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# COVID-19, Retention in HIV Care, and Access to Ancillary Services for Young Black Men Living with HIV in Chicago

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## Abstract

This study conducted 28 semi-structured, in-depth interviews with Young Black Men who have Sex with Men in Chicago to investigate the impact of COVID-19 on their HIV care and ancillary service access. The qualitative analysis identified both negative and positive effects. The negative effects included: (1) mixed disruptions in linkage to and receipt of HIV care and ancillary services, and (2) heightened concerns about police and racial tensions in Chicago following the murder of George Floyd, contributing to possible disruption of retention in care. The positive effects included: (1) the ability to reflect and socially connect, contributing to heightened self-care and retention in care, and (2) some improvements in receipt of medical care. These findings suggest that while COVID-19 disruptions in care reduced in-person use of HIV care, the expansion of telemedicine allowed more administrative tasks to be handled online and focused in-person interactions on more substantive interactions.

**Keywords** YBMSM · Chicago · COVID-19 · HIV care continuum · Medical care improvements

## Introduction

COVID-19 emerged in 2019 and was recognized as a global phenomenon in 2020 [1]. However, to date, there is a dearth of empirical studies that have been conducted about the impact of COVID-19 on the HIV care continuum, especially as it relates to Black men who have sex with men (BMSM). The HIV care continuum outlines the stages in accessing services from; diagnosis of HIV infection, linkage to HIV

medical care, receipt of HIV medical care, retention in medical care, as well as achievement and maintenance of viral suppression [2–4]. BMSM relative to their white male counterparts report lower engagement in HIV care, less adherence to antiretroviral treatment, and subsequently lower individual and community suppressed viral loads. Notably, young Black men who have sex with men (YBMSM) have poorer HIV care continuum outcomes relative to their older same-race counterparts [5–9].

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Partly due to structural disadvantage and social and racial inequality, YBMSM bear a high burden of unemployment, lower engagement in HIV care, mistrust of formalized health care settings, and racism relative to their other racial/ethnic MSM counterparts [10–12]. Similarly, driven by structural inequality, African Americans have experienced a disproportionate burden of COVID infections and deaths in the United States [13]. What we currently know about the impact of COVID-19 on the HIV care continuum generally relies on clinical observations or insights from service providers [14–17]. This emerging body of research suggests that COVID-19 has negatively affected service access and health outcomes [16, 17]. For example, at the onset of the pandemic, researchers in Chicago speculated that in addition to the risk of contracting COVID-19 itself, “the indirect effects of the pandemic including shelter-in-place orders, record unemployment, and widespread social anxiety may interact synergistically to worsen health outcomes for PLWH [persons living with HIV]” [16]. There is insufficient empirical evidence about the effects of telemedicine on access and care, widely used during shelter-in-place mandates. Scholars have argued that telemedicine might “worsen disparities in access for those with certain social disadvantages, such as low health literacy or those without Internet or adequate phone or computer-based technology” [15, 18]. Chicago provides an important site for examining the effects of the pandemic on the HIV care continuum for YBMSM who represent 56% of new HIV diagnoses, 56.9% of AIDS diagnoses, and 56.6% of late HIV diagnoses [19]. Young YBMSM in Chicago continue to face disproportionate high rates of HIV infection and over the past decade have had the lowest antiretroviral treatment rates [5, 19–21].

What are the effects of COVID-19 on aspects of the HIV care continuum for YBMSM and how can providers use these lessons for improving HIV care continuum engagement? To address this question, this study presents a qualitative analysis of interviews with YBMSM in Chicago and focuses on their experiences with HIV care during the early phases of the COVID-19 pandemic.

## Methods

Between October 2020 and December 2021, we conducted semi-structured, in-depth interviews with 28 young YBMSM in Chicago to investigate the impact of COVID-19 on their HIV care engagement. The interview guide was piloted and revised with members of the focal population, who were compensated for their participation. Participants were recruited using a variety of methods to obtain diversity in the sample between October 2020 and December 2021: (a) purposeful sampling that relied on establishing networks of HIV service providers and researchers in Chicago, (b)

recruitment flyers distributed on online platforms such as Instagram, Snapchat, community e-list serves, and in person at community events; (c) a snowball sampling that relied on referrals from men who participated in the study, where participants who referred eligible participants were given a \$10 referral bonus. Study enrollment continued until saturation in topics relating to HIV, violence, and COVID-19 was reached. Saturation was determined through bi-weekly study team meetings where interview content was discussed, and concepts and categories were identified [22–24].

