Losing “The Look”: In/visible Illness Throughout HIV/AIDS and COVID-19

Introduction

The COVID-19 pandemic and HIV epidemic have had disproportionate impacts on various vulnerable and marginalized groups. The HIV epidemic has (had) disproportionate impacts on cisgender men who have sex with men (MSM) (Centers for Disease Control and Prevention [CDC] 2024a), transgender people (CDC 2024b), IV drug users (CDC 2022), and Black and Latino communities (CDC 2024C). People living with HIV (PLWH) are among the groups most impacted by the COVID-19 pandemic (Spinelli et al. 2022). As a group at higher risk of severe COVID-19 infections (Spinelli et al. 2022) and long COVID-19 (Barth et al. 2024), long-term survivors (LTS) of HIV have experienced both of the epi/pandemics as vulnerable populations.

Previous studies have shown that the COVID-19 pandemic induced unique struggles among PLWH, which involved isolation and loneliness. HIV-positive MSM faced greater rates of pre-pandemic isolation (Marziali et al. 2021), and, some studies have found that in comparison to all HIV-positive adults, older HIV-positive adults reported higher rates of loneliness (Greene et al. 2017). LTS who lived through the earlier days of the HIV/AIDS epidemic may be uniquely susceptible to this, as Owen and Catalan (2012) found that AIDS-related loss in early adulthood deprived LTS of social networks and people they would have aged with. When the COVID-19 pandemic started, HIV-positive MSM’s isolation increased and they lost social and sexual connections, including decreased engagement with the gay community (Cascalheira et al. 2022). For some, this was exacerbated by precautions taken due to their positive status and consequential COVID-19 infection concerns.

In addition to isolation, COVID-19 was also associated with increases in anxiety and financial struggle among PLWH (Cascalheira et al. 2022). Pantelic et al (2021) found that COVID-19 triggered painful memories for PLWH who lived through the earlier days of the HIV/AIDS epidemic. However, studies have also shown a sense of resilience and preparedness among PLWH due to their experience with the HIV/AIDS epidemic (Ballivan et al. 2020; Diaz-Martinez et al. 2022; Pantelic et al. 2021; Pantelic et al. 2022; Quinn et al. 2020). One study directly comparing people with and without HIV found that PLWH showed less COVID-19 anxiety and more resilience than people without HIV (Diaz-Martinez et al. 2022). PLWH's experiences with COVID-19 have entailed unique forms of struggle and coping.

To my knowledge, no previous research has examined the shift of these experiences in the more recent stages of the ongoing COVID-19 pandemic, as public attention and protections wane. LTS may offer valuable perspectives on collective response as they reckon with HIV and continue to face high risk for severe COVID-19 amid a sense of post-pandemic normalcy. However, pandemic experiences among disabled people have been shown to be diverse (Mietola and Ahonen 2021; Nicholls et al. 2024), and one study on immunocompromised people's social participation post-vaccine found results with high variability (Heesen et al. 2022). In-depth semi-structured interviews may allow participants to articulate their perceptions and experiences with the greatest level of accuracy. Instead of attempting to impose strict measures of proximity to dominant COVID-19 narratives/experiences, or PLWH's early COVID-19 experiences, the open-ended nature of the interview allows participants to maintain complex relationships with this pandemic and the grander shift towards normalcy. In this project, I ask: What are the social experiences of long-term survivors of HIV amid the HIV and COVID-19 epi/pandemics? How do they make sense of the collective response to these two epi/pandemics?

Methods

This study uses a constructivist grounded theory approach to answer these questions. Between June and August 2024, I conducted ten in-depth interviews with LTS of HIV. Participants were recruited through gatekeeper recruitment via local and national organizations involved with PLWH, snowball sampling, and distribution of flyers via X (Twitter) and at Brooklyn Pride. This study's eligibility criteria were: (1) Acquired HIV in the 80s, 90s, or early 2000s; (2) Was 18 or older when acquired HIV; (3) Speaks English fluently; and (4) Lives in New York City. Participant diagnosis years ranged from 1986 to 2008. Their ages ranged from 57 to 72, with a mean age of 64. Participants identified as Black (n=5), White (n=3), and White-passing (n=2). The majority of participants were queer (n=7), including cisgender gay men (n=5) and trans women (n=2). The remaining participants were cisgender heterosexual women (n=2) and men (n=1).

