The Looking-Glass Avatar: Representing Chronic Pain through Social Virtual Reality Avatar Movement

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Abstract

With recent movements toward disability as a social identity, we explore whether pain associated with chronic pain conditions (e.g., arthritis, Crohn's disease, lupus) is also linked to identity and representation preferences. Prior work showed social VR users with invisible disabilities noted preliminary interest in using their avatar's body language to represent their disability-related identities. We examined movement-based social virtual reality (VR) avatar representation preferences by conducting semi-structured interviews with five participants with such chronic pain conditions. Participants incorporated social norms, cultural considerations, and internalized self-stigma into their decision-making about pain disclosure and representation in different contexts. Aligning with previous work on self-presence and embodiment, in order to avoid discomfort, most participants wanted to avoid experiences where their avatar moved in ways that they did not, or could not, move in the physical world (i.e., jumping, bending over from the spine). Two participants also wanted to be able to represent their personal use of clothing and fashion as accommodation in the physical world. We believe this study will further our understanding of how disability-related identities should be represented in social VR spaces.

CCS Concepts

- **Human-centered computing → Accessibility**.

Keywords

accessibility, avatars, avatar movement, chronic pain, customization, disability disclosure, invisible disabilities, social virtual reality, virtual reality

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1 Introduction

Virtual realities alter our social landscape, inviting us to replicate or transcend the affordances of the physical world [6]. Users can take part in superhero-esque activities, like flying and teleporting. They can also embody fantastical avatars. However, virtual worlds are not yet equally available to all. Among the many accessibility needs that remain to be addressed is the ability to represent one's self with avatars. Avatars mediate all social interactions on VR platforms, so it is important for users from diverse backgrounds, including users with visible and invisible disability-related identities, to be able to represent and explore their identities in virtual spaces [15, 21, 33]. Users thus can symbolically make explicit these invisible or misinterpreted experiences of disability [11], which has been a documented use in both immersive VR platforms and the desktop-based VR platform Second Life. Still, there remains an untapped area of potential in social VR avatar customization to "shape narratives about the body" [20] beyond avatar symbolism.

According to the International Association for the Study of Pain (IASP) [16], pain is "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage." Chronic pain refers to disabilities that impact approximately one-fifth of U.S. adults [8] and is defined by Johns Hopkins as "long standing pain that persists beyond the usual recovery period or occurs along with a chronic health condition, such as arthritis… [it] may be "on" and "off" or continuous. It may affect people to the point that they can't work, eat properly, take part in physical activity, or enjoy life" [17].

Only in recent years has the social component of pain been recognized, coinciding with progression in disability justice movements' advocacy for acknowledging disability as a social experience

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[1]. In 2020, the most formal definition of pain was amended, for the first time in three decades, to acknowledge its social aspects. Among other bulleted items, the IASP [16] wrote: "Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors." The amendment also underscored a key tenet of the present study, which seeks to expand our understanding of physical behaviors that communicate pain: "Verbal description is only one of several behaviors to express pain."

This study explores chronic pain representation preferences in social VR avatars as an extension of disability identity expression. In this poster, we present preliminary findings related to these research questions:

RQ1: In what social VR contexts do people with chronic pain conditions want to disclose or conceal pain? How is this informed by non-virtual experiences?

RQ2: If people want to modify their social VR avatar's appearance or movements due to pain, how? And what do they hope to communicate to others?

2 Related Work

Pain communication serves as a complex interface that intersects personal experience, cultural norms, and societal structures. It involves both the transmission of sensory information and the intricate dynamics of emotional and psychological expression [2, 19], and it does not occur in a vacuum; rather, larger social stigmas shape experiences and expressions of pain. In particular, stigma has a direct impact on childrens' hesitation to communicate their pain and/or invisible disabilities [27, 31]. Moreover, chronic pain's manifestation can impact platonic, professional and romantic social contexts; external perceptions and responses are impacted by the "visibility" of the disability or injury [30]. Thus, pain communication has significant practical applications that range from communicating pain to a physician [18, 28], expressing accommodations needs in the workplace [3] [22], and emphasizing social support needs to one's daily circle [12, 23]. However, research on how people with pain present themselves is still in its infancy, thus far only relating to communicating pain through facial expressions [9] and symbolic visual art [26].

The gap in literature on movement-based representations of pain becomes especially relevant as technology-mediated platforms like VR proliferate, offering new, avatar-based venues for representing and managing pain beyond the limitations of the physical world [4, 5]. VR platforms generate a sense of presence and embodiment that fosters a strong connection between users and their avatars, as virtual extensions of the self [10, 13]. Notably, avatar design and behavior can significantly influence users' experiences, including social interactions and self-perception [32].

In recent years, research has highlighted how avatar customization can provide a platform for the represention and communication of disability-related identities by incorporating assistive technology and symbolic signifiers in social VR environments [15, 33]. While these prior studies have focused more broadly on open-ended representations of visible and invisible disability, to our knowledge, this study is the first to focus on invisible chronic pain conditions in particular, many of which involve flare-up cycles and physical responses to environmental factors (e.g., temperature, seating type, activities warranting strenuous physical activity) that can impact movement. It is also the first to center movement-based avatar representations of disability, an exciting new direction that accentuates how we might use VR's unique, multimodal affordances to generate more inclusive representations.