All study participants were screened for eligibility by research team members. Participants were eligible if they self-identified as Black men who have sex with men, were between the ages of 16 and 30, were living with HIV for 3 months or longer, and resided in the city of Chicago. We targeted this age range due to their heightened vulnerability to showing poorer outcomes related to aspects of the HIV care continuum [25]. At the end of the interview, participants were allowed to provide a fake name or pseudonym. In the analysis, all participants are referred to by their pseudonyms to protect their identities.

Trained research team members conducted the in-depth interviews, which lasted up to 90 min. The interviewers used a semi-structured interview guide that was developed based on our team’s prior work with young Black sexual minority men living with HIV, as well as based on the early COVID-19 and HIV literature [16, 26, 27]. The interview guide had several topics: (1) participant background; (2) HIV history and experiences with COVID-19; (3) experiences with violence and racism; (4) coping and social support related to HIV care and COVID-19; and (5) general future life goals and expectations. The guide included both closed-ended questions (e.g., What percentage of your family and friends, from 0 to 100, know that you are gay/bi/queer? Tell me more about how you make these decisions. About how many times a month do you forget or choose not to take your HIV medications?) and open-ended questions (How did the COVID-19 pandemic change your HIV care experience?). The flexibility of the interview guide allowed the team to make edits to the guide as needed. After the first few interviews, we updated the guide to re-order several of the questions and add additional questions about participants’ COVID-19 experiences. The team followed the order of the interview guide during interviews, skipping questions if participants chose not to answer. Participants received a \$50 gift card for their participation. All study participants provided informed consent. Study protocols were approved by the Institutional Review Board at the Medical College of Wisconsin.

All interviews were digitally recorded, transcribed verbatim, checked for accuracy, and coded using MAXQDA software. We used a team-based approach to developing a codebook. First, five members of the research team independently

**Table 1** Primary themes and illustrative quotes from thematic analysis

| Themes   | Brief description of theme  | Example quote   |
|--|---|---|
| (1) Negative Effects of COVID-19: Disruptions in linkages to HIV care and treatment  | Linkages to HIV care and ancillary services were disrupted and uneven during the pandemic   | “But the one thing that I didn’t really particularly care for – there was two other case managers. I don’t know if they were assigned to me temporarily or what, but they came to help me one time. And I never saw them again. I never heard from them again.”   |
|  | The pandemic led to disruptions of preferred in-person medical care. Some persons indicated a preference for in-person HIV care service delivery and COVID-19 led to a decline in face-to-face medical appointments with doctors and therapists | “This doctor’s appointment I got today was real hard to set up. . . . I normally just do a walk-in instead of planning ahead. I don’t really like to plan my doctor’s appointment ahead because I don’t like thinking about it [HIV care service]. And since COVID they say we gotta plan it two weeks ahead, which is always hard for me.”   |
| (2) Broader negative pandemic effects: Heightened concerns about police and racial tensions and potential effects on retention in care | Some participants remarked how there was a heightened awareness of police violence during the pandemic, contributing to potential challenges to retention in care   | “But in quarantine, it was different. It was just like when all this stuff happened with George Floyd, it would just come up in my dreams. It was just very different than all the [other] times before. And there’s so much content showing what’s happening. I’m on Twitter, I see all those things.”   |
| (3) Positive pandemic effects: Ability to reflect and some improvements in care  | Participants saw the pandemic’s policy responses (e.g., shelter-in-place and work from home) as opportunities to deepen social connections, broaden their ability to provide self-care and maintain HIV care continuum engagement               | “Honestly, since Covid and since all of these things that have been happening, I think everybody wants to take care of themselves a lot more.”<br>“It [the pandemic] kind of forced me to be shut up in an apartment with – hell, it gave me the time that I’ve always wanted, the time that we had always dreamed about since the first time we laid eyes on each other. I’m grateful for that.” |
|  | The pandemic did not worsen HIV care continuum engagement as many physicians were also operating virtually  | “It’s easier going to the doctor because I only have to go every six months as opposed to three.”   |

read two randomly selected interview transcripts and developed a list of candidate codes and categories. We met as a team to discuss our draft codebooks and create a single agreed-upon codebook. Team members then independently applied this updated codebook to two additional interviews, refining code definitions, combining codes, and identifying duplicate or overlapping codes. The team met again to discuss and update the codebook. We continued this process one additional time until all members reached a consensus on the finalized codebook.