The study was initially advertised as uncompensated, and three uncompensated interviews were conducted. However, after challenges in finding respondents, I started to provide compensation. This was done to attract more participants and ensure that my sample included people who could not afford to spend their time uncompensated. Seven interviewees were compensated $50 through cash or a banking app (Venmo, Paypal) at the end of each interview.

Participants underwent a brief screening survey over the phone, using a Google Voice number. For eligible participants, this was followed by interviews in person or virtually over Google Meet. Interviews were audio recorded and ranged from 47 minutes to 147 minutes, with a mean length of 97 minutes. After interviews were completed, I recorded a brief respondent overview where I took note of anything I thought was important. Interviews were then transcribed using Otter.ai and corrected while I took notes. The transcripts were analyzed with a

grounded theory analytic approach using ATLAS.ti. Transcripts were line-by-line coded, and patterns among the line-by-line codes were grouped together, and gradually built into theories, supplemented by other studies and texts. The present study was approved by the Institutional Review Board at Barnard College and participants gave informed consent for study activities.

Positionality statement

I am a transgender person who is usually identified as a masculine lesbian and/or non-binary/transgender person by others, which likely made LGBTQ participants disclose more details to me while also limiting explanations that they felt weren't needed. Participants often spoke of a shared community with me, and sometimes noted the importance that my generation of LGBTQ people learned about their experiences. To minimize the amount of information that was left unspoken, I encouraged participants to share as much detail as possible and clarified that I may ask seemingly obvious questions because their words were the data for the project. On the flip side, my LGBTQ presentation may have made some cisgender heterosexual participants hesitant to share any homophobic sentiment they (once) had, though one participant was open about previous HIV/AIDS misconceptions, and another openly blamed queer people for the ongoing nature of the HIV/AIDS epidemic. During the interviews and within my respondent memos I tried to take note of anything that felt influenced by my LGBTQ identity.

I wore a mask when I conducted in-person interviews which likely influenced participants' statements about the COVID-19 pandemic and masking. However, I tried to limit this as much as possible by enthusiastically affirming all interviewees' views—particulalry when it seemed they were censoring themselves because of me—and explaining that there was no judgment or right answers before certain questions. My personal COVID-19 cautiousness means that I have extensive knowledge about COVID-19, "COVID conscious/cautious" online

communities, and the experiences of some immunocompromised people since I have an immunocompromised loved one. I got COVID-19 as I conducted these interviews, which meant that I also had immediate reference of a (long) COVID-19 experience during my interviews. I also had a reference to the experience of being ill and attempting to fix a relatively new illness with no established medications, which I used and considered in my interviews. However, this meant that I managed others' misconceptions, theories, and unsolicited advice about my illness during interviews, such as inquiry into my immune system and diet. Managing this as I dealt with health issues (such as fatigue) after my COVID-19 infection might have in turn influenced my approach towards participants, though I made a conscious effort not to.

Lastly, as White student at an elite college, I worked to demonstrate my belief in participants' authority over their own experiences and their meanings. At the beginning of the interviews, I asked participants to tell me a little about themselves rather than survey questions, so that they could let me know what they felt to be most important to their experiences. I inquired about these identities throughout the interview when they seemed potentially relevant. Generally throughout the interviews, I remained conscientious to follow their lead and reaffirm their beliefs about both HIV/AIDS and COVID-19 without explicitly building on them.

Findings

HIV

During the earlier days of the HIV epidemic, participants often performed threat assessments based on the presence of AIDS(/HIV) in their loved ones and surrounding communities. Participants who witnessed many others around them with HIV/AIDS—particularly AIDS—were often moved to view themselves as vulnerable and take

steps such as preventive measures and testing. This sometimes took the form of rumors in queer social spheres, visibly ill people on the street, and close loved ones testing positive or getting ill. The sight of ill people on the streets and in hospitals was talked about extensively and often had a significant effect on those witnessing. One participant explained that he went to get tested for HIV simply because of the widespread visible suffering throughout his community. Another participant called it "the look" among his friends:

> "[People who were visibly ill were] just a constant reminder. And as it more and more was centered on the gay community, it became very creepy, you know. It became a case of, you don't know where it is or how you get it and what you should do to protect yourself."

