

LOSING “THE LOOK”:

IN/VISIBLE ILLNESS THROUGHOUT HIV/AIDS AND COVID-19



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INTRODUCTION

The COVID-19 pandemic and HIV epidemic have had disproportionate impacts on various vulnerable and marginalized groups. 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 of HIV have experienced both of the epi/pandemics as vulnerable populations. Previous studies on long-term survivors and other people living with HIV (PLWH) throughout COVID-19 lockdown have shown increases in anxiety, pre-pandemic isolation, and financial struggle (Cascalheira et al. 2022), as well as reliving painful memories from the HIV epidemic and diagnosis (Pantelic et al. 2021). Other studies have shown a sense of resilience and preparedness among long-term survivors, due to their familiarity with an epi/pandemic (Diaz-Martinez et al. 2022; Pantelic et al. 2021; Pantelic et al. 2022; Quinn et al. 2020). 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. 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?**



GOALS & OBJECTIVES OF THE WORK

The purpose of this project is to explore the epi/pandemic experiences of higher-risk groups, particularly when health crises overlap. Long-term survivors 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. By placing COVID-19 within a historical context, I hope to illuminate present processes that may otherwise remain elusive.

METHODS

I conducted ten in-depth interviews with long-term survivors living in NYC.

The interview guide consisted of three parts:

1. Experiences in the earlier days of the HIV/AIDS epidemic
2. Experiences during the COVID pandemic
3. Perceptions of COVID & HIV/AIDS

Eligibility Criteria:

1. Acquired HIV in the 80s, 90s, or early 2000s
2. Was 18 or older when acquired HIV
3. Speaks English fluently
4. Lives in NYC

Recruitment:

- Gatekeeper recruitment via local and national organizations
- Snowball sampling
- Distribution of flyers at Brooklyn Pride & through X (Twitter)

Procedure & Analytic Lens:

- Brief screening survey over the phone
- Interview in person or over Google Meet (audio recorded)
 - Participants provided informed consent at the beginning
 - 47-147 min long; mean interview length = 97 min
- Interviews were transcribed (Otter.ai), line-by-line coded (ATLAS.ti), & analyzed using a grounded theory analytic schema
- This study takes a constructivist grounded theory approach

Challenges & Reflexivity

- Initial issues with finding respondents, especially a more diverse sample → I started to provide compensation → seven out of the ten participants were compensated \$50 via a banking app (Zelle, Paypal) or cash
- I practiced reflexivity and attempted to account for my positionality as a White visibly queer college student; also in regards to how wearing a mask at the interviews could influence the participants' responses

NEXT STEPS

Work at a community organization, distribute PPE, and share findings via zines and teach-ins (with community building activities).

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. For the HIV/AIDS epidemic and now the COVID-19 pandemic, an absence of public health information leads 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 presentations 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 long-term survivors who had faced greater adverse effects.

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RESULTS

HIV/AIDS & IN/VISIBILITY

Participants' perceived threat of HIV/AIDS was shaped by its visibility in their loved ones and communities. Some affected communities decided to invisibilize HIV/AIDS and its victims before it invisibilized them, creating cultures of denial. Some participants believed the driving force was fear of the virus—especially in the face of uncertainty/inaction—as well as fearing a return to a repressed queerness. HIV/AIDS was invisibilized through the exile of those who acknowledged it in body or word, as well as a bodybuilding culture seeking to present a look of health “beyond reproach.” 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. While participants noted the social fragmentation HIV/AIDS caused individually and societally, multiple participants also highlighted the resulting unity, whether in denial or in struggle, care, and advocacy.

