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Avatar-Mediated Illness Disclosure and Health Advocacy in the Case of Ironmouse

Lucas K. Tang*

College of Osteopathic Medicine of the Pacific-Northwest, Western University of Health Sciences, Lebanon, OR 97355, USA

* Correspondence: Lucas.Tang@westernu.edu

Abstract: Virtual YouTubers, or VTubers, livestream through animated avatars, and some use the medium for health communication. There is substantial scholarship on topics of identity, authenticity, and fandom for VTubers, but little work describing the role of VTubers in health communication and advocacy. This paper examines how the medium of VTubing changes how illness is disclosed and communicated through analysis of the VTuber Ironmouse, who lives with common variable immunodeficiency (CVID), and campaigns for plasma donation and for the Immune Deficiency Foundation. This paper analyzes interviews and organizational materials documenting Ironmouse's experiences with CVID, and her use of her VTuber social media platform to engage in health communication and advocacy. The analysis finds that VTubing allows people with chronic illness and disability to separate discussion of their chronic illness from display of a physical identity, while giving them greater control on the timing and methods of discussion. Ironmouse's charity and advocacy efforts demonstrate that physical visibility is not necessary for chronic illness advocacy to facilitate public engagement. Analysis of Ironmouse in this paper suggests VTubing can offer a unique form of health communication and advocacy for people with chronic illness as mediums of communication change with evolving social media technologies.

Keywords: VTubers; avatars; health communication; disability; virtual persona; digital culture

1. Introduction

Virtual YouTubers, colloquially known as VTubers, are online entertainers that engage with audiences through virtual personas and an avatar controlled by motion tracking; unlike traditional broadcasters or livestreamers, the animated avatar used by VTubers creates an additional layer of separation between the person producing digital content and the identity presented to audiences. English scholarship on VTubers is scarce due to their recent rise in popularity in the past decade in Japan and recently rising popularity in the West in the past few years. Scholarship has focused on analyzing fandom phenomenon, investigating VTubers as identity experiments, or studying them as a new kind of creator business (Bredikhina 2020; Bredikhina and Giard 2022; Miranda et al. 2024; Schmieder 2024; Tang 2025; Wan and Lu 2024; Wang 2024; Wei and Tyson 2025; Zhao et al. 2025). This paper serves as a critical overview to take a first look into VTubers as health communicators through the case of Ironmouse, and her representation of chronic illness; asking how the technical and social features of avatar-mediated livestreaming affect how chronic illnesses are discussed, embodied, and communicated, to inform how VTubers in particular change digital health communication and advocacy in our modern era. This paper provides a critical overview rather than a qualitative analysis of Ironmouse's work.

Ironmouse is a Puerto Rican VTuber and livestreamer in the platform Twitch.tv who lives with common variable immunodeficiency (CVID). CVID is a primary immunodeficiency marked by low levels of antibodies and a weakened immune system. The main treatment for CVID is immunoglobulin replacement therapy, which uses antibodies extracted from pooled donated human plasma (Immune Deficiency Foundation n.d.). In addition to her regular work as an entertainer, Ironmouse has also done significant work to promote plasma donation and serves as a spokesperson for the Immune Deficiency Foundation, the largest primary immunodeficiency patient advocacy group in the United States (Immune Deficiency Foundation 2024a, 2024b). Ironmouse began livestreaming in 2017 (Amos 2022). In an interview with the Washington Post, Ironmouse stated she started livestreaming as VTuber keeping her real identity private because she was lonely and nervous about appearing on camera, after CVID had ended a prospective career in opera (Grayson 2022).

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Beginning her career on the streaming platform YouNow and using a commercially available avatar, Ironmouse moved to Twitch in 2019 and started using an originally designed persona that she maintains to this day.

