been diagnosed with Parkinson's disease. According to the National Institutes of Health, more than 500,000 people in the US suffer from Parkinson's disease, with "50,000 new cases reported annually" (NIH, 2012). An online search of support groups for these people reflects more than 4 million results, most of which are face-to-face meetings or online forums.

What makes the support group included in this study extraordinary is that they meet in a 3D social space in the form of avatars. Anecdotal evidence from these individuals suggests that as a result of agency, or the *sense* of being physically present in this environment, and by engaging with other individuals in real time that they have experienced improved mobility and/or reduced symptoms of the disease such as depression in their physical lives.

Evidence of effective health-related activities and healthcare support groups in virtual worlds is relatively new with the earliest research emerging in 2008 (Toro-Troconis et al., 2008, Norris, 2009, Krebs et al, 2009, Beard et al, 2009) as virtual reality became more accessible and user traffic became more wide spread. Although the traffic numbers pale in comparison to the more mainstream social

media destinations, there are powerful media effects based on the sense of presence in these environments (Heeter, 1992; Lee, 2004) that warrant further exploration for healthcare community development and outreach.

Virtual environments are hyper-social, providing an alternative location for in-depth interaction and meaningful exchange. Studies continue to show that individuals who operate as avatars in virtual environments often express a level of social capital equal to or greater than what they may experience in the physical world (Davis, 2011; Bargh and McKenna, 2004). Social capital has been shown to have tremendous potential value in patient support and recovery.

As technology has permitted individuals to connect to their networks through highly interactive social media, connecting is also now accessible to almost anyone, almost anywhere. This does not disavow the notion of a “digital divide” that might in fact prohibit remote or financially disadvantaged individuals from participating. However, these individuals are also often lacking other simple resources required to develop social capital (including transportation or the economic resources to participate in community organizations) especially when their communities lack places or programs that provide support services. Such is especially the case with individuals who suffer from disabilities or debilitating conditions such as Parkinson’s disease when mobility is further diminished. Can attending such support meetings and functioning in a virtual community provide equal or even greater benefit? This study sought to answer this important question.

Methodological approach and theoretical underpinnings

Because this research is exploring the evolution of a new form of community about which very little is currently known, this ethnographic study employed participant observation in two stages: First, the researcher attended both the public social events of the “Creations for Parkinson’s” group in the virtual world, Second Life. Second, the researcher attended the organizations’ weekly support group as an observer. Following approximately six months of engaging in the community, clear themes emerged which guided the development of protocols for measuring the experience of individuals who will be recruited for longitudinal study in collaboration with medical researchers.

From a theoretical perspective, media effects, uses and gratifications and social capital theories guide this study. In his exploration of media effects, McLuhan suggested nearly half a century ago that media was an “extension of man” (1964). Although there were no virtual worlds or avatars to reference his concept of media as an extension of man in 1964, perhaps his prediction is even more applicable to digital media, especially the immersive 3D virtual world where humans function and interact with others in the form of digital surrogates, also called avatars. If, in fact, individuals whose physical function is diminished as a result of Parkinson’s disease are able to continue to live what they perceive to be a “normal” life similar to the one they had prior to their illness, is this not perhaps the most literal definition of media as an extension of man?

Likewise, uses and gratifications theory assumes the media consumer takes an active role in which medium they choose and how they use it (Blumler and Katz, 1974). Although more recent interpretation has extended to internet uses and gratifications (Stafford, Stafford & Schkade, 2004; LaRose & Easton, 2002), this research may further our concept of uses and gratifications when the medium provides basic human need such as social connection and potentially the ability to function in a community where their physical world no longer allows or is significantly limited.

Conclusions and discussion

Preliminary findings have laid the foundation from which to launch a long-term study on the effects of avatar performance on individuals diagnosed with Parkinson's disease. Anecdotally, individuals currently report experiencing increased social support and positive effect from emotional bonds built in their virtual world. Perhaps more important, one study participant reports increased mobility and reduced symptoms of her Parkinson's disease since she began watching "herself" (her avatar) engage in physical activities such as dance and tai chi in the virtual environment.

Given the ease of access to this virtual world from anywhere in the world with a computer and Internet access, if indeed people can experience the same benefit, this research could prove to be profoundly important.

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Disability and the Immateriality of Information

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Abstract

The goal of this paper is to use ethnographic data to speak to a theoretical debate. Specifically, I show how the experiences of persons with disabilities in the virtual world Second Life can intervene in current work on the materiality of information. Their experiences can help us rethink the mind/body dualism and avoid treating the online as “immaterial.” Thus, while I will address exciting ways that virtual worlds provide possibilities for social support and even rehabilitation for people with disabilities, their words and deeds can also be taken seriously as powerful conceptual interventions. This underscores how effective ethnographic research involves treating interlocutors as sources of theory as well as data.

