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What Do Epidemic History and Sexual Minority Men's Experiences of HIV and COVID-19 Teach Us About Pandemic Preparedness?

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COVID-19 has forever changed how we think about the threat of contagion. For many individuals, COVID-19 feels like the first, massive, life-threatening epidemic of infectious disease they have personally faced. However, for sexual minority individuals and communities who have experienced trauma and loss stemming from the HIV epidemic, there are many similarities.[1] What might these two epidemics have in common? How might they differ?

In the context of epidemic disease, individuals and communities must make sense of their uncertain circumstances and choose courses of action. Silences, politicized misinformation, evolving public health guidelines at the community, state, and national levels, the perceived state of medical capability with respect to prevention and treatment, and cultural narratives about what constitutes moral behavior are all consequential for daily decisions and (in)action.[2]

KEY FINDINGS

- Men who lived through both the HIV and COVID-19 pandemics believe the government did not do enough to respond to either crisis.
- Respondents perceived that the epidemic response is associated with the group(s) most affected by the disease, with less attention given to marginalized and stigmatized populations.
- To better prepare for future epidemics, public health efforts must be less fragmented, including a more through dissemination of prevention messaging, public health regulations, health care resources, and vaccine efforts.

In the late 1980s, Charles Rosenberg attempted to connect the HIV epidemic to the longer history of epidemics and their consequences.[3] To do this, he developed a theater metaphor, in which epidemics were likened to a play in three acts: progressive revelation, managing randomness, and negotiating public response. Using Rosenberg's framework, this brief summarizes our findings from interviews with 30 sexual minatory men to understand their thoughts about COVID-19 considering their knowledge and/or memories of the HIV epidemic.

Act 1: Progressive Revelation—It's Here

Progressive revelation refers to the process by which accumulating cases and deaths are ultimately recognized by the public and officials. There is generally a reluctance to accept the presence of epidemic disease in its early stages. Early in the COVID-19 epidemic, some of the men with whom we spoke dismissed the threat:

> "At first, I think I envisioned COVID to be more along the lines of H1N1, the swine flu, where it was a virulent version of influenza that hopefully could be addressed and stamped out pretty quickly. I didn't foresee that was going to be a broader global infection" (Gray).

However, over time, as cases mounted, the reality could no longer be denied:

> "Anyway, it was over there, and I am like, 'oh, they're going to contain this, they're going to get it together, they're going to have a cure'...Then, it started getting closer to the East Coast...They were talking about this pocket in Long Island, and I was like, 'Oh my gosh, that's just down the street'...That's right here in our neck of the woods. That's when it became real."

As was the case in the early days of the HIV epidemic, when "everybody knew somebody who had HIV/AIDS" (Adam), the presence of epidemic disease was made real for others through personal connections to those with COVID-19. Tom told us:

> "Maybe when this woman that I knew started posting messages about the status of her condition. That made me pay attention to her as somebody I knew that I could follow and see if she's going to die, or if she's going to stay alive, or if she's going to get better. There were two people like that, that I knew that documented their own situation. That brought it home."

Act 2: Managing Randomness—Why Us? Why Me?

The drama of an epidemic continues with efforts to contain and make sense of the threat. Are we all at risk? Is this random? Or, are some people more at risk that others? Understandings of risk and susceptibility shape individual choices and support (or lack of support) for collective action As in the case of HIV, for the men interviewed, increasing anxiety due to rising COVID-19 caseloads and deaths was associated with uncertainty regarding transmission routes:

> "I remember during the beginning of the pandemic, like the grocery stores, it felt like everyone was on edge, because no one really knew how do you get it or how the virus worked, which I guess is similar to how HIV was for a while" (Nick).

> Jason pointed out: "For one thing, you can't see it. It's not like an ailment that's visible, at least at the first stage of COVID...Because of that, there's this mind game. People are concerned because they don't know. They don't know if someone has HIV. They don't know if someone has COVID."

As information about the pandemic evolved, the men we interviewed sought to gain control over fear by dividing individuals into those who were susceptible to COVID-19 and those who were not. As in the case of HIV, some assessments were based on social categories and/or social identities, and others were associated with "irresponsible" action. Tom said:

> "I feel like you got people, like they did with the HIV epidemic, blaming certain groups of people—Haitians, hemophiliacs, ex-homosexuals, and whatever the other H was. Now, you see people stereotyping and blaming Asians for it."

> Similarly, Jay told us: "When someone becomes HIV positive, they purposely did something to acquire [the] virus. Likewise, there's a certain amount of that same attitude towards COVID. You didn't practice safe distance. You weren't wearing your mask. A stranger shook hands with somebody. That's going on in people's minds."

Importantly, many of the men with whom we spoke believed that HIV was more stigmatized than COVID-19 because of the affected populations and the modes of transmission. George summarized this sentiment by stating:

> "I like to draw this analogy very much. 'If you don't wear masks in public, you get coronavirus; if you don't wear condoms while you're having sex you get HIV.' It's literally the same thing, but there seems to be so much more stigma towards HIV. Could be because it's a sexually transmitted disease. It could be because it's been transmitted amongst gays in the first time."

Act 3: Negotiating Public Response—What Do We Do?

In the face of the disruptions brought about by epidemics, there is often debate and negotiation about what should be done, when it should be done, to whom it should be done, and what cannot be done. Thus, there is considerable negotiation about the appropriate public response.