Her visibility grew in 2022 when after a 31-day subathon (a portmanteau of "streaming marathon" where viewers extend the length of the broadcast by paying for subscriptions), Ironmouse earned nearly 172,000 subscriptions (Grayson 2022). Ironmouse won Content Creator of the Year at the 2023 Game Awards (Silberling 2023). In 2024, the Immune Deficiency Foundation (2024b) awarded Ironmouse its Plasma Hero Award. In September 2024, Ironmouse set a Twitch record for subscribers during a month-long subathon, where half of the proceeds were donated to the Immune Deficiency Foundation (Horetski 2024). Throughout her career, Ironmouse has been a vocal advocate for people with CVID, sharing her own stories and experiences, and using her platform to raise awareness and increase efforts for CVID research and treatment (Immune Deficiency Foundation 2024c). As a prominent member of the VTuber community, analyzing Ironmouse as a health communicator and advocate in the context of her position as a VTuber can inform the role VTubers can play as health advocates as their popularity continues to grow.

For people with chronic illness, visibility of their condition and its impacts on daily living, and access to information play important roles. Disability studies on people with chronic illness provides tools for discussing those needs for visibility and access (Goering 2015). VTubers remain an underexplored topic in disability studies and can offer insight into how visibility and access are shaped by different forms of representation. Goffman (1963) separates people with visibly obvious differences from people with concealed differences that have to manage disclosure. For people with chronic illnesses that are often invisible, a virtual avatar may bring more comfort to disclosure without fear of stigma associated with their real identity. Ironmouse provides a valuable example for analysis with disability studies, as a person with chronic illness that uses her platform as a VTuber to increase visibility and access. This can inform how the VTuber as and the virtual avatar change visibility and access for people with chronic illness compared to traditional representations in media and broadcasting.

2. Literature Overview and Theoretical Framework

2.1 VTubers, Virtual Influencers, and Audiences

Research on VTubers has been growing since 2020 when their popularity gained more traction outside of Japan, but this subfield is still considered limited and emerging (Tang 2025; Wang 2024). One branch of research into VTubers examines identity and self-presentation because of the freedom of separation or lack thereof between the virtual persona and the real person behind it. In an interview study, Lu et al. (2021) reports that virtual avatars lead to different audience expectations and interpretations of behaviour compared to livestreamers that use their real likeness. Bredikhina and Giard (2022) describe VTubing as a masquerade that gives VTubers more independence than their real life identities. Wan and Lu (2024) examined how flexibility and modifiability of a virtual avatar impacted how livestreamers chose to present themselves. Chen and Hu (2025) studied the phenomenon they called "virtual breaking," analyzing 300 videos from 64 VTuber accounts to identify when, how, and why VTubers choose to reveal their real identity. The literature shows that although disclosure for VTubers has been explored, an understanding of what role chronic illness and resulting vulnerabilities in disclosure may play is less clear.

Another topic that has been documented is the authenticity and parasocial fan attachment. Schmieder (2024) examined why VTubers prefer to keep their identities private. They argued that VTubers can still maintain authenticity even when their real identities are unknown. Furthermore, they claim that VTubers challenge the sociological habit of equating authenticity to being able to see the other person's real face. In contrast, Tang (2025) found from their study of VTubers in China that well-designed virtual personas are deemed authentic by viewers. Research describing parasocial fan attachment studies the different fan communities that have formed in response to VTubers. Horton and Wohl (1956) coined the term "parasocial" to describe the one-sided bond that forms between a spectator and a performer, which may inform how viewers respond to the disclosure choices of VTubers. Berryman, Abidin, and Leaver (2021) contextualize parasocial relationships and VTubers by describing how fans formed non-reciprocated relationships with virtual idols and other online influencers before VTubers were popularized. Wang (2024) studied the publicly traded entertainment agency Cover Corporation and their VTuber department, Hololive, to identify how real-time fan engagement during livestreams shapes the performance of a VTuber. Hu and Ge (2025) identified how VTubers can blend a human performance with the appeal of a fictional character to create intimacy with fans. The literature may give context to how Ironmouse is able to be seen as authentic and form parasocial relationships with fans as a VTuber to spread awareness of CVID and be an effective communicator and advocate.

2.2 Chronic Illness, Identity, and Disability

Chronic illness, such as CVID, has been shown to disrupt how individuals understand and perceive their identity. Sociologist and social psychologist Erving Goffman (1959) describes one's presentation of self as a form of impression management where individuals try to control how others see and perceive them. In later work, Goffman (1963) separated people with visible or invisible differences and how information or disclosure is managed. For people with CVID, such as Ironmouse, this invisible condition allows greater influence over what they choose to disclose and how they present themselves to others. Connecting disclosure to self-identity, Charmaz's (1983) study of patients with chronic illness describes how patients will have deteriorating self-images of their past selves without forming a new self-identity of equal value. This may explain Ironmouse's description of VTubing and the control over keeping her personal life private, and how that led to Ironmouse regaining parts of her identity (Grayson 2022).