Proximity and visibility were often key to sensing this threat, especially in the absence of public health information. One participant was warned early on by a doctor friend that there was a disease spreading around but did not feel threatened by HIV/AIDS despite being a gay man in an epicenter. He attributed this to being in a (mostly monogamous) long-term partnership, not living in the queer neighborhoods of New York City, and, not witnessing visible signs of AIDS—one of his friends with HIV killed himself while he was still "healthy," and the other was "still healthy…[with] just a little dementia and stuff like that." Another participant was very young when HIV/AIDS started and initially witnessed it through media, which did not elicit any sense of threat. For these participants, diagnosis in a person close to them is what suddenly brought HIV/AIDS to their "doorstep."

A visible absence of HIV/AIDS might have reflected an actual absence, but often, especially for those in more affected communities, it was a combination of invisible illness and social processes. Some affected communities decided to invisibilize HIV/AIDS and those

affected before it invisibilized them, creating cultures of denial and/or silence. Some participants believed this was done out of fear of HIV/AIDS, especially in the face of uncertainty and government inaction. Others noted that many queer people feared a return to repression, especially so soon after gaining widespread visibility:

> "And more often than not, people would make fun of me when I tried to give them a condom, because we had just, just not so long ago, earned that right to be out about our sexuality. So there were people were like, I'm not going back in the closet, I'm not gonna stop having gay sex because of this thing that we don't know anything about. I actually got spat at a couple a couple times, and made fun of. And I had the condoms thrown back at me, not everyone was that way. But it was, it was, it was about a 50/50 there where half of the community was worried about it, half the community was like, fuck this, we're gonna just keep going as we've just finally got to come out [unintelligible]."

Beyond these fears particular to the communities most affected by HIV/AIDS, one participant found it reminiscent of other responses to tragedy, noting similarities between a denial culture he was immersed in and the cultural attempts to forget Vietnam.

This invisibilizing work was done through a bodybuilding culture and the social exile of those who marked the presence of HIV/AIDS in body or word. Two participants noted that many gay men started to bodybuild in an attempt to seem healthy "beyond reproach." One participant described this in the environment in South Beach, where he moved to after his diagnosis, which had a lively gay culture: "It was like the AIDS graveyard. But people weren't dying, and they were—they looked fabulous on the beach. Everybody looked, like, amazing." Simultaneously, those who were ill and marked it, along with their associates, were socially abandoned. One participant told his friends and partner after he tested positive, only for them to all abandon him.

He stated that if they were known to associate with a positive person, they would have been rejected by the queer community, losing access to queer social spheres. This kind of culture led people—including the participant's loved ones—to avoid getting tested and treated: "...they died out of fear. And…because they didn't want to get rejected from the community." Denial was so all-consuming for some that the participant who went to South Beach spent the last few minutes of his interview bewildered, emphasizing the questions our interview raised, like why he never saw or talked about sick/dying people:

> "that was really amazing that in Miami Beach, we just…did not talk about it. And I didn't see people dying and whatever, but that's what I went there for, right? That's what I was looking for. Did I—now, then the question is, did I plan it that way, or did—was I so in denial, I didn't, it was happening around me, but I didn't see it? Or, you know, did it actually—was it actually like that? Was just everybody just slipp[ing] away quietly? Or was it like some agreement in the…collective conscience of the community? Was it just there? You know, like, did we all have this agreement that you just *pops tongue* [wordlessly disappear]?"

Alternatively, some took their proximity to the illness—especially the visible signs of AIDS that one participant called "the look"—and confronted it through self/community care, as well as HIV/AIDS advocacy. Multiple participants spent much of their time—especially since they had to go on disability to receive treatment—in activism with ACT UP!. Participants noted numerous kinds of support towards others affected by HIV/AIDS: caring for partners up until their deaths; visiting hospitalized friends; bringing meals to people's hospital beds when nurses left them outside the door; caring for ill/dead people's pets; paying people's bills; passing out condoms at pride (even when they were thrown back); standing outside queer spaces talking

about their positive status and educating others; and compiling all of the latest research and disseminating it. This was not very present for cisgender heterosexual participants, who often lacked pre-established community spaces and networks of affected people. While queer participants noted the fragmentation that HIV/AIDS caused individually and societally, multiple participants also highlighted the resulting unity, whether in denial or in struggle, care, and advocacy.