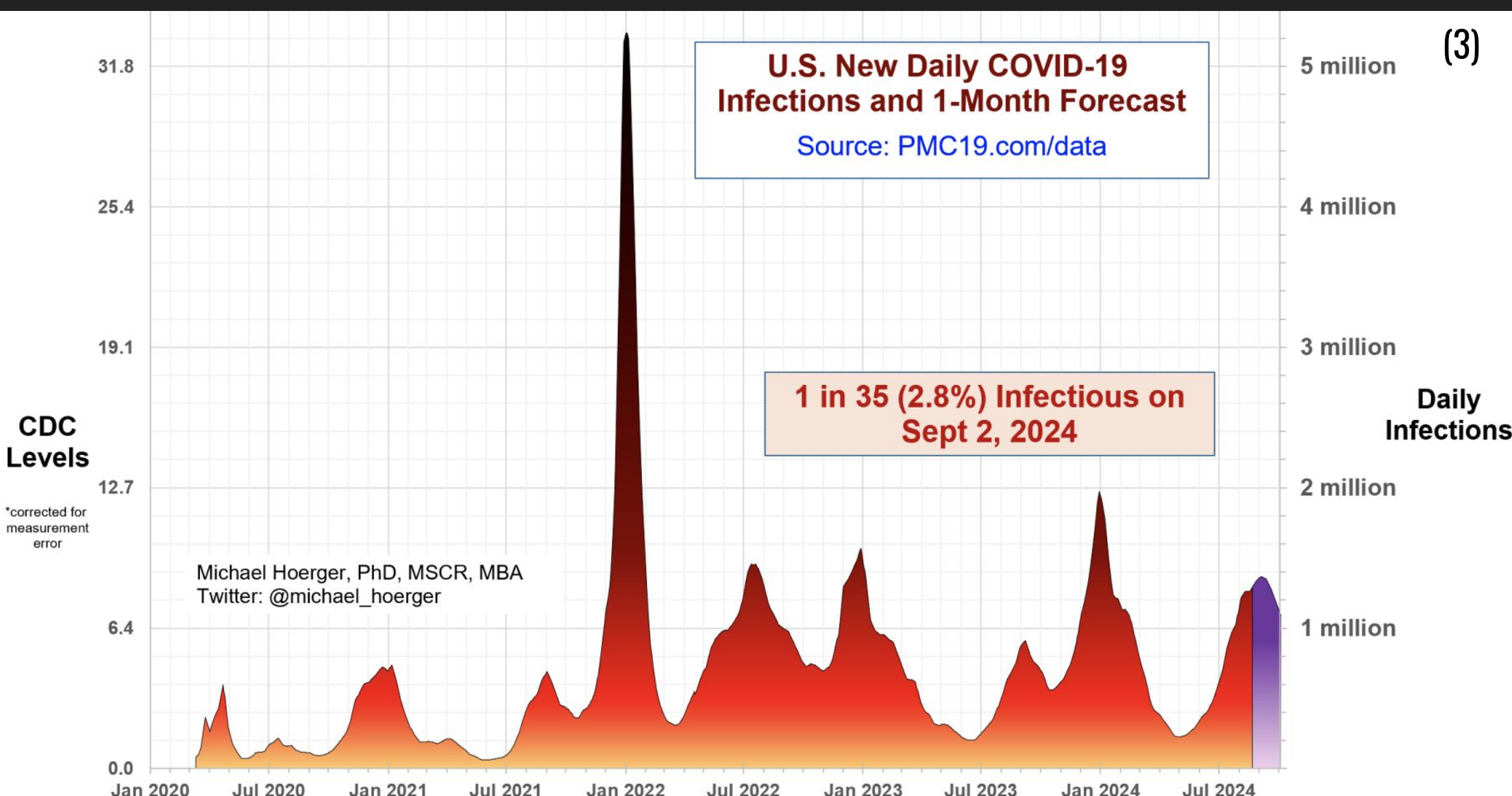


COVID-19: FAMILIAR FEARS, IN/EQUALITY, & IN/VISIBILITY

In the earlier days of the COVID pandemic, long-term survivors of HIV often felt intense fear and endured painful memories resurfacing. They saw parallels between HIV/AIDS and COVID in isolation, fear, and initial government inaction. Participants saw differences in COVID's lack of stigma, wide-spanning effects, and government initiatives. For some, the sense of “everyone being in the same boat,” unawareness of COVID cases and sequelae, and mild/non-existent COVID infections led them to trust governmental messaging. Half of the participants believed people rarely caught COVID and/or died from it, and only two participants mentioned long COVID despite its outcome in 10-20% of COVID infections (World Health Organization 2022); many expressed shock when presented with COVID information at the end of interviews. For some participants, struggles with illness, witness of COVID infections, and/or immunocompromised statuses created a greater awareness of and precaution towards COVID.

Multiple participants noted/experienced parallels between the COVID pandemic's current state and the invisibilizing HIV/AIDS culture. Participants who continued to talk about COVID and/or wear masks were often subject to questioning, harassment, and accusations of negative/unreasonable mindsets. In the absence of widely known information about long COVID—a largely invisible illness—and COVID transmission levels, others continued the invisibilizing work through silencing and exiling these participants.

COVID's intensification of long-term survivors' pre-pandemic isolation continued to affect participants past the earlier days of COVID, both in health-based limitations and intensified stigma-based relationship difficulties. Despite the sense of a unified experience, these unique struggles with COVID, as well as the great diversity among the participants' experiences, demonstrated otherwise.



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