Furthermore, disability studies has developed tools for understanding visibility and access, for both visible disabilities, such as paraplegia, and invisible disabilities, such as CVID. The social model of disability describes how institutional and environmental barriers that create conditions of diminished ability are what defines disability (Oliver 2013). Goering (2015) describes applying the social model of disability to chronic illness because of how chronic illness changes how a person can interact with their environment and engage in society. Garland-Thomson (2009) addresses visibility from the angle of staring in social relationships, arguing that a broader range of bodies should be seen in public life to reduce the unknown that leads people to stare. On the other hand, Young (2014) argues against needing to disclose or present disability, criticizing the practice of displaying people with disabilities as inspiration for people without disabilities. Sannon et al. (2023) connects these ideas together by describing how although visibility

is essential to disability activism on social media, activists have to balance dealing with stigma, suppression by algorithms, and online harassment. In Ironmouse's case, her online digital platform as a VTuber offers her increased visibility to discuss and advocate for CVID. The literature has not fully dissected how the creation of disability through social barriers or visibility of disability are impacted by virtual personas. Ironmouse therefore offers an interesting case of study.

2.3 Disclosure, Avatars, and Health Influencers

Ironmouse's disclosure and discussion of her experiences with CVID and CVID in general were choices made by her. Petronio's (2002) communication privacy management theory describes how people decide what information they keep private or disclose to others based on rules-based boundaries. This offers an interpretation for how Ironmouse manages the disclosure of her health information. It is possible that having a virtual avatar, setting a rule to only use that virtual avatar and not present her real person, and livestreaming as a VTuber shapes how Ironmouse manages those decisions around disclosure. This is supported by Yee and Bailenson's (2007) report that how an individual represents themselves online can influence their behavior. This literature gives an interpretation of Ironmouse managing her disclosure and discussion of CVID through her character as Ironmouse; the veil of a virtual avatar and the presentation of herself through a virtual identity lets Ironmouse have greater control of how she tells her story.

3. Methods

This paper is a critical overview of Ironmouse as a health communicator and advocate in the context of her position as a VTuber. This paper is not an analysis of the content that Ironmouse livestreams and does not conduct qualitative analysis of how she discloses or discusses CVID in particular livestreams. Ironmouse is the individual VTuber that analysis in this paper will be focused on because she is a highly visible Vtuber with a large and continuous public record, including her reasons for using a virtual avatar and being a VTuber, and documented information about her advocacy and charity efforts. Searches were conducted between May 2026 and August 2026, and supplemented in October 2026, using Google Search and through relevant organizational and news websites, for combinations of Ironmouse's name with relevant terms, including, CVID, plasma, avatar, and subathon. Pieces were included based on dates ranging from her first marathon livestream in February 2022 until her largest Immune Deficiency Foundation charity in July 2025 to best represent the core aspects of Ironmouse's health communication and advocacy efforts. Fourteen sources were retained (Table 1). Exclusion criteria were sources based on speculation, including fan wikis, ambiguous health blogs, and unsourced media commentaries. Analysis concerns only what Ironmouse has publicly said and there are no speculations about her real life identity.

Table 1. Sources Identified in the Case Study of Ironmouse's Health Communication and Advocacy

