"Invisible Illness Is No Longer Invisible": Making Social VR Avatars More Inclusive for Invisible Disability Representation

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ABSTRACT

As social virtual reality (VR) experiences become more popular, it is critical to design accessible and inclusive embodied avatars. At present, there are few, if any, customization features for invisible disabilities (e.g., chronic health conditions, mental health conditions, neurodivergence) in social VR platforms. To our knowledge, researchers have yet to explore how people with invisible disabilities want to self-represent and disclose disabilities through social VR avatars. We fill this gap in current accessibility research by centering the experiences and preferences of people with invisible disabilities. We conducted semi-structured interviews with nine participants and found that people with invisible disabilities used a unique, indirect approach to inform dynamic disclosure practices. Participants were interested in toggling representation on/off across contexts and shared ideas for representation through avatar design. In addition, they proposed ways to make the customization process more accessible (e.g., making it easier to import custom designs). We see our work as a vital contribution to the growing literature that calls for more inclusive social VR.

CCS CONCEPTS

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

KEYWORDS

accessibility, avatars, customization, disability disclosure, invisible disabilities, social virtual reality, virtual reality

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1 INTRODUCTION

As people integrate more aspects of their lives into social VR spaces, the importance of diverse mechanisms for self-expression grows. Avatars are vessels for identity expression in VR [4], and their characteristics provide cues that mediate interpersonal interactions. Prior work explored how people with visible disabilities want to express themselves through avatars [8, 14] and found that users favored attaching assistive technologies to avatars. However, many people with disabilities do not have characteristics or assistive technologies that are immediately visible.

According to the Invisible Disabilities Association, "[a]n invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movements, senses, or activities" [7]. Approximately 10% of people in the U.S. (33 million) have invisible disabilities [13]. Non-exhaustive examples include diabetes, depression, and autism. Broadly, social VR platforms lack diverse customization options (e.g., regarding body and racial diversity), and invisible disability representation in social VR is even less present. Despite the invisible nature of some disabilities, identity representation is important. For one, by rendering invisible experiences visible, doors open for building awareness of underrepresented experiences. Further, social VR offers unique affordances for users to represent aspects of their identities in different ways compared to non-virtual contexts.

To broaden the inclusivity of identity representation in virtual spaces, we explore the wants and needs of people with invisible disabilities. In this poster, we present the preliminary findings of a study designed to answer the following:

RQ1: Which aspects of non-virtual and virtual social contexts inform invisible disability disclosure decisions?

RQ2: How would people with invisible disabilities want to represent their identities through social VR avatars, if at all?

2 RELATED WORK

VR enables embodied social experiences, allowing people to meet, interact, and socialize in the form of avatars [4]. Thus, avatars are important forms of self-representation where people balance authentically representing their identities with how they want

others to perceive them [6]. Prior work that explored identity and social VR avatars focused on groups such as LGBTQ [3, 5] and racial minorities [2]. For example, Freeman et al. [4] found that most participants made their avatars similar to their physical selves because they considered avatars self-extensions. Another study [5] discovered that users changed their avatar's outfits and accessories frequently to represent gender-fluid identities.

Disability can become integrated with identity, as seen in the adoption of the term "spoonie," a nod to spoon theory, which likens the number of "spoons" of energy one has to their fluctuating capacity for tasks in a given day [1, 10]. However, avatar representation of disability remains understudied, with two exceptions. Zhang et al. [14] found users disclosed disabilities by attaching assistive technology to their avatars (e.g., hearing aids) and adopted various disclosure strategies to represent themselves in social VR. Mack et al. [8] noted they participants with intersectinal identities had to choose between representing their disability or racial identities in digital avatars.

No research has focused on the representation preferences of social VR users with invisible disabilities, though VR provides greater embodiment and immersion. Studies found that embodied avatar representation, such as eye blink frequency [12] and synchronous voice chat [4], influenced how others formed impressions of users. These findings exemplify how VR avatars provide unique affordances, distinguishing our contribution from prior work on non-embodied avatar customization via social media.

3 METHODOLOGY

We conducted semi-structured interviews with people with invisible disabilities to understand their perspectives on disability representation and disclosure in both non-virtual and social VR settings.

Participants. This is an in-progress study. So far, we have recruited 9 participants through various mailing lists. Their ages ranged from 20 to 56 years old ($mean = 32.67, SD = 10.21$). Six identified as women and three identified as men. The eight participants who disclosed specifically identified as having disabilities such as dyslexia, chronic pain, ADHD, and depression. All participants had experience with at least one social VR platform, but many had used multiple (e.g., VRChat, AltspaceVR, Spatial, Rec Room). Most used VR on a daily or weekly basis.

Procedure. We conducted semi-structured interviews with a creative component. We asked participants about their existing social VR representations and perspectives on representing their invisible disability. During the creative component, we invited participants to a collaborative whiteboard application. They were tasked with sharing ideas for their "ideal avatar representation" in social VR. We concluded by asking participants to reflect on disclosure in different social settings, features helpful for self-representation, and comparisons between social VR and non-virtual contexts.