COVID

In the earlier days of the COVID-19 pandemic, LTS of HIV often felt intense fear and endured painful memories resurfacing. Multiple participants said that COVID-19 induced PTSD from the HIV epidemic, and one participant noted that all of his LTS friends felt the same way. This participant felt that the COVID-19 pandemic has given people a greater understanding of what HIV-affected communities went through, though participants were quite varied in their comparisons of the pandemics to one another. Some saw similarities between the two health crises in initial government inaction, isolation, and fear.

The more universal isolation throughout COVID-19 was often—and sometimes continued to be at the time of the interview—compounded by their HIV-positive status. One participant lost his career after having to go on disability and then started working off the books, but lost his position when COVID-19 started and everything went remote. For another, COVID-19 served as an obstacle to rebuilding the relationships he had previously lost from internalized stigma and shame. Another lost hard-earned romantic and sexual relationships to COVID-19 restrictions and then struggled to find new connections because of HIV stigma. Multiple participants took intense precautions due to their HIV-positive (and sometimes immunocompromised) status(es), which thoroughly isolated them and harmed their mental

health. Most of those participants loosened at least somewhat as COVID-19 guidelines relaxed—though usually not as fast as the general population, and often not to the point of zero precaution. One immunocompromised participant continued to take extensive precautions, resulting in intense social isolation in the current state of the pandemic:

> "…yes, I go in the neighborhood. And if it's not too crowded, I go in. But my guard is, is still up…COVID is still [threatening], for me—it's probably because of my preexisting condition and my age. I'm—it scares me. It still scares—it's still very real. And I, as I said, I can't, there's a lot of [things I want to do]—I can't do it. And the isolation, that's why I spend so much time in my, my books or my authors."

This participant mentioned a friend who is a LTS, emphasizing that he and his friend cannot take the same risks as other people. Multiple participants who did not take the same level of precaution voiced similar sentiments that they feared suffering more alongside their positive status.

Participants saw differences between HIV/AIDS and COVID-19 in COVID-19's lack of stigma, lower severity, wide-spanning effects, and government initiatives. Though there was initial silence and inaction towards COVID-19 on the part of Donald Trump (Shabad 2021), as noted by a few, there were still restrictions implemented relatively soon in comparison to the years-long government silence about HIV/AIDS (Bennington-Castro 2023). COVID-19 was also not transmitted via stigmatized (or "intimate" according to participants) means, nor consequently concentrated within stigmatized groups. The airborne transmission of SARS-CoV-2 meant that the threat was widely (though not evenly) distributed, and the widespread (though uneven) restrictions led participants to feel a sense of "everyone [being] in the same boat."

Some participants felt that COVID-19 was no longer severe or out of control because of Biden, vaccines, and/or progress in scientific research. Three participants noted the Biden administration as achieving the move towards normalcy and safety, and one of those three cited a specific vaccine distribution policy. Vaccines also induced a sense of ease among four participants. One participant believed that current COVID-19 infections may be present in unvaccinated people only, and another felt the same about COVID-19 death when he was presented with a statistic. Multiple participants also stated more broadly that there has been greater research on COVID-19, which has allowed the government to get it "under control."

Only two participants mentioned long COVID without being asked about it, and no one mentioned COVID-19 death as an ongoing phenomenon. Two believed people rarely got sick with COVID-19, and if they did, they never died or were hospitalized. One of these participants, a Black low-income trans woman, noted the contrast between the present state of COVID-19 and the days when she witnessed widespread death within her community (including family members). Another believed no one ever got COVID-19 anymore. Some people noted their own mild experiences with COVID-19 infection as reducing their fear of it. Three participants said they'd never gotten COVID to their knowledge.