Source	Type	Date	Used for
Grayson (2022), Washington Post	Interview/profile	Apr 20, 2022	Avatar, illness, subathon, income, pity, self-recovery
Amos (2022)	Interview/profile	Jul 22, 2022	Early concealment, avatar as privacy, software origin
Hill (2022)	News report with her statements	Sep 6, 2022	First Cyclethon and her reaction
Amos (2023)	Interview/profile	Sep 6, 2023	Partnership with CDawgVA; disclosure
Glaze (2025)	Report on podcast interview	Jan 23, 2025	Face reveal, privacy, doxxing fears
Ironmouse (2025), post on X	Primary: her own post	Mar 2, 2025	Response to claims that her illness is a gimmick
Immune Deficiency Foundation (2024a)	Press release	Jun 13, 2024	Documentary, conference, IDF description of her
Immune Deficiency Foundation (2024b)	Press release	Jul 11, 2024	Awards, scholarships, reach
Immune Deficiency Foundation (2024c)	Organizational interview/profile	Aug 12, 2024	CVID, disclosure, medical experiences, plasma advocacy, relationship with the IDF
Immune Deficiency Foundation (n.d.)	Organizational information page	n.d.	Definitions of CVID and treatment
Lada (2025), Siliconera	News report	Jul 23, 2025	July 2025 fundraising total and broader charitable activity
Silberling (2023), TechCrunch	News report	Dec 8, 2023	Game Awards win
Horetski (2024)	News report	Oct 16, 2024	September 2024 subathon record
Bennet (2025)	News report	Mar 4, 2025	Claims that her illness is a gimmick; early concealment

4. Results and Discussion

4.1 Disclosure Without Display

Ironmouse told the Washington Post that she began livestreaming because she was feeling lonely, but her chronic illness with CVID and personal circumstances led her to be nervous about showing her real face online, so she started using a virtual avatar at the suggestion of a friend (Grayson 2022). Ironmouse also told the Post that having a chronic illness led to her losing parts of her identity:

> I think with a lot of people who go through the motions of having a disease, sometimes you kind of forget who you are and lose yourself in the process," she said. "I kind of became a zombie in my life. But with streaming, I feel like slowly I've been regaining pieces of me again and finding myself. I don't feel like a zombie anymore. I feel more alive. (Grayson 2022)

A loss of a sense of self in people with chronic illness has been previously described by Charmaz (1983), who discussed the psychological suffering of patients with chronic illness when their illness restricts how they can live their lives. Ironmouse's description of her experience with CVID aligns with this report and gives more context to why she started livestreaming and became a VTuber. Having a chronic illness, a longitudinal condition that follows someone throughout all aspects of their life, has broad consequences. Per Charmaz's (1983) discussion, these impacts can chip away at a person with time. When Ironmouse describes being able to find herself again as a VTuber and feeling more alive, this explains her motivations for becoming and maintaining her lifestyle as a VTuber.

This theme is consistent throughout her interviews where Ironmouse has stated that regularly taking on the VTuber identity of "Ironmouse" allows her to feel more in touch with herself and regain pieces of her identity that CVID had taken away. In a different interview, Ironmouse stated:

> For me, I've never felt more myself in my life. I've never felt more independent. Ironmouse brought the best in me and I'm starting to feel more comfortable with myself. (Amos 2022)

Ironmouse's reflections about her livestreaming career and her VTuber persona demonstrates that the virtual avatar may act as both a shield and means of regaining parts of her identity that CVID had eroded away. This can be interpreted as describing how Ironmouse chooses to disclose her history and experiences with CVID because the freedom and independence that being a VTuber may act as protections that lessens the perceived cons of disclosure. In other words, this empowerment offered by taking on a virtual persona and displaying herself as a VTuber may impact how Ironmouse discloses information relevant to her CVID. This freedom and regaining of her sense of self that Ironmouse describes may be an example of prior literature discussing how individual behaviour conforms to how someone represents themselves online (Yee and Bailenson 2007). Under this interpretation, Ironmouse's self-representation as a VTuber and the character of Ironmouse that she uses to represent herself, influences her behaviour and lets her be more comfortable with disclosing and discussing CVID.

The purposefully constructed virtual persona is unique to VTubing. All livestreamers and entertainers in general take up a persona that is not completely representative of their true self in front of audiences. This aligns with Goffman's (1959) discussion of self-presentation that differs depending on social context. But VTubers craft an explicitly fake persona, where a character is designed and roleplayed, and what facts or items are true to the VTuber's real identity are left to individual discretion. In Ironmouse's case, she plays a demon character with a backstory formed initially as a joke her community picked up and grew from there (Grayson 2022). Of note, Ironmouse further described in a different interview that the character of "Ironmouse," is a more complete and chaotic version of herself (Amos 2022). As a health communicator representing herself with a crafted character, Ironmouse does not have to make her chronic illness the focus of her content creation. The Immune Deficiency Foundation (2024c) reports that she speaks about CVID from time to time for educational purposes and to increase awareness, or to explain to her viewers why she may not feel well and need to take a break from livestreaming. This indicates that Ironmouse has freedom of choice over when to discuss CVID.