All interviews were initially coded with basic demographic information (e.g., age, date of HIV diagnosis, sexual identity). We then applied the finalized codebook to the data. All interviews were coded twice, by separate team members, to enhance coding reliability. To conduct these specific analyses, one team member led the thematic analysis to identify

how YBMSM experienced COVID-19 and HIV care in this study. The thematic analysis aimed to identify statements in the transcripts that connected the COVID-19 pandemic and other events with participants’ HIV-related care and ancillary service access. As a team, we examined codes and text extractions to inductively identify themes, which were revised and refined through an iterative process [28]. Our final themes are presented in our results section (Table 1).

## Results

The 28 YBMSM participants were between the ages of 23 and 30 years (mean = 27), with 32% of participants reporting having completed high school and 14% reporting that they completed college (Table 2 summarizes the participant

**Table 2** Demographics characteristics of study participants (n = 28)

| Continuous variables              | <i>M</i> | Range |
|-----------------------------------|----------|-------|
| Age                               | 27       | 23–30 |
| Categorical variables             | <i>n</i> | %     |
| Sexual identity                   |          |       |
| Gay                               | 20       | 71    |
| Bisexual                          | 4        | 14    |
| Queer                             | 1        | 4     |
| Non-conforming                    | 1        | 4     |
| Pansexual                         | 1        | 4     |
| Gay and bisexual                  | 1        | 3     |
| Employment status                 |          |       |
| Full time                         | 5        | 18    |
| Part time                         | 4        | 14    |
| Unemployed                        | 18       | 64    |
| Missing                           | 1        | 4     |
| Relationship status               |          |       |
| Single/casually dating            | 18       | 64    |
| Living together/BF/GF             | 6        | 21    |
| Married                           | 1        | 4     |
| Missing                           | 3        | 11    |
| Education                         |          |       |
| High school graduate/GED          | 10       | 36    |
| Some college or technical school  | 13       | 46    |
| College graduate                  | 4        | 14    |
| Missing                           | 1        | 4     |
| Viral load (self-report)          |          |       |
| Undetectable                      | 12       | 43    |
| Missed ART doses in the last week |          |       |
| None                              | 16       | 57    |
| 1–2                               | 8        | 28    |
| 3+                                | 2        | 7     |
| Missing                           | 2        | 8     |

characteristics  $n = 28$ ). The employment rate among the 28 participants was 32% and about 29% reported being partnered or in a relationship (see Table 2).

The coding process indicated that, for these 28 YBMSM, COVID-19 and its public health policy responses were associated with both negative and positive effects on their HIV continuum of care engagement. The negative effects included: (1) mixed disruptions in linkage to and receipt of HIV care and ancillary services, and (2) heightened concerns about police and racial tensions in Chicago following the murder of George Floyd in Minneapolis, contributing to possible disruption of retention in care. The positive effects included: (1) the ability to reflect and socially connect, contributing to heightened self-care and retention in care, and (2) some improvements in receipt of medical care. Each of these themes is discussed below.

## Negative Effects of COVID-19: Disruptions in Linkages to HIV Care and Treatment

### Mixed Disruption in Linkages to Ancillary Care

Linkage to ancillary care was defined in this study as case worker engagement, access to mental health services, and use of supportive services (e.g., for basic needs). Paul (age 23 years) reported that he was assigned two case workers who delivered some hygiene supplies to support him, but once they provided him with the supplies, he never heard from them again. Before the pandemic, Paul mentioned having a good relationship and communication with his caseworker but that the COVID-19 public health policy responses made it more difficult to get in touch with his caseworker, as they were also negatively impacted by COVID-19. He shared:

It's very hard to get in contact with her [his caseworker] because I believe the COVID-19 pandemic has made it harder on them coming in the office as often as they used to. Prior to this whole pandemic, it was a lot of good communication, no problem getting in touch with them at all. But after the pandemic kinda happened, it was very hard getting in contact with them. I have to leave messages and hope that they would call me and hope that my phone would actually ring because sometimes my phone wouldn't ring. And I wouldn't get their call and stuff like that. It was just messy a little, but it wasn't bad.

Others had trouble accessing services, which was illustrated by Kyle's experience (age 30 years). He shared that he was facing barriers finding a new therapist due to COVID-19. When asked if he was able to speak to his case manager regarding being matched with a new therapist he said:

"Yeah, we talked about it, but this COVID shit happened, and we couldn't get to it."