Participants' unawareness of COVID-19 cases and sequelae, mild/non-existent COVID-19 infections, and the aforementioned sense of unity in battling (and winning against) the pandemic led many to trust government messaging about COVID-19. One participant explicitly articulated a relationship between widespread precautions/effects and his trust in the government: "I don't know—if [COVID-19] affected just the gay community—if I'd had the same kind of faith [in the government]. But [I feel faith] because it affected everyone and because they took care of it pretty quickly." However, this did not translate to an uncritical

acceptance of all government officials. Multiple criticized Donald Trump, and multiple angrily commented on Kathy Hochul's proposed mask ban, questioning her authority on medical matters.

For other participants, struggles with illness, witnessing COVID-19 infections, desires to avoid medical care institutions, and/or immunocompromised statuses created a greater awareness of and precaution towards COVID-19. Three of the four participants who regularly masked in public (beyond public transit) noted experiences of facing health issues to defend their decision to mask. One participant, who had recently faced a severe respiratory infection, explained that he was afraid of suffering and hospitals due to his experience with HIV/AIDS, and noted the lack of support he received when he was ill:

> "But my guard is, is still up because—I want to make it very clear: I'm not afraid of dying. What I'm afraid of is suffering, okay? I can't. I've done enough of that physical hospital pain. Uh-uh. That's why I'm scared…after I came back, I had a respiratory infection that I got on the plane, I believe. I was really fucking sick…I called two people. I texted them. [They replied] "Hang in there be strong."...[Did they ask] "What happened? Do you need anything? Do you need food?" No. And it's like, the other person that [I told]---I said, [unintelligible], "Can you please just---you know, I can't order online---could you, would you pick something up?"...But that was it. I was on my own."

This participant also knew about long COVID-19 in part because of his his psychiatrist, who had been prescribing long COVID-19 patients with low-dose naltrexone. Another participant, who did not note any personal experiences with illness as directly contributing, indicated that someone at a community center she attended had just tested positive for COVID-19 a few days

before our interview, and used this to explain that COVID-19 is still around, and that she should continue taking steps to protect herself.

Two experiences explicitly drew parallels between the COVID-19 pandemic's current state and the invisibilizing HIV/AIDS culture. The participant who witnessed a denial culture in South Beach replied to the email with my COVID-19 information sheet (sent after the interview),

> "Good information that helps one decide what precautions to take going forward. Wish it was more accessible thru public messaging on transportation, billboards, etc. It's one thing to say Covid isn't as great a threat, it's another to stop messaging about it, entirely. That seems to be what happened. I guess everyone was so ready to distance themselves from it that we stopped talking about it. Maybe that's why we weren't talking about HIV/AIDS in South Beach. Like I said, the government could have handled this transition better."

Other participants who continued to talk about COVID and/or wear masks were sometimes subject to questioning, harassment, and accusations of negative/unreasonable mindsets, which at times silenced them and removed them from public view. The most cautious participant asked me if I thought he sounded crazy or unreasonable many times throughout the interview and described experiences of being harassed or shut down for his precaution/concern. He had recently been harassed in Whole Foods for masking, which led him to abandon his groceries and go home. This participant compared wearing a mask to being visibly ill with AIDS in the earlier days of the HIV/AIDS epidemic, explaining that both have welcomed a level of harassment that has traumatized him. He doesn't speak to anyone about these kinds of encounters:

> "But I'm just…I don't talk about---I don't like talking about negative [things]. See people

> [have said this]…I tried to talk to my friend about this…because of what I was experiencing, and what I'm trying to explain to you. And what I got was, 'Raphael, you're being so negative, you know, can't you just move on?' I'm going, I'm sorry, I'm just not as strong as you are. I'm trying to put this [out there] and and I'm trying to share because I am trying to deal with this. I am grieving. And I'm really sorry."

Another participant whose experiences were far less intense explained that he received strange looks from others when he masked but didn't feel bad about it. He implicitly referred to further social pushback he'd experienced by explaining that he just tells people that he is immunocompromised when they question his persistence in masking.