3 Methodology

We are in the process of conducting semi-structured interviews with people with chronic pain conditions (e.g., endometriosis, irritable bowel syndrome) to learn about their daily experiences of pain and interest in translating their pain into social VR representations.

Participants. Our preliminary sample includes 5 participants (all identified as female, ranging from ages 19 to 27, with a mean of 23 and a standard deviation of 3.16) who were recruited through an undergraduate extra credit portal and social media postings at a large U.S. research university. Their chronic pain conditions included (or resulted from) postural orthostatic tachycardia syndrome (POTS), irritable bowel syndrome (IBS), disk herniation, ankylosing spondylitis, vulvar vestibulitis, arthritis and endometriosis. When asked about their race, three participants identified as White, one participant identified as Black and White, and one participant identified as multiracial.

Procedure. We conducted in-lab semi-structured interviews where participants began by describing their physical and contextual experiences of pain. Next, they customized a ReadyPlayerMe avatar [24] and embodied that avatar in a private Spatial.io environment [29] using a Meta Quest 2 headset. After exploring for several minutes, we instructed participants to move in front of a mirror in the virtual environment and describe their thoughts on their avatar customization experience. Finally, we introduced them to the Mixamo avatar movement library [25], where they identified movements that represent the pain-related behaviors they would want made available to their avatars in various social, educational and work contexts.

Analysis. All interview transcriptions were auto-generated by audio recording software and coded for thematic analysis [7]. Three researchers individually coded the first transcript and compared codes to create a preliminary codebook that continued to be iterated upon as the remaining four transcripts were double-coded between two researchers. After all transcripts were coded, three researchers met to discuss emerging themes.

4 Findings

4.1 Stigma Concerns Affect People's Willingness to Communicate Pain

Participants cited societal misconceptions, internalized self-stigma and cultural norms as factors that influenced their day-to-day pain communication. P3 and P4 described concern about their self-accommodations for chronic pain being misinterpreted. P3 mentioned, *"I could probably be perceived as lazy because I take the elevator instead of the stairs because that's what feels better for me."* Similarly, P4 described others' reactions to her habit of cracking her back to alleviate pain: *"I'm always cracking my back to the point where I can't stop, even if I want to. When people are like 'you're in a public place' or 'your supervisor is gonna see you'... I just don't think people know that people crack if they're feeling in pain or locked up.*

I think people just think it's something people do to annoy them or something."

When it came to VR representation preferences, P3 and P5 wanted to use their avatars to conceal their pain from friends in social settings. P3 elaborated, *"In that context, I would actually take [the pain] away and have myself blend more with the average person that doesn't experience back pain."* Along a similar vein, P5 shared she was less interested in representing pain through avatar movement than other components of appearance, because even though people might be accommodating, *"you don't want to feel like you're a buzzkill."* Due to cultural norms, she felt most drawn to makeup customizations to conceal sickness, stating: *"In my culture, you're always supposed to be very well-presented. I cannot be caught in my home country wearing sweatpants, for example, in public. You will never hear the end of it. And so you don't wanna seem sick. You're trying to seem as healthy and put together as possible all the time."*

4.2 Pain-Related Movements Should Mirror Self-Accommodations in the Physical World

Participants were accustomed to making self-accommodations, adjusting their movements to conceal or alleviate pain in the physical world. Thus, they were interested in adapting their movement accommodations to virtual platforms.

P3 wanted to adapt avatar movements to authentically represent her physical adjustments, suggesting customization libraries allow her nuanced customizations, like gait patterns, to reflect what she described as her *"old man walk,"* saying: *"I've always been true to myself...I think that represents who I am."* As she explored the Spatial environment through an embodied avatar, P3 would cringe every time she accidentally brushed the "jump" button. She later explained she wanted to remove the button, elaborating: *"I'm not going to jump because I know that when I land, there will be pain."*

Rather than remove the "jump" button, P2 wanted to swap it out for a modified bending down to pick up virtual items, which was more relevant to her own accommodations for chronic back pain. In the physical world, she described her adjustment as: *"doing small things, like leaning over and washing my face in the morning, I kind of have to bend my legs now. Or, if I drop something on the floor, I'll bend my legs all the way and grab instead of leaning over and grabbing it."* She wished to reproduce this accommodation in virtual environments, especially when the furniture might default to short heights rather than matching her own height, according to her environmental self-accommodations.