### Mixed Disruptions in Receipt of HIV Care and Adherence

Several participants reported that COVID-19 led to disruptions of preferred in-person medical care. Many participants indicated a preference for in-person HIV care service delivery and reported that COVID-19 led to a decline in face-to-face medical appointments with doctors and therapists. Some participants were not able to see their physicians as frequently as they did pre-pandemic and Roger (age 29 years), as an extreme example, reported: "I ain't seen no doctors [for] over a year because of COVID-19."

Several participants reported that while their preference was for in-person care and treatment, they tolerated online appointments with varying degrees of dissatisfaction. Paul (age 23 years) said:

It didn't affect my HIV care. Or it didn't affect my HIV meds. But it just took a big part of like me going to see my doctor. Because I like to see my doctor face-to-face versus like over the phone. It's been like two times I could say of the whole of this since the whole pandemic started that I've seen my doctor in person versus over the phone.

Tyrone's (age 30 years) example indicated the nuances of the COVID-19 impact on medical lab testing, which heightened his concerns about possible resistance. He stated:

It hasn't affected my care. But I continue to take my medication through this pandemic. I actually had caught COVID last year. And I still was taking my medication. [There were] times where my medical provider had to tell me 'don't come in.' We ha[d] to do over-the-phone visit. So, that had impacted ways as well, where I went six months without getting labs drawn. So, I was curious, is my medication still working because sometimes it can go into resistance if you miss sometimes. So, it did have a big impact on my medical treatment.

While several participants reported that COVID-19 did not directly affect the frequency of medical appointments given that these had now moved online, they did indicate that keeping medical appointments required extra planning. Trey (age 23 years) expressed that he found the process of making a doctor's appointment 2 weeks in advance difficult as he had grown accustomed to walk-in appointments. Trey reported:

I don't like to plan my doctor's appointment ahead because I don't like thinking about it. And since

COVID they say we gotta plan it 2 weeks ahead, a week or two ahead, which is always hard for me. I talk myself out of going to see the doctor a lot.

Many participants shared that they would sometimes forget to take their medication doses because of the disruption in their daily routines, such as a daily work schedule. When employment transitioned to working from home, these medication regimens became detached from their pre-pandemic daily work routines. Dain (age 25 years) described the disruption in this way:

So, it was just like every day I had a schedule. It was just like, okay, if I didn't remember to take my pill while I was at work, I would definitely remember to take it while I was doing my makeup. Like, it would be something to definitely – it was something that I did consistently every day that required me to remember it. But when quarantine came, some days feel like you do absolutely nothing or some days the days go together, it's like, you forget to take it in the morning and then you remember to take it in the afternoon, and you're like, 'Did I take this this afternoon, or did I take that yesterday afternoon?' And then you're like, 'Well, I don't want to take two doses, so I just won't take a dose at all today.' It's like, it's very that.

### **Broader Negative Pandemic Effects: Heightened Concerns About Police and Racial Tensions and Potential Effects on Retention in Care**

Several participants remarked how there was a heightened awareness of police violence during the COVID-19 pandemic, contributing to potential challenges to retention in care. Shelter-in-place measures led to several participants being more attuned to news coverage, anti-Black racism, and a sense of increased vulnerability. Such emotional burdens often translated into a fear of being outdoors or at times a preoccupation with external stressors that negatively impacted medication adherence. For example, Derrick (age 25 years) discussed how police brutality was different from in the past due to the COVID-19 pandemic and the circulation of police violence on social media. He shared:

When things [in the past] happened, it didn't affect me as much because I had a million other things to worry about. But in quarantine, it was different. It was just like when all this stuff happened with George Floyd, it would just come up in my dreams. It was just very different than all the [other] times before. And there's so much content showing what's happening. I'm on Twitter, I see all those things. So, I definitely think

that was the main thing that was different then, like, I didn't want to do any drag. We didn't have to do online drag, but that's how the girls were making their money, doing drag videos. And it was like the drag video that I did do were all very somber, and I guess emotional, and more thought-provoking. And so, it did have an effect on me.

Many participants spoke about how these changing interpretations and awareness about police violence made them paranoid, nervous, or scared to navigate White neighborhoods. These concerns affected their capacity to address their basic needs and socially interact, contributing to their potential engagement with the HIV care continuum. Tristan (age 29 years) shared:

I don't wanna go out that much because of everything and the PTSD [Post Traumatic Stress Disorder] and because of that. I'm not gon' lie to you. Also, I was going to say light bulbs blinking in my head when I answer these questions. But also, I felt strange when I do, because when I get on the train, and I do have to go towards more White neighborhoods. And I feel scared of being around White people sometimes too because I don't know. What if somebody gets me like cuffed – I don't know. I just be so paranoid if something's going to happen. When I go around in more predominant White neighborhoods, I feel like I play the part. I'll be polite and might be real extra friendly, and I try to make sure that I'm not like scary to people, if you get what I'm saying.

