#### **ORIGINAL PAPER**



# Mental Health, Social Connectedness, and Fear During the COVID-19 Pandemic: A Qualitative Perspective from Older Women with HIV

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#### **Abstract**

Older women with HIV (WWH) confront significant biopsychosocial challenges that may be exacerbated by the COVID-19 pandemic. Between May 2020 and April 2021, following a resiliency intervention conducted as part of a randomized parent trial, 24 cisgender WWH (M=58 years old) completed quantitative assessments and qualitative interviews exploring the impact of COVID-19 on mental health. Qualitative data were analyzed via rapid analysis. Most participants were Black (62.5%) and non-Hispanic or Latina (87.5%). Emergent themes included (1) increased anxiety and depression; (2) a loss of social connectedness; (3) fear of unknown interactions among COVID-19, HIV, and other comorbidities; and (4) the use of largely adaptive strategies to cope with these issues. Findings suggest that older WWH face significant COVID-19-related mental health challenges, compounding existing stressors. As the pandemic persists, it will be important to assess the impact of these stressors on wellbeing, identify effective coping strategies, and provide increased support to mitigate COVID-19-related mental health issues over time.

**Trial Registration**: ClinicalTrials.gov identifier: NCT03071887.

Keywords HIV · Aging · Women · Mental health · COVID-19

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### Introduction

As of October 2022, the COVID-19 pandemic continues to negatively impact the health and wellbeing of individuals in the United States (US). At the start of 2022, the US averaged more than 800,000 new cases per day for the first time since the first confirmed case of the virus in January 2020, with now nearly 80 million total reported cases and over 967,000 deaths [1]. Specific populations are at higher risk for severe morbidity from COVID-19, including older adults [2] and those with obesity [3], compromised immune systems [4], and other comorbidities [5]. Adults with HIV face elevated risk for COVID-19 and its associated challenges [6, 7]; this may be more pronounced for older women with HIV (WWH). Older persons with HIV represent a growing percentage of the HIV epidemic in the US, with over half of people with HIV estimated to be aged 50 and over in 2018. The proportion of WWH has more than tripled in the past decade, with women over the age of 55 accounting for 17% of newly diagnosed adults in 2021 [8]. WWH already experience increased biopsychosocial stressors at



the intersection of gender, age, and HIV-related comorbidities relative to men with HIV [9–13]. Challenges resulting from the ongoing COVID-19 pandemic may exacerbate preexisting stressors and disproportionately impact older WWH, particularly women of color. Higher COVID-19 death rates documented in communities of color [14] are likely driven by economic disparities – including disparate access to testing and treatment – that are associated with underlying health conditions in these communities (both related to and independent of COVID-19) [15, 16]. As a result of these disparities, women from underserved communities and/or communities of color, who constitute the majority of older WWH in the US [17], may be at heightened risk for major COVID-19-related disruptions in their environments.

The interaction of COVID-19 and HIV—in which the two co-influence one another and interact in ways that worsen health issues or outcomes—has been conceptualized as a syndemic health challenge [18]. Defined as two or more epidemics or diseases that interact synergistically to exacerbate the prognosis and burden of disease [19], syndemics typically develop in the context of health disparities. Within this framework, HIV and its associated challenges may increase the risk of poor COVID-19-related outcomes, and vice versa; for example, women experience more weight gain while on antiretroviral therapy (ART) than men [10], and obesity is a risk factor for COVID-19 morbidity and mortality [20]. COVID-19 may also function in tandem with the many other biopsychosocial difficulties that older WWH must navigate, including mental health symptoms and co-morbid medical conditions. To fully understand the ways in which COVID-19 has affected the lives of older WWH, the pandemic must be considered alongside HIV and the other conditions that already impact this population.

The experience of aging with HIV is associated with psychosocial challenges for women, including high rates of anxiety and depression [21, 22], as well as increased isolation and low levels of social support [23–25]. Societal biases around aging and sexual activity may compound stigma for older people with HIV [26], with particularly negative implications for women (referred to as the "double standard of aging"[9]), who are judged more harshly than men of the same age for their appearance and behavior. For example, signs of aging, including gray hair and facial lines, confer descriptions like "distinguished" and "wise" among men, whereas women are merely perceived to be "old" and may be judged for refusing to "act their age" [27]. The negative impact of intersecting stigmas around ageism (i.e., older people should not engage in sexual activity) and HIV (i.e., people living with HIV should not engage in sexual activity) may therefore be heightened among women. Moreover, relative to men with HIV, WWH are at a disproportionate risk for co-morbid medical conditions, such as cardiovascular disease (CVD), cancer, bone health issues, and metabolic disorders [12]. Older WWH experience more menopausal symptoms than uninfected women [28], which may intensify or complicate the menopausal transition. They also report higher levels of chronic pain and fatigue [29, 30], and, compared to men, they have lower levels of health-related quality of life, as well as greater mortality [13], even after adjusting for the use of ART [11]. For older WWH, these biological factors and common medical issues create a context of chronic stress and serve to increase allostatic load above and beyond the demands of HIV management and its effects on mental health.