Keywords

disability; embodiment; ethnography; materiality; virtual worlds

Introduction

In this paper, I explore what the experiences of persons with disabilities who build community in the virtual world Second Life can tell us about the materiality of information. That’s a lot packed into one sentence, but it’s not as complicated as it sounds. It is a story of appropriation, of making something new from a given state of affairs. My goal is to take the everyday insights of a community—in this case, persons with disabilities participating in a virtual world—and put those insights into conversation with a theoretical debate—in this case, regarding what is termed the “materiality of information.” In treating my ethnographic interlocutors as a source of theory as well as data, I seek the kind of conceptual dialogue associated with the best ethnographic work in anthropology and beyond. In a classic statement of this approach, Clifford Geertz emphasized:

[A] continuous dialectical tacking between the most local of local detail and the most global of global structure in such a way as to bring them into simultaneous view... [an ethnographer] moves back and forth between asking himself, “What is the general form of their life?” and “What exactly are the vehicles in which that form is embodied?” (Geertz, 1983, pp. 69–70).

Disability and social life

In the case at hand, the form in which the lives of persons with disabilities who participate in virtual worlds are embodied involves avatars, digital objects, and online landscapes. These persons teach us something about materiality and its relationship to what is known as “social constructionism” (in essence, the idea that we create our social worlds through social norms). As the disability theorist Tobin Siebers notes:

In a society of wheelchair users, stairs would be nonexistent, and the fact that they are everywhere in our society seems an indication only that most of our architects are able-bodied people who think unseriously about access... [But] disability scholars have begun to insist that... [social constructionism]... either fails to account for the difficult physical realities faced by people with disabilities or presents their body in ways that are conventional, conformist, and unrecognizable to them. These include the habits of privileging performativity over corporeality, favoring pleasure to pain, and describing social success in terms of

intellectual achievement, bodily adaptability, and active political participation. (Siebers, 2001, p. 740)

These questions of disability and social experience take on new meanings in the context of online technologies. Linkages between technology and disability are, of course, of great antiquity, but novel possibilities emerge with the internet: “for many disabled people there have been not only improvements, but also first-time occurrences of great significance” (Anderberg and Jönsson, 2005, p. 719). For instance, against the tendency to see online interaction as “mediated,” it is striking that for some persons with disabilities, interaction online can be less mediated than interaction offline “by opening up new arenas for contact that [one] is able to control without the presence of a PA [personal assistant]” (Anderberg and Jönsson, 2005, p. 724).

Mind, body, and dualism

The material I draw on in this analysis comes from fieldwork I have been conducting since June 2012 with persons with disabilities who participate in several communities in Second Life, and also building on earlier ethnographic research in this virtual world (Boellstorff, 2008, 2011, 2012; Boellstorff, Nardi, Pearce, and Taylor 2012). I will discuss how my interlocutors often talk about the importance of a division between mind and body, and how this shows up in their interactions online. I want to take this seriously. In insisting on a distinction between mind and body, these persons with disabilities are speaking to the tendency in much social theory to claim that the mind and body are unified, and analogously that the online and offline are “blurred.”

Persons with disabilities active in Second Life are quite aware of their physical-world bodies. However, their interactions with the online and offline are only possible because of the distinction between the two, the “digital” gap between virtual and physical that recalls the gaps between zeros and ones without which the digital itself would be impossible. When a woman with a disability is dancing with a group of friends as an avatar in Second Life, and says “it thrills me to see me dancing; this is who I am,” this person is not delusional or mistaken. She is not lost in a technological fantasy; she is reconceptualizing embodiment. While beyond the scope of this article to discuss in detail, I will mention how one entailment of this reconceptualization is the possibility that virtual worlds could be used to mitigate certain symptoms of disorders like Parkinson’s disease.

From embodiment to immateriality

To extend even further the insights gained from my ethnographic collaboration with persons with disabilities, I will briefly address how these understandings of embodiment link up to questions of materiality. In recent years there has arisen a body of literature concerned with “the materiality of information.” This work responds to a feeling that some internet research of the last two decades has overemphasized the supposed placelessness and immateriality of the online. While this is an important intervention, the danger is of the pendulum swinging so far in the other direction that future scholars will denounce current work for overemphasizing materiality.

I will conclude my analysis by mentioning three ways that the experiences of persons with disabilities can help us avoid underestimating “immateriality” in relation to internet sociality. First, physical-world conditions are underdetermining: you cannot predict what will happen online by looking just at infrastructure, physical bodies, and hardware. Second, in important ways “materiality” is not limited to the physical world: there are forms of digital materiality, including digital artifacts, digital embodiment, and digital places. Finally, despite the tendency in many traditions (including most Western traditions) to treat the immaterial as relatively important (as the phrase “that is immaterial” suggests), the immaterial has real causal force and social significance.

This suggests exciting pathways for future research, including collaborations with a range of virtual communities. Such collaboration can investigate how virtual worlds provide new possibilities for sociality and rehabilitation for persons with disabilities (Carr, 2010; Hoch et al., 2012; Krueger,

Ludwig, and Ludwig, 2009; Stewart, Hansen, and Carey, 2010). However, in this brief talk I hope to indicate how the experiences of persons with disabilities are also a source of general theoretical insight. This does not mean that ethnographers do not take responsibility for their claims. It does not mean that we assert “ethnographic authority” (Clifford, 1983) by implying that our analyses are unassailable because they have the imprimatur of those we study. However, it does mean that we get ideas as well as data from the people we study. Recognizing that fact can lead to a more dialogical and vulnerable (Behar, 1986) intellectual practice, online or offline.

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