### **Positive Pandemic Effects: Ability to Reflect and Some Improvements in Care**

#### **More Reflection and Efforts to Socially Connect Contributed to Heightened Self-care**

The effects of COVID-19 on the YBMSM interviewed were not always negative. For some participants, the effects were not negative or positive but made HIV care continuum engagement differently. For others, the pandemic led to deep connections with family and other loved ones and the time to self-reflect, unpack unresolved issues and engage in a deeper level of self-care, which also included living healthier with HIV and supporting HIV care continuum engagement.

Other participants saw the pandemic's policy responses (e.g., shelter-in-place and work from home) as opportunities to deepen social connections, and in so doing, broaden their ability to provide self-care and maintain HIV care continuum engagement. Dale (age 24 years) described the positive dimensions of the pandemic in this way:

It [the pandemic] kind of forced me to be shut up in an apartment with – hell, it gave me the time that I’ve always wanted, the time that we had always dreamed about since the first time we laid eyes on each other. I’m grateful for that. It gave me time to be able to vibe out and connect with my mom on more a platonic level instead of her just being my mother. It allowed me to be able to tackle deeper demons – well, demons that I still had underlying within myself that I will always try to cover up with someone else’s problems. COVID – it’s a bittersweet thing, but I will say a double-edged sword, but this one got a lot of hits to it. But, I’m very appreciative – not of COVID, but just of the lessons that have come about during this pandemic. It’s certain things that you just can’t avoid, and if the one thing that you can avoid is yourself and your own wrongdoings, it’s really nothing else to do outside of make it right.

### Alternate and Improved Receipt of Care

Some participants said that the pandemic did not worsen HIV care continuum engagement but did make this engagement different. Many participants said that many physicians were operating virtually and that this did not disrupt their health care. Cyril (age 30 years) stated:

Nope. Well, yeah, because it kind of makes things ... the places are closed. That’s pretty much it though – or not closed – it’s more of a virtual thing now. The places where I get care like the counseling sessions and having different meetings. Everything is more so like either virtual or in and out situation. [Covid] hasn’t disrupted [my HIV care]. It’s just different.

The elimination of in-person visits for some participants actually focused them on the most important aspects of care. Derrick (age 25 years) shared that he has fewer appointments, and he only really needs to go in person for blood work. He said:

It’s gotten so much easier now because at first, it was like I had to go to the doctor every three months, but now I only have to go to the doctor every six months, which is really just to get my blood tests done. And then, with COVID, I do like a 15-minute telehealth appointment. But before, since I worked at [occupation], it was really just my doctor sending me – or I am on the side saying like, ‘Hey, everything’s okay. Do you have any problems?’ ‘No.’ So, really, the only time I go to the doctor is for something actually going on that doesn’t have to do with HIV, which doesn’t happen often. So, care has been very lax and not difficult to access. I know some people have

issues with their doctors, but I luckily don’t need a lot out of my doctors, like, my blood tests read and my medication to be filled.

Tristan (age 29 years) also expressed his HIV care has not been negatively affected since HIV care appointments have become virtual. He shared that the common screening questions asked by the doctor’s administration office were now completed over the phone and he only had to go in for routine blood work. Tom said:

It hasn’t affected it [medical care] that much because they have switched it up since the COVID happened and all this has happened. They call me. Usually, all the questions and things that they do in the doctor’s office, they call me and do that virtually. And then, when I go in, I just do blood work. So, that way I don’t have to be with that much contact or anything like that, so it’s convenient. And also, since I don’t have to stop doing on phone calls and stuff, I’m glad I can stay in the house.

Numerous participants shared that the COVID-19 pandemic in many ways provided more access to care because medications were delivered to their homes. Tevon (age 28 years) shared:

I wasn’t really affected, but I feel like the pandemic, it kinda helped. It’s more easy access to certain things. Masks, okay, yeah, whatever, but they said this is our last month with them, so I feel like it’s easy. They’re – now they’re delivering medicine because they don’t want people coming in contact with others, just easy things. You really don’t have to leave the house. That’s kinda good too. I mean, certain things, I think that they should consider keeping when we go back to being regular, as they say. Sometimes there’s a thing with transportation. Certain people can’t make it. They have phones. They have Wi-Fi to communicate with their doctor online, and they don’t have to have a big – they don’t have to have some big funding about getting bus cards or bus fare for – it’s all cheap. You could just talk to them through a video.