Additionally, Ironmouse's virtual persona also speaks to what Young (2014) describes as the Inspiration Trope. Young describes how people with disabilities are frequently presented through narratives of overcoming adversity for the sake of better reception from audiences without disability. This could be a reasonable concern for Ironmouse who chooses how she presents herself through her activities as a VTuber. Ironmouse has not explicitly discussed being for or against serving as an inspirational figure. However, in her statements, Ironmouse has deliberately resisted this framing, stating she disliked being treated like a "...porcelain doll…" and did not want people to pity her (Grayson 2022). As a VTuber, Ironmouse has more control over her representation by deciding when she shows and discusses her CVID. This control over the frequency and modality of Ironmouse's discussion of her CVID may allow her to advocate for CVID without the typical risk of falling under the Inspiration Trope.

This warrants the discussion that having a virtual avatar may change how Ironmouse discloses her CVID. Goffman (1963) argues that disclosure changes depending on how one is able to hide their condition or not, including the who, when, and how of disclosure. Although immunodeficiencies are not immediately obvious, consequences of it can be. That means that under Goffman's model, CVID possibly impacts Ironmouse's decisions surrounding disclosure. Ironmouse described to the Washington Post that she is frequently bedridden and on supplemental oxygen (Grayson 2022). In that same interview, Ironmouse shared that her health limited how long she could livestream for and when she could start her livestreams; longer livestreams and marathons were only possible after her income as a VTuber afforded her better care (Grayson 2022). In her later interview with the Immune Deficiency Foundation (2024c), "From Bedridden to Beloved: Ironmouse's Journey as a Plasma Advocate," Ironmouse told them that early in her VTuber career, viewers could hear medical devices in the background. She stated that she worried about how her audience members would react to learning about her CVID; Ironmouse feared being treated as someone abnormal. Ironmouse's CVID had impacts on her activity as a VTuber. But the lack of immediate visibility of her CVID that being a VTuber offers may significantly change Ironmouse's presentation and discussion of CVID compared to traditional, in-person presenters.

In that same interview with the Immune Deficiency Foundation (2024c), Ironmouse stated she chose to be honest about her condition to be true to herself to her viewers. As a VTuber, Ironmouse was able to conceal the physical aspects of her CVID, including her body and medical equipment. This allowed Ironmouse to make intentional choices about disclosing her CVID separate

from having to show it physically. Ironmouse later stated that an intentional choice of disclosure was one of the things that inspired her to pursue advocacy for CVID; stating, "I didn't realize how talking about it could raise awareness," (Immune Deficiency Foundation 2024c). This suggests that the way Ironmouse's disclosure may have been affected by the presentation of her CVID and may have also impacted the way she conducts her advocacy. In other words, being able to exercise this control over disclosure of her condition may have been a source of empowerment along Ironmouse's advocacy journey.

On the other hand, the VTuber avatar does not hide all parts of Ironmouse's body. Her high-pitched and distinctive voice is a product of her CVID:

> "I've had a fluctuating voice for a long time," she said, attributing it to throat problems. "I've had issues in my personal life where people don't take me seriously. They're like, 'Little girl, can I talk to your mom?' I've had a couple streamers find my voice strange, but then I talked to them in private and they're like, 'Holy s---, it's real!' " (Grayson 2022).

Additionally, her medical equipment produces an obvious sound in the background of her livestreams. The physical burden of her CVID on her body limits how long she can livestream for. Nonetheless, she is able to utilize her experiences with CVID and act as an advocate and increase awareness of CVID through discussion of how immune deficiency impacts individuals and their families, educating on treatments, such as immunoglobulin replacement therapy, and Ironmouse has frequently promoted the benefits of plasma donation. Not having her CVID physically perceived and standing behind her VTuber avatar still allows Ironmouse to share her story. Ironmouse was nonetheless able to act as a health communicator and participate in health advocacy surrounding CVID.