Participants who were not being invisibilized sometimes faced the implications of it, which sometimes seemed to be enabled by the broad (airborne) spread of COVID-19 and its most adverse effects. One participant's evidence that COVID-19 was over was the lack of information on the news about new strains and symptoms. Another participant said that he knew nothing about long COVID-19, but that he expected people with the condition to be in a similar situation to LTS, which he restated once learning more about long COVID-19 "because you don't hear about us [LTS] and you don't hear about that." He didn't know anyone (or likely know he knows anyone) with long COVID-19 and when I presented him with COVID-19 data, he asked me where I'd gotten the info, emphasizing with shock that it is not on the news. I explained I obtained some of it through high-risk individuals I am close with, and the online COVID-cautious communities one of them connected me to. He believed the accessibility of in-person community to learn from made a difference in COVID-19 and HIV/AIDS: "And back then we all talked about it. So there's no searching. It was like people would always bring something to conversation that we could learn from. And here, like it's just so. Spread out, I

guess. I mean, it's just---I had no clue about those things. Wow." In the earlier days of HIV/AIDS, this participant stood outside of a queer coffee shop and informed people about HIV/AIDS as an openly HIV-positive person. Another participant collected files of HIV/AIDS research that he received from a GMHC newsletter, and then copied it for other people. He also pursued a support group to learn more about the illness. Once I informed the former participant that I had tested positive for COVID a few days after our interview, he responded that he "should've been masking up and paying attention to Covid like [he does] HIV aids." This (post-interview) response—though very possibly shaped by his knowledge about my stance—may speak to the role COVID-19's invisibility has played in people's actions and perceptions of it.

Participants also perpetuated this kind of invisibilization. One participant responded to news of my (long) COVID-19 by stipulating that I was immunocompromised (before my COVID infection), which I rebuted. Then he asked about my diet and explained that my experience with COVID-19 may be due to a poor diet, comparing it with his nutritious diet and lack of infection. A different participant explained that his close friend used to take strict COVID-19 precautions (beyond the time when mask mandates dissolved). As he explained, he criticized the perceived flaw in her execution because she continued taking risks going as she went on Tinder dates. The participant criticized his friend's routine exposure amid her strict avoidance, telling her that he was "willing to accommodate whatever [made her] feel comfortable with [him], but [she] [had] to acknowledge that it's faintly ridiculous." She apparently agreed with him and stopped taking precautions. He inferred that "she sort of had this epiphany of oh, I guess this is crazy. And I guess, you know, I need to just go on with my life."

This perception also demonstrates what multiple participants noted about COVID-19 : a sense of unavoidability due to its airborne transmission.

Discussion

The experiences of participants in the earlier days of the HIV/AIDS epidemic display the great importance of visibility and proximity of illness in sensing threats. As mentioned, even when a physician friend warned a participant about HIV, he continued to feel little worry until his partner tested positive. The rejection and disdain one participant experienced from other queer men as he tried to distribute condoms at pride further emphasizes that (especially distant) individual warnings can be easily dismissed when people do not want to reckon with a public health crisis (or its perceived implications). This is further illustrated by the two participants who felt little threat after learning about celebrities with HIV/AIDS. Witnessing HIV/AIDS in people up close, often as they faced significant health issues, was what made the epidemic feel real.

Within the HIV/AIDS epidemic, AIDS was discovered first, not HIV. The initial impacts that HIV/AIDS had on the well-being of individuals and communities were, of course, driven by HIV transmission. Still, it was first made known through the widespread severe illness and death of AIDS. “The look” was not only a marked and horrifying shift in the well-being of one’s surrounding community, but, for the viewer (part of higher-risk communities), it was often interpreted as a “creepy” symbol of their personal vulnerability. This also suggests why invisibilizing efforts like that of bodybuilding and social exile were utilized, and why they were effective in maintaining a sense of distance from HIV/AIDS. Barbour et al. (2011) reported that people may avoid health information to maintain hope (that it is harmless) or deniability, to account for a sense of unavoidability, and/or when they do not want to make necessary lifestyle changes. Amid mass suffering and death, maintaining hope or deniability and (once information

about transmission emerged) avoiding lifestyle changes might have required looking away. When people are not testing, they are not showing symptoms, and everyone who has symptoms becomes an outsider, a sense of normalcy may be maintained, with illness (artificially) hidden.