Similarly, Jerry (age 30 years) reported:

Since COVID – I know my doctor – they usually call me when they have meds for me. And I wouldn’t even remember to call to get meds. But she would call me and tell me they had them. And they usually deliver them by FedEx. So, I didn’t have any issue with that.

Kyle (age 29 years) also mentioned transportation challenges for face-to-face meetings with providers that were overcome with virtual telemedicine. Kyle said:



We go through Zoom. We [also] have this thing called MyChart, there's an app you download, it's called MyChart. You can download it on your app store and you're actually going to be in full control over your health care and things like that. So, you're able to set up appointments, you're able to see time, see date and all these things, and it's actually, it's really good.

## Discussion

The interviews with 28 YBMSM in Chicago highlight the mixed effects of the COVID-19 pandemic on HIV care engagement and their interviews highlighted the additional challenges caused by racial tension over ongoing police violence toward Black men. These data provide some insight into both the challenges YBMSM faced in accessing HIV care during the peak of COVID-19 in 2020 and 2021, but also highlight how various strategies employed by clinics and providers may help improve HIV care engagement for YBMSM going forward (Table 1).

During the COVID-19 pandemic, most participants reported using phone or telemedicine visits for their HIV care. Although this enabled many to remain engaged in HIV care and access ancillary services, participants also described how the lack of in-person visits resulted in delayed blood tests and lab results. Participants also described how the shift away from face-to-face services also meant more limited contact with case managers. As case managers worked to develop a new approach to virtual case management and simultaneously cope with the pandemic themselves and support their clients through the pandemic, some participants fell through the cracks and did not receive the level of care they needed and wanted.

Our findings align with prior research that has shown how the COVID-19 pandemic created barriers to treatment and care services because of the inability of in-person medical visits, staffing disruptions, and fewer blood tests and lab results [29–31]. Additionally, patients have also reported dissatisfaction with online and virtual telemedicine, including needing longer lead time and planning for medical appointments [30]. Our results illuminated that adherence was also disrupted because of the inability to schedule and carry out lab visits, and the confusion by some YBMSM participants about whether their medication regimens were effective if they were COVID-19 infected. This effect has not been documented in any existing literature of which we are aware. Working from home and stay-at-home mandates also served to disrupt work and personal daily routines [32], which also challenged the YBMSM participants' ability to maintain adherence. Participants described, for example, how their daily routines (e.g., waking and eating breakfast at the same time every day or going to bed at the same time)

were disrupted by the COVID-19 pandemic with its employment and schooling changes, which led some individuals to miss medication doses.

The interviews also indicated that the pandemic and concomitant racial and social upheaval may also affect HIV care and ancillary service access among YBMSM with HIV over the longer term. The pandemic coincided with police and neighborhood violence and racial protests following the death of George Floyd. The YBMSM interviewed discussed the complex racial navigating they practiced during the pandemic to reduce racial tension and how neighborhood violence disrupted their HIV care and access to ancillary services. The pandemic for these YBMSM was not just about HIV care and ancillary service access but also centered on how racial politics intersected with economic and health service disruption. What is clear from these qualitative results is that the pandemic is occurring within the context of longstanding disparities in HIV care and ancillary service access. Future research should continue to assess the longer-term effects of the pandemic, particularly, whether the pandemic exacerbated racial/ethnic disparities.

But this analysis also showed that the pandemic's effects on HIV care and ancillary service use by the YBMSM interviewed were not always negative. There were clear positive effects on treatment and access to HIV care and ancillary services that participants thought should be continued post-pandemic. Participants were able to continue their HIV care and ancillary service use because of the increase in the capacity of telemedicine. The use of telemedicine also meant that administrative tasks could be completed via phone rather than in person, with in-person visits focused on lab work. This also eliminated transportation challenges, as some participants reported long or difficult travel to their provider visits. Medications were more often delivered to the YBMSM participants' homes, providing a more convenient way of receiving their medications. These positive effects of the HIV care continuum pivot to accommodate COVID-19 may continue to improve access to care and treatment, but future research should assess the sustainability of such efforts and the effect on HIV care for YBMSM.

As in all studies, there are limitations. While YBMSM is an important population, these findings are only generalizable to YBMSM living in Chicago and similar cities. In terms of recruitment, we employed several diverse recruitment methods to recruit an adequate sample size. Snowball sampling tapping into participants' social networks may have resulted in data saturation being achieved more quickly given that we captured persons with similar profile networks and dynamics. We also used self-reported measures for viral load suppression and ART adherence. Future studies might use more objective measures such as biological markers.