Two participants identified movements they were not interested in applying to their avatars during social interactions but felt drawn to as metaphors for their experiences of pain. P2 selected the high kick, which represented her frustration and *"anger – or why is this happening to me?"* P5 was uninterested in drawing attention to her pain but instead highlighted a movement as *"how I feel on the inside."* She cracked a smile as she pointed to the screen, explaining, *"This is kind of funny. This is sometimes how I lay when I'm in pain. Also on my side. This one's called 'kick to the groin.' I don't actually fall to the ground. But I will lay down like this, kind of."*

Unlike other participants, P1 was not interested in representing her chronic pain through her avatar. She perceived VR as a space for escapism from pain and preferred to avoid it altogether, even during a flare-up. *"I guess I don't really think about being perceived when I'm in VR, because I'm usually focusing on whatever interaction I'm having with other people. I don't want to think about my pain, even when I'm in pain."* P1 also expressed an interest in VR's unique affordances, such as *"things that you couldn't do in real life."* She explained, *"I really like when I have the ability to do things like cartwheel, or flight...I like being able to do things I won't be able to do physically in real life."*

4.3 Physical and Virtual Clothing Double as Identity Expression and Self-Accommodation

Interestingly, P4 and P5 both raised the importance of fashion and clothing selections as dual identity expression and self-accommodation they were interested in extending to the virtual customization library. P5 wanted to adjust her avatar's clothes the same way she does in the physical world: *"Usually, I'm very active and want to be outside and stuff. And then, at [some] point, I just want to stay at home, sitting down and wearing very loose clothing, so I feel less uncomfortable."* She discussed how different styles of physical clothing might manifest differently in her avatar customization, explaining the avatar she designed during the study:

> *"Kind of presents more how I would dress when I'm having a flare up, 'cause it's more baggy and a lot less constricting...So, I guess it represents how I would probably dress and feel most comfortable when I'm in pain. And so it's also, you know, kind of hiding my lower abdomen and my hip and making it a bit more loose so that I feel less self-conscious about how bloated it feels and looks when I'm in pain."*

P4 also had difficulty finding clothing options that made her feel comfortable. Avatar fashion was especially important to her because overhauling her wardrobe in the physical world was an important self-accommodation. *"Literally what I wear, that material of clothing, apparently plays a role. So I like more cotton and breathable fabrics, longer skirts in the winter, and wide-leg trousers."* When looking at her avatar's clothes in the mirror, P4 felt the tight clothing would create *"a lot of needless friction"* resulting from her chronic pain. She broke down her reasoning as follows: *"It's the classic pant debate: they're all skinny. They're all leggings. They're cargo shorts, like all of this. Which is already irritating for me to even look at... None of these pants are really working for me. All of these are structured, hardware materials that don't move with you. So, that's not good. That's not accurate, if we're going for accuracy."*

5 Discussion

VR avatar embodiment provides an immersive experience that fosters psychological connections between users and their virtual bodies [10, 13, 32]. In line with discourse around designing non-virtual spaces to accommodate people with disabilities, it is important to design avatars to account for the identity expressions and self-accommodations of social VR users with chronic pain-related disabilities. Our findings so far highlight how desired accommodations can enhance both the identity-related and embodied aspects of self-presence.

Our first five participants described context-dependent stigmas and concerns about others' perceptions that might prevent them from freely expressing pain in physical and virtual spaces. They were especially concerned about judgment from strangers in public venues. Some did not want to disclose to friends either, instead preferring to conceal their pain to avoid negatively impacting their close relationships.

Such perceptions of stigma might cause some social VR users with chronic pain to opt for adjusting their virtual movements to conceal their pain. However, several of our participants stated they wished to fine-tune their avatars' movements to better capture their self-accommodating movements (e.g., removing the "jump" button, bending down at the knees to retrieve an object rather than leaning over). This preference may be related to the self-avatar follower effect [14] in which immersive VR users unconsciously adapted their physical movements to match their avatar's slightly inaccurate movements. In other words, participants might want to avoid having their avatar's movements influence their physical bodies. Our preliminary findings affirm the importance of giving users with chronic pain greater control over their avatars' movements. Standardized affordances, such as the "jump" button, might better serve users with diverse abilities and movement needs by allowing users to customize which movements are made easily available to them, whether that might be jumping or a more accessible alternative.

Finally, incorporating a range of clothing styles and textures into customization libraries (i.e., a broader selection rather than skin-tight clothing) will allow for more comfortable embodiment for users who use fashion-based accommodations in their daily lives. Prior work has established the importance of identity representation through avatar clothing [15], but this study uniquely underscores the utility of diverse fashion options as a form of accommodation.

We acknowledge limitations of sample size and demographics at this in-progress stage and look forward to expanding the perspectives represented in our study through additional data collection.

6 Conclusion

In recent years, there has been much progress in disability-related social movements, but one underexplored avenue is the relationship between chronic pain and disability identity. This study examined how people with chronic pain conditions might want to communicate or conceal pain through social VR avatar movements. Participants expressed an interest in incorporating more accurate representations of their physical self-accommodations into avatar customization libraries, whether that manifests through adjustments to avatar movements, makeup, or clothing. Our findings also add to the discussion around movement transformations for participants needing accessibility accommodations in social virtual reality. To our knowledge, this study is the first to examine pain communication through VR avatar movement, and more broadly, to consider how pain might relate to disability identity in the context of social VR. We aim to generate important dialogue around nuanced and community-generated representations of disability in social VR spaces.

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