The men with whom we spoke believed that the U.S. government did not do enough in response to both the COVID-19 and HIV epidemics. Kevin stated the point like this: "It all sounds cynical, but I would say that the residing administration in the White House during both times [HIV and COVID-19] when it became an issue in America, seemed to care less than they could have." Other participants believed that the federal responses to HIV and COVID-19 differed in scope and intensity due to differences in those who were considered susceptible (i.e., sexual minority men versus the general public):

> "The response [to COVID-19] has been overwhelmingly more intense, more comprehensive [than the response to HIV]. Because originally [HIV] was labeled a gay disease, it's like, 'Oh well, that's them. They're bringing it on themselves. We don't have to worry about it. That's their problem.' We care, but we only care so much. It's something other people are going to have to work out. With COVID, it's like, 'Oh, this is everybody. This can affect everybody" (Steve).

Others referenced how the politicization of the epidemic led to inaction. Gray said:

> "I think the Congress, the Senate, and the White House being three very different bodies with different perspectives and entities, have come about this in a really horrible way, where they've been somewhat responsive, then entirely unresponsive. Their politicization of so many matters that truly are not political matters. They're matters of science. They're matters of data. They're matters of public conscience and the social contract in terms of how we treat each other."

In the context of present-day epidemics, public health institutions take center stage. However, some men with whom we spoke expressed concern about the public health response. For example, Adam said:

> "I'm not seeing widely published and accessible, unavoidable messages. I'm not seeing things on the sides of buses enough. I'm not seeing enforcement."

Some men pointed out that COVID-19-related grassroots efforts were largely being undertaken by individuals who opposed safety measures, while those relating to HIV were undertaken by a community whose very existence was being threatened by contagion. Ethan told us:

> "With AIDS, originally, we have a right to be respected and treated with dignity and receive appropriate healthcare. We have nothing to lose for adequate treatment, adequate funding, adequate this and this. With this, there's a push for, 'OK. Stay at home, quarantine, and here's how to protect yourself.' Then, you've had the pushback of, 'But Karen needs a haircut.' *[laughs]* It just has an ironic feel to me."

As this quote indicates, demands for individual liberty trumped calls for civic responsibility in some realms. In contrast, many of the men with whom we spoke connected their own COVID-19 risk management with a sense of personal responsibility and a desire to promote the public good:

> "It's more of a value type thing. Like sexually, you wear a condom to prevent HIV, and you're protecting yourself and others. I think that it's along the same types of values where you do what you can do to protect yourself, and in a way, you're also protecting others too by doing that" (Jeff).

We Must Improve Pandemic Preparedness

In a recent public address, Sarah Gilbert, one of the creators of the Oxford-AstraZeneca vaccine for COVID-19 stated: "This will not be the last time a virus threatens our lives and our livelihoods. The truth is, the next one could be worse. It could be more contagious, or more lethal, or both...We cannot allow a situation where we have gone through all we have gone through, and then find that the enormous economic losses we have sustained mean that there is still no funding for pandemic preparedness...The advances we have made, and the knowledge we have gained, must not be lost."[4]

It would indeed be a mistake to think that COVID-19 is the last pandemic we will face. We live in a web of biological inter-connection and will face threats like HIV and COVID-19 again. Yet, each time a new epidemic emerges, it seems like we are insufficiently prepared. It has recently been suggested that the optimal response to emergent infectious disease outbreaks includes: global surveillance, transparent communication, investment in public health infrastructure, coordinated and collaborative basic and clinical research, the involvement of the afflicted communities in policy decisions, and flexible funding mechanisms.[5] This is echoed by our findings, which suggest that coordinated leadership, sustained public heath capacity building, and attention to the social, cultural, and political experiences (historical and contemporary) of different subpopulations of citizens is critical.

We need to learn the lessons from epidemic history, as well as more recent epidemics like HIV and COVID-19, to be better prepared to deal with future epidemics. In the fragmented nature of public health efforts to mitigate COVID-19 transmission—due to variations in the strength and content of interventions enacted by local and/or state health departments, which were in themselves shaped by an inadequate federal response—we see opportunities for leaders to do better in the future. We also see opportunities for the United States to do much better when it comes to prevention messaging, the implementation and enforcement of public health regulations, the distribution of health care resources, and vaccine management. Once the immediate crisis of COVID-19 is past, policymakers must develop

a coherent and enforceable framework for managing epidemic threats and safeguarding lives.

Finally, we must realize that how we treat individuals and communities in the present shapes future responses. Just as the shadow of the inhumane treatment of Black men in the Tuskegee Syphilis Study shaped the experiences and responses of Black individuals and communities in the U.S. HIV pandemic,[6,7] it is likely that emergent, community-based oral histories, cultural accounts, and experiences with COVID-19 will shape response to future epidemics of infectious disease. Thus, looking to the future, we need better leadership and capacity for public management and a better understanding of how social and cultural factors shape individual and collective responses to epidemics.

Data and Methods

Data are from a qualitative interview project that explores how sexual minority men assess and manage COVID-19 risk during sexual encounters that take place outside of the bounds of quarantine. Participants (n = 30) were residents of an area of the United States under quarantine (i.e., with restrictions on gatherings), who had in-person sex with someone with whom they were not quarantined since March of 2020. Data were collected via semi-structured interviews from May to September 2020. Additional details about this project are available here.[8,9]

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