Analysis. We transcribed all interview recordings, then conducted qualitative coding. Three researchers double-coded three transcripts, created the codebook, and split up the remaining transcripts for individual coding. After coding all nine transcripts, we conducted thematic analysis.

4 FINDINGS

4.1 Stigma Perceptions and Shifting Motivations Inform Disclosure

Multiple participants did not want to disclose their disabilities because of their perceptions of stigma but shared nuanced perspectives on how the intersection of stigma and social VR influenced their willingness to disclose. For example, P5 noted that his prior experiences contributed to his concerns of being disrespected due to a *"negative public perception"* of disability. P8 – the participant who did not feel comfortable disclosing his specific disability to the research team – was especially reluctant to represent his disability in social VR. As someone who concealed his invisible disability in almost all non-virtual social situations, he did not want to disclose in social VR because he felt that *"[others] wouldn't be very receptive or kind to that"* and he did not want to be treated as *"lesser than someone else."*

Alternatively, P4 had interest in disclosing two invisible disabilities but not a third. He felt comfortable representing dyslexia and chronic pain, but not epilepsy: *"I've had more hatred for [having epilepsy] than dyslexia, because most people understand dyslexia."* Others, such as P9, shared that they felt comfortable and open to disclosing their disability in social VR but wished to have more flexibility in toggling disclosure features on and off to avoid ableism in unwelcoming settings. Participants wanted to use this toggling feature to adjust their avatars based on fluctuating preferences, whether they be motivated toward disability representation or escapism, as P3 explained: *"My VR Avatar is whatever I'm feeling at the moment. If I'm feeling immersed in my invisible illness, then I'm probably gonna want my avatar to be also. And if I'm feeling like, 'I'm escaping reality,' I don't want my avatar to be even close to what I am."*

4.2 Context Influences Avatar Presentation

A variety of social factors influenced participants' disclosure strategies. For several, the intended audience significantly influenced their avatar design choices. Participants stated they were more likely to disclose in a disability-specific community rather than a large social situation, because they could *"match with what other people are sharing"* and evoke the empathetic feeling of *"here is something that I struggle with as well"* (P9). Additionally, some participants felt more open to disclosing disabilities in social VR, due to the persistence of labels in non-virtual spaces. P9 explained: *"I feel like once I label myself [with disability] in real life, it becomes something that kind of follows you around."* They perceived social VR to be a relatively safe space where they could freely express their disability-related identities without worrying as much about the judgments and stigma they faced in the non-virtual world.

Major distinctions are not exclusive to virtual versus non-virtual contexts. Due to the embodied nature of social VR avatars, P9 found it to be much more engaging and immersive than other social media platforms:

> *"[Social VR is] an order of magnitude above anything you would see on Instagram, anything you see on any other website, because those are just two-dimensional, static images or videos. [You] can't interact with a photo.*

> *[However,] when you're there in VR, you can see all the details on the avatar...their facial expressions, movements, and body language, and it's real time. No other kind of social platform comes even close to VR."*

4.3 Suggested Features and Customization Mechanisms

At present, there are no explicit invisible disability representations available in avatar customization platforms. Participants were interested in increased body and racial diversity, in addition to more ability representation, and offered a broad range of suggestions related to disability. Below are suggestions for improving disability representation in avatar clothing and accessories, as well as recommendations for refining the customization process.

Clothing-related suggestions for disability advocacy. Participants suggested incorporating customizable clothing and patterns that featured disability-related logos. For example, P1 wanted to have an avatar wearing a zebra-printed shirt and beret to advocate for rare disease month. Similarly, P4 suggested an explicit representation for communicating the experience of dyslexia through apparel or logos:

> *"[On clothing,] have the word dyslexia, but then have it jumbled up so people can see what it looks like when we try to read. Then, they'll be like, 'Whoa, that's not fun.' And we're like, 'Well, welcome to my hell.' Make it a joke, but also kind of be like, 'Hey, this is really what it feels like.' And then they can be like, 'Oh, now I see.'"*

Accessory-related suggestions for disability disclosure. Participants wanted to include assistive technology (e.g., wheelchairs, canes, crutches, hearing aids), an assortment of chronic-illness specific items (e.g., a brooch that says *"POTS"*, P6), a medical alert bracelet, and *"spoonie"* gear like a giant spoon, P1) to disclose their disabilities. Some participants (P2, P6) were interested in disability representations that floated above their avatars, such as an awareness flag or a dynamic energy bar that correlated with their energy level. However, P3 preferred more subtle accessories: *"I would do it with accessories, [but] I don't want a big sign saying, 'disabled' or a different color flashing over here that says 'invisible illness is no longer invisible.' But I would do it with subtle accessories. Something a little more real."*