My findings build on previous research documenting the unique struggles that PLWH have endured throughout the COVID-19 pandemic. As Cascalheira et al. (2022) predicted, restrictions-induced social isolation has continued to affect LTS, even as restrictions have eased. However, the greater sense of precaution, anxiety, and fear—which fed isolation at one point in time—eased among most participants. For some, this easing seemed to be a reaction to the immense fear of COVID-19 that they previously endured due to their HIV-positive status. A lack of severe COVID-19 outcomes also seemed to shape this. The lack of severe COVID-19 outcomes among participants despite their risk factors could be shaped by the quick sampling method via social organizations and small sample size, without concentrated effort to reach more isolated members of the population.

The noted differences between HIV/AIDS and COVID-19 in government action and lack of stigma aided participants in trusting the government's present COVID-19 response and information. For one participant, and perhaps others, experiencing prolonged and extreme neglect of marginalized and stigmatized groups in the earlier days of the HIV/AIDS epidemic gave a point of comparison and logic about public health neglect. A sense of unity and safety in responding to the COVID-19 pandemic fueled a sense of security in its management since it seemingly affected everyone. Among some participants, there seemed to be a sense of resolution in the story of COVID-19: it came, it was managed decently enough because it implicated everyone (rather than stigmatized groups), and now it's over or under control with the help of vaccines, scientific research, and/or the Biden administration's measures. In *The Viral*

Underclass (2022), Thrasher asserts that the Democratic party has perpetuated much of the same harm as Republicans—particularly with regards to HIV/AIDS and COVID-19—but is rarely recognized as doing so, in part because it "sometimes *says* it feels viral pain while causing so much of it to proliferate" (167). This may be why, even though 741,397 of the 1,208,804 reported COVID-19 deaths happened under Biden—including 154,657 (CDC, n.d.) after he declared COVID-19 over in mid-September 2022 (Sullivan et al. 2022)—one of my participants attributed one million COVID-19 deaths to Donald Trump. Common assumptions about Democrats and their achievements (among the more progressive population) may further feed into the trust and unawareness created by the dominant COVID-19 narrative, dissipating any previous doubts about the government's priorities. The significant shift in COVID-19-induced harm being concentrated around death to more nebulous chronic illness may also aid in providing a sense of resolution. Interestingly, this also reinforces the sense of invisibility that one LTS saw as parallel between LTS and people with long COVID-19. Facing long-term impacts from a virus given little public attention or concern—as they continue to circulate and especially impact marginalized communities—contradicts the sense of resolution that emerges with advancements in prophylaxis and/or treatment.

For COVID-19, especially after vaccination, infections can present asymptomatically or with cold or flu-like symptoms. This was the case for some participants. Additionally, unlike many manifestations of HIV/AIDS, post-acute sequelae of COVID-19 are often not deadly and can be incredibly invisible and/or asymptomatic. Long COVID-19 symptoms can be so unrecognizable that a human challenge study found that when a group of people were infected with COVID-19, they did not report any subjective cognitive deficits despite presenting them in testing (Trender et al. 2024). Additionally, COVID-19 testing has become decreasingly

accessible, with most free testing programs closed down, leaving relatively expensive and inaccurate at-home tests as the only available option for many. Testing, let alone precautions, may become less incentivized when COVID-19 information is unavailable, symptoms feel indistinguishable from "harmless" ailments, and those who face/avoid the most adverse outcomes are often invisibilized or avoided. Most participants did not know that an estimated 10-35% of COVID-19 infections lead to long COVID-19 (Mayo Clinic Staff 2024), and that the risk increases with each infection (Soares et al. 2024). They also did not know that while death has significantly decreased, it still persists—there were a little over 60,000 reported COVID-19 deaths over the course of a year from May 13, 2023 to May 11, 2024 (CDC, n.d.). Participants' proposals of taking more precautions when presented with this information may speak to the role that inaccessible information plays in some people's approach to COVID-19.