Despite these limitations, our results suggested that even among these YBMSM there was variability in how

participants fared with regard to the impacts of COVID-19 and HIV treatment and care. Some indicated that telemedicine and fewer care visits improved their perception of care while others were dissatisfied because of a lack of in-person care visits and concern about not having up-to-date lab results on their HIV (and for some, COVID-19) medication. Service providers should be aware that YBMSM may respond differently to telemedicine, with some being more satisfied and some continuing to prefer in-person care. Service providers should consider customizing treatment approaches post-pandemic based on the extent to which participants are self-directed regarding their HIV care.

This study focussed specifically on YBMSM who were living with HIV. However, future studies might examine how COVID-19 influenced HIV prevention and testing for YBMSM. Additionally, we used several avenues for recruitment, including partnerships with HIV clinics and service providers. As such, our sample may have higher levels of engagement in care, ART adherence, and viral suppression than their counterparts who are not connected with these organizations and clinics.

## Conclusion

The COVID-19 pandemic has affected HIV care continuum engagement in both negative and positive ways for the YBMSM interviewed for this study. The negative effects confirm existing clinical observations and service provider experience, while the positive effects indicate that there are opportunities for leveraging the lessons learned for systems change. Future research is needed to ascertain the longer-term effects of the pandemic on the HIV continuum of care engagement for varying groups experiencing the twin crises of COVID-19 and structural racism.

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**Authors Contributions** DRV, TE, and LMT conceptualized the paper, conducted the analysis, wrote the first draft and revisions; SV-T, HS, CO, NB, AD and KQ collected the data and wrote revisions. DRV and KQ secured the funding for this research project.

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**Data Availability** Not applicable.

**Code Availability** Not applicable.

## Declarations

**Conflict of interest** There are no conflicts to report.

**Ethical Approval** The study complied with all human subject protocols and there is no conflict of interests. Study protocols were approved by the Institutional Review Board at the Medical College of Wisconsin. Approval Number: PRO00037098.

**Consent to Participate** Participants provided informed consent.

**Consent for Publication** Not applicable.

## References

1. Cucinotta D, Vanelli M. WHO declares COVID-19 a pandemic. *Acta Biomed.* 2020;91(1):157–60.
2. Bradley H, Hall HI, Wolitski RJ, Van Handel MM, Stone AE, LaFlam M, et al. Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV — United States, 2011. *MMWR Morbidity and mortality weekly report.* 2014;63(47):1113–7.
3. Centers for Disease Control and Prevention. Understanding the HIV care continuum. 2019;4.
4. Medland NA, McMahon JH, Chow EP, Elliott JH, Hoy JF, Fairley CK. The HIV care cascade: a systematic review of data sources, methodology and comparability. *J Int AIDS Soc.* 2015;18(1):20634.
5. Engels T, Cheever LW, Hauck H, Dempsey A, Matthews T, Woodland CA, et al. Ryan White HIV/AIDS program: annual client-level data report. 2020. p. 145.
6. Hightow-Weidman L, LeGrand S, Choi SK, Egger J, Hurt CB, Muessig KE. Exploring the HIV continuum of care among young black MSM. Paraskevis D, editor. *PLoS ONE.* 2017;12(6):e0179688.
7. Millett GA, Flores SA, Peterson JL, Bakeman R. Explaining disparities in HIV infection among black and white men who have sex with men: a meta-analysis of HIV risk behaviors. *AIDS.* 2007;21(15):2083–91.
8. Rosenberg ES, Millett GA, Sullivan PS, del Rio C, Curran JW. Understanding the HIV disparities between black and white men who have sex with men in the USA using the HIV care continuum: a modelling study. *Lancet HIV.* 2014;1(3):e112–8.
9. Whiteside YO, Cohen SM, Bradley H, Skarbinski J, Hall HI, Lansky A. Progress along the continuum of HIV care among blacks with diagnosed HIV—United States, 2010. *MMWR Morb Mortal Wkly Rep.* 2014;63(5):85–9.
10. Brooks RA, Etzel MA, Hinojos E, Henry CL, Perez M. Preventing HIV among Latino and African American gay and bisexual men in a context of HIV-related stigma, discrimination, and homophobia: perspectives of providers. *AIDS Patient Care STDS.* 2005;19(11):737–44.
11. Levy ME, Wilton L, Phillips G, Glick SN, Kuo I, Brewer RA, et al. Understanding structural barriers to accessing HIV testing and prevention services among black men who have sex with men (BMSM) in the United States. *AIDS Behav.* 2014;18(5):972–96.
12. Tempalski B, Beane S, Cooper HLF, Friedman SR, McKetta SC, Ibragimov U, et al. Structural determinants of black MSM HIV testing coverage (2011–2016). *AIDS Behav.* 2020;24(9):2572–87.
13. Wright JE, Merritt CC. Social equity and COVID-19: the case of African Americans. *Public Admin Rev.* 2020;80(5):820–6.