Two other participants (P5, P9) were interested in representations of personal significance rather than using them to communicate with other users. For example, P9 used vibrant colors: *"It's a way that I can visually differentiate myself from a room full of other people. It's my way of not just indicating to others that this person's a little different, but it's also indicating to myself that I'm a little different."*

Meanwhile, P9 desired knee and elbow pads for personal symbolism:

> *"I really want to add knee and elbow pads. If you have ever gone roller skating, you need to put on knee and elbow pads, just in case you fall... The bipolar makes me swing really hard to the left and right. I get these mania phases and these depression phases that have a whiplash to them. And sometimes... I can get hurt or accidentally hurt others. So these pads on my knees and elbows would be a way to symbolize that if I do fall, I gotta make sure I'm protected. I don't fall too hard, and I can stand up again."*

While P5 wished to use glowing veins to represent chronic pain, they acknowledged that other users might not understand the disability-related symbolism: *"That would show things more, but that still wouldn't even show pain, because people are gonna look at that and just go like, 'cool.' They just see glowing things on your arm."*

Accessible avatar customization process suggestions. Five participants (P1, P2, P4, P5, P7) expressed interest in easier processes for importing and creating custom designs. P4 suggested: *"It'd be nice to have different options, like with different logos or different quotes that you want to put on shirts. It'd be nice to have a set-up so that you can do it pretty easily [because] I definitely don't have the coding experience to be able to go any further."*

Additionally, P5 wanted to minimize arm movement requirements due to Repetitive Strain Injury and shared ideas for optimizing user experiences through evolving technology:

> *"I could copy and paste it. That's my ideal customization because I don't like the menus. If you have the option of pressing a bunch of buttons, or just being able to think it and it appears on the page, why would anyone want to have all the billion options when they could do the exact same thing? It has occurred to me, though, like with the recent AI developments, where you can produce pictures, it seems like it's not too far away where they could just produce a 3D model using those systems. Like if there was a system where you could describe it, and it would generate one."*

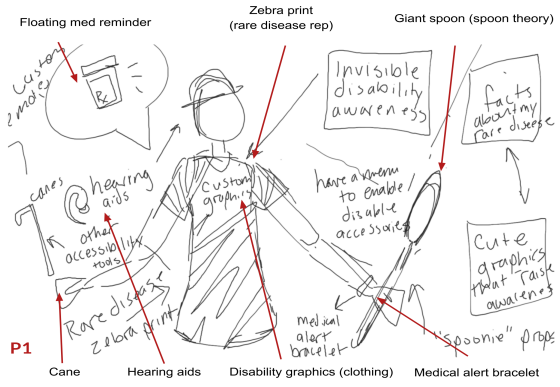

Figure 1: P1's Customization Suggestions

5 DISCUSSION

Avatar customization libraries decide *who* gets to express *what identity*, and current options do not enable the explicit expression of invisible disabilities. That said, disability disclosure preferences often vary by context and condition, a nuanced choice that becomes more pronounced with social VR embodiment and real-time immersion [4]. Mack et al. [8] explored contextual differences across digital gaming and social platforms such as Roblox and Snapchat, but did not explore embodied avatars. As acknowledged by P9, the engagement afforded by social VR, compared to digital social

media platforms, can greatly influence avatar perceptions. Since avatars are the predominant form of self-expression in social VR, it is imperative to ensure that people have just as much, if not more, flexibility in representing their identities as they do in non-virtual spaces. However, we recognize that designers must balance fostering creative and authentic self-expression with mitigating harm. Some participants expressed concerns about disclosing to strangers who do not share their disabilities, given perceived social stigmas. It is important to offer an easy-to-use toggle for disability representations so users can operate with the utmost autonomy in their avatar disclosure decisions.

At present, avatar design processes are complex. Customization platforms such as Ready Player Me [9] offer *"hundreds of options"* but are often inaccessible to people from non-technical backgrounds. To streamline the customization process, we suggest that avatar design processes eliminate the need for code, improving access for users from non-technical backgrounds. Further, taking inspiration from participant suggestions like the dynamic energy bar, we suggest that future avatar designs incorporate intuitive and universally applicable design conventions (e.g., traffic light color guidelines [11]), allowing users to effectively express themselves.

Given that we recruited from primarily U.S.-based organizations, we acknowledge the geographic limitations of this study and recognize the importance of situating findings in diverse cultural and socioeconomic contexts.

6 CONCLUSION

Avatars mediate interpersonal interactions between social VR users, but at present, no options exist for people to explicitly represent invisible disabilities. In this study, we explored the avatar customization preferences of people with invisible disabilities. Some were interested in the option to represent their disabilities through various avatar features (e.g., clothing, floating icons), and many expressed a need for an easily usable mechanism that could toggle disability representations on and off in different contexts. To our knowledge, this is the first study to capture the avatar representation wants and needs of social VR users with invisible disabilities. Broadly, our findings contribute to the ongoing conversation of designing with and for people with invisible disabilities.

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