COVID-19 also markedly contrasts HIV/AIDS in the broadness of who it affects. While some communities affected by HIV/AIDS in the earlier days turned to denial, others mobilized and cared for one another. The level of community care noted by multiple participants dramatically contrasted with one participant's experience enduring a severe respiratory infection and being offered no material help by those he contacted. In *Impure Science* (1996), Steve Epstein explained that pre-established networks and medical skepticism in the gay community were integral to the effectiveness and popularity of HIV/AIDS activism (10-12); it would make sense that these networks also mediated general mobilization beyond protest. Mobilization was also made possible by many HIV-positive people who faced years of relatively "normal" health before symptom onset (10)—which does not have the same kind of temporality as a COVID-19 infection. Members of the population who face severe COVID-19 and long COVID-19 are not necessarily concentrated within pre-established communities, nor given a period to mobilize

before symptom onset (aside from time in anticipation of infection for those who are able). Their conditions also possibly isolate them from the population both socially and physically. Markedly, this isolation could be shaped by the highly infectious airborne transmission of COVID-19, especially as its decreasingly mitigated spread persists, along with the thirteen communicable diseases that now surge past pre-pandemic levels (Shristava 2024). This could drive higher-risk people and people with long COVID-19 to spend less time in public, contributing to invisibility. On a micro level, even when this doesn't entirely push people out of the public sphere, it is enough for one participant to never enter crowded trains and always wait for another, reducing the number of people they are witnessed by. These kinds of precautions can take other similar forms. Manifestations of long COVID-19 and high-risk conditions can also be literally immobilizing. The groups most at risk for severe COVID-19 and the most severe manifestations of long COVID-19 are capable of making someone bedbound, which means that gathering in person is much less accessible for the most affected people.

While the group of people facing severe implications of the COVID-19 pandemic are more and more shut out from the world, most of the population has returned to a sense of normalcy. Considering the HIV/AIDS denial culture provides greater depth for the potential reasoning and mechanisms behind this. The present implications of learning COVID-19 information may feed avoidance of it, especially using the framework of Barbour et al. (2011). COVID-19 transmission is highly infectious and has become almost entirely unmitigated in the United States, long-term symptoms are relatively common,[1] the population was bombarded by (highly divisive) COVID-19 information and restrictions for long periods of time, and, maintaining perfect precaution is nearly impossible. Barbour et al. (2011) showed that people

[1] In the Household Pulse Survey of late August 2024, 17.9% of American adults reported that they'd ever experienced long COVID (National Center for Health Statistics 2024)

avoided health information to: accept the feeling that they couldn't take any preventative action; "maintain hope or deniability" of distressing news; "avoid overexposure" to a health issue they felt tired of; felt information would interfere with "habitual or enjoyable activities" (220); and avoid seemingly untrustworthy or contradictory information, which aligns with COVID-19 mis/disinformation and the contrast between COVID-19 data and general understandings.

Conclusions

While HIV/AIDS was neglected by larger institutions and mainly affected stigmatized groups, COVID-19 affected all of the nation. The sense of unity and government concern resulting from COVID-19's initial impact now aid in the invisibility of COVID-19 infections and sequelae; even some of my participants, who are vulnerable to severe COVID-19 outcomes, felt little concern about COVID-19 infection (during the largest summer COVID-19 surge since July 2022 (Goodman 2024)). For the HIV/AIDS epidemic and now the COVID-19 pandemic, an absence of public health information may lead people to make threat assessments according to the experiences they witness. This strategy has proven to fail when illnesses present in asymptomatic or invisible ways—which is especially prevalent in COVID-19, contrasting the extremely visible and intense manifestations of AIDS. But this invisibility is also manufactured, too—participants noted and/or experienced parallels between HIV/AIDS and COVID-19 in the social exile and silencing of people who marked the epi/pandemics' presence.

Future research would benefit from using a larger and more diverse sample, and noting how participant positionality shapes their perceptions of governmental/collective response—Gwadz et al. (2021) showed that knowledge of medical racism influenced PLWH's (mis)trust in governmental responses. Additionally, it would be apt to pursue more isolated long-term survivors of HIV. Almost all participants either never had COVID (to their

knowledge) or had mild infections despite their higher-risk status, leading me to believe that the (quick) recruitment method may have excluded some LTS who had faced greater adverse effects.

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