14. Jiang H, Zhou Y, Tang W. Maintaining HIV care during the COVID-19 pandemic. *Lancet HIV*. 2020;7(5):e308–9.
15. Mgbako O, Miller EH, Santoro AF, Remien RH, Shalev N, Olender S, et al. COVID-19, telemedicine, and patient empowerment in HIV care and research. *AIDS Behav*. 2020;24(7):1990–3.
16. Ridgway JP, Schmitt J, Friedman E, Taylor M, Devlin S, McNulty M, et al. HIV care continuum and COVID-19 outcomes among people living with HIV during the COVID-19 pandemic, Chicago, IL. *AIDS Behav*. 2020;24(10):2770–2.
17. Sun S, Hou J, Chen Y, Lu Y, Brown L, Operario D. Challenges to HIV care and psychological health during the COVID-19 pandemic among people living with HIV in China. *AIDS Behav*. 2020;24(10):2764–5.
18. Pellowski JA, Kalichman SC, Matthews KA, Adler N. A pandemic of the poor: social disadvantage and the U.S. HIV epidemic. *Am Psychol*. 2013;68(4):197–209.
19. Chicago Department of Public Health. HIV/STI surveillance report, 2019. Chicago: Chicago Department of Public Health; 2020. p. 60.
20. Rao D, Kekwaletswe TC, Hosek S, Martinez J, Rodriguez F. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*. 2007;19(1):28–33.
21. Singh S, Bradley H, Hu X, Skarbinski J, Hall HI, Lansky A. Men living with diagnosed HIV who have sex with men: progress along the continuum of HIV care—United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2014;63(38):829–33.
22. Walker JL. The use of saturation in qualitative research. *Can J Cardiovasc Nurs*. 2012;22(2):6.
23. Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–907.
24. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. *Qual Rep*. 2015. <https://doi.org/10.46743/2160-3715/2015.2281>.
25. Kapogiannis BG, Koenig LJ, Xu J, Mayer KH, Loeb J, Greenberg L, et al. The HIV continuum of care for adolescents and young adults attending 13 urban US HIV care centers of the NICHD-ATN-CDC-HRSA SMILE collaborative. *JAIDS*. 2020;84(1):92–100.
26. Quinn KG, Walsh JL, John SA, Nyitray AG. “I Feel Almost as Though I’ve Lived This Before”: insights from sexual and gender minority men on coping with COVID-19. *AIDS Behav*. 2021;25(1):1–8.
27. Pinto RM, Park S. COVID-19 pandemic disrupts HIV continuum of care and prevention: implications for research and practice concerning community-based organizations and frontline providers. *AIDS Behav*. 2020;24(9):2486–9.
28. Saldaña J. The coding manual for qualitative researchers. 3rd edition. Los Angeles: SAGE; 2016.
29. Thirunavukkarasu A, Alotaibi NH, Al-Hazmi AH, Alenzi MJ, Alshaalan ZM, Alruwaili MG, et al. Patients’ perceptions and satisfaction with the outpatient telemedicine clinics during COVID-19 era in Saudi Arabia: a cross-sectional study. *Healthcare*. 2021;9(12):1739.
30. World Health Organization. COVID-19 continues to disrupt essential health services in 90% of countries [Internet]. 2021 [cited 2022 Jan 23]. Available from: <https://www.who.int/news/item/23-04-2021-covid-19-continues-to-disrupt-essential-health-services-in-90-of-countries>.
31. Yelverton V, Qiao S, Weissman S, Olatosi B, Li X. Telehealth for HIV care services in South Carolina: utilization, barriers, and promotion strategies during the COVID-19 pandemic. *AIDS Behav*. 2021;25(12):3909–21.
32. Buckner JD, Abarno CN, Lewis EM, Zvolensky MJ, Garey L. Increases in distress during stay-at-home mandates during the COVID-19 pandemic: a longitudinal study. *Psychiatry Res*. 2021;298: 113821.

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