Being a VTuber empowers Ironmouse by allowing her to regain control of aspects of her life despite her fragile, physical body. Disability studies into activism online have raised concerns about the importance of being publicly visible in challenging stigmas and how purely digital activities create limits in audiences only meeting illness as information (Sannon et al. 2023). However, not being a physical presence still allows Ironmouse to share her experiences and advocate for CVID. Throughout her career, Ironmouse has been open about her life with CVID, including implications, adverse health effects, and different treatments (Immune Deficiency Foundation 2024c). By raising awareness of CVID, the Immune Deficiency Foundation has stated that Ironmouse has increased knowledge of the organization's efforts and demonstrated the importance of plasma donation to a younger generation, leading to increased plasma donation rates. Her charity work has made significant contributions to CVID research and treatment; raising $1.07 million USD in April of 2025 with another digital celebrity, CDawgVA, and raising $1 million USD in a separate campaign in July 2025 (Lada 2025). Without showing her physical self, Ironmouse as a VTuber kept the ability to tell her story, teach others as a health communicator, and increase awareness and efforts towards CVID as a health advocate. A selective display and disclosure of her condition that being a VTuber allowed shows that VTubing as a medium has the potential to empower individuals with chronic illness, and increase discussion and awareness around chronic illness and disability.

4.2 Implications and Future Directions

Analysis of Ironmouse as a case shows that the medium of VTubing allows people with chronic illness and disability to pursue health communication and advocacy while keeping their real identities private; Ironmouse has described for herself how having a virtual avatar is protective, and her career has significantly increased awareness of CVID online and mobilized her audience to donate plasma and to charity. These findings suggest that VTubing may provide useful opportunities for health communication, but do not suggest the effects on audiences and have limited generalizability to other digital content creators.

These findings on Ironmouse suggest that a lack of physical visibility may not hinder advocacy related to chronic illness. Ironmouse is able to share her experiences and discuss CVID in depth with her public platform without needing to make the same sacrifices others who use their real identity might need to make, due to not showing her physical identity. Ironmouse's work in health communication and advocacy show that a digital content creator's personal experiences with chronic illness and disability can draw attention to conditions that are usually not as visible. To that extent, Ironmouse has also demonstrated through her charity efforts that audiences can engage with discussions of chronic illness without a need for engaging with the patient's physical body. For people with chronic illness who have otherwise invisible presentations or find it challenging to make their condition easily visible, Ironmouse is one example showing that health communication and advocacy can still be pursued. This demonstrates that people with chronic illness and disability can still have their conditions be recognized through speech and narratives without being forced to display or disclose physical evidence of illness.

Future study should look deeper into how health advocacy is interpreted by audiences and what differences arise between traditional health communication with in-person advocates and when information is presented through a virtual avatar, such as, effects on credibility, vulnerability, and trust. Ironmouse's case shows that audiences will respond to discussions of chronic illness even when they cannot visualize that directly with the patient's body. However, this analysis does not show what impacts Ironmouse's virtual avatar had on viewer reception. For example, qualitative interview studies or surveys comparing audience reception between livestreamers who show their real identity and VTubers could address these questions. More research into VTubers as health communicators and advocates would be beneficial for identifying modalities for how people with chronic illness can share their experiences and be advocates without having to face the stigma that may come with displaying their physical identity.

5. Conclusion

Ironmouse's case offers a change in how the literature can think about health communication in virtual environments as social media continues to grow and evolve. Traditionally, health communication and advocacy has been done by people who rest their credibility on showing their physical identity, such as physicians or influencers with publicly known chronic illnesses. VTubing allows for disclosure and discussion of chronic illness while giving the speaker greater control of how they display and represent themselves. This can be important for people with chronic illnesses that are invisible or not clearly visible because Ironmouse shows that disclosure of experiences with chronic illness does not require disclosure of personal identity. Ironmouse also demonstrates that VTubing and using a virtual avatar does not hinder health communication and advocacy. Her discussion of CVID has successfully

increased CVID awareness alongside significant charity efforts. As an emerging modality in digital social media, VTubing offers a unique avenue for people with chronic illness and disability to work as health communicators and advocates by separating representation of illness from having to display their physical identity. Future research should examine the impacts of health communication and advocacy with a virtual persona compared to traditional livestreaming and broadcasting with physical identities.

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