The COVID-19 pandemic is now well into its third year. For older WWH who are already navigating chronic stressors, the pandemic and associated increases in isolation resulting from physical and social distancing, per recommendations proposed by the Centers for Disease Control (CDC) and state authorities, may aggravate existing challenges. With increased risk for negative COVID-19 outcomes, these women may have to do more to keep themselves safe from infection. Given the intersecting challenges that older WWH already face, it is important to investigate the psychosocial impacts of COVID-19, the ways in which the pandemic exacerbates existing challenges for this population, and coping strategies that may mitigate overall negative effects. These areas have not been thoroughly explored in the existing literature. In the current study, we aim to fill this gap by leveraging a sample of participants from an ongoing randomized-controlled trial (RCT), completed in April 2021, that assessed the feasibility, acceptability, and preliminary efficacy of a resiliency intervention developed for older WWH. With a subset of the sample, we conducted brief quantitative assessments and semi-structured qualitative interviews to explore the overall impact of COVID-19 on participants' lives, as well as pandemic-related changes in their quality of life and mental health status, interactions with others, engagement in activities, and concerns about COVID-19 infection.

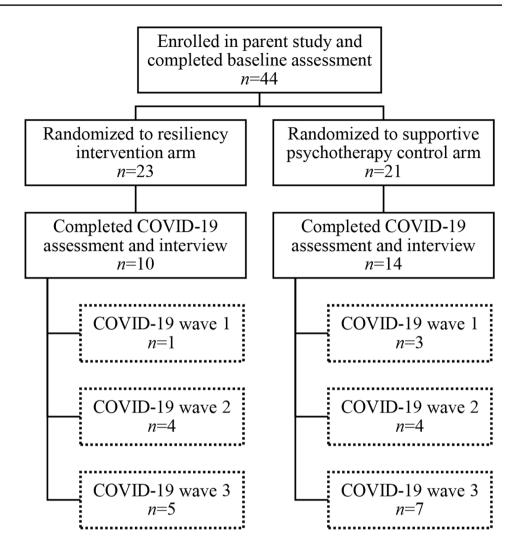
#### **Methods**

# **Parent Study**

In the parent RCT, a total of 44 WWH aged 50 and older were randomized to either a 10-week, group-based resiliency intervention adapted for older WWH (n=23)—which incorporated skills for addressing HIV-related stigma, managing chronic illness while aging, and sexual decision-making—or a time-matched supportive psychotherapy control group (n=21) [31]. In addition to the 10 weekly group



Fig. 1 Parent study recruitment and enrollment flow. Note: COVID-19 waves are approximate, and are defined as follows: Wave 1 (May 2020 through August 2020), Wave 2 (September 2020 through November 2020), Wave 3 (December 2020 through April 2021)



sessions, participants also attended individual assessment visits at baseline, post-treatment, and three months post-treatment, each of which involved a battery of self-report questionnaires. The post-treatment assessment also included an in-depth qualitative exit interview to solicit participants' feedback on their experiences in the study.

Five pairs of groups (both intervention and control arms) were conducted between November 2018 and February 2021. Groups 1–3 were conducted in-person, group 4 was shifted to audio-only Zoom following the onset of the pandemic in March 2020, and group 5 was conducted entirely via audio-only Zoom. Institutional Review Board (IRB) approval was obtained from the Partners Healthcare Human Research Committee (2018P001803).

## **Participants**

All participants for the parent study were recruited via convenience sampling through community outreach (e.g., attending events hosted by local organizations serving the HIV community), flyers posted in waiting areas of Bostonarea hospitals and HIV organizations, and referrals from healthcare providers in the Infectious Disease unit of a Boston-area hospital (chosen due to the high number of WWH who receive HIV care in the unit), and they met the following inclusion criteria: (1) cisgender women; (2) living with HIV/AIDS; (3) age 50 or over; (4) English-speaking; and (4) able and willing to sign informed consent. Exclusion criteria included: (1) presence of an active (i.e., untreated) and interfering psychiatric disorder (e.g., bipolar disorder, schizophrenia, substance abuse) that would make participation in a group-based intervention challenging; and (2) participation in a cognitive behavioral therapy and/or mindbody intervention in the past year. Of the 44 WWH enrolled in the parent study, a subset of 24 participants completed the COVID-19-related quantitative assessment and qualitative interview (Fig. 1).

Among parent study participants who did not complete COVID-19-related assessments (n=20), the reasons included having withdrawn from the study (n=7), being



unreachable or lost to follow-up (n=7), having enrolled but not participated in group sessions (n=2), and declining to complete the standalone COVID-19 assessment (n=4). Though the sample size precludes formal statistical analyses, there were no meaningful differences in age, race, or ethnicity between parent study participants completed the COVID-19-related assessments and those who did not; however, there did appear to be some difference in education level, with at least a high school graduate/GED reported by 66.7% of completers vs. 90% of non-completers.

#### **Procedures**

Participants in Groups 1–3 (who participated in the parent study prior to the pandemic) were invited to participate in an additional assessment visit, which involved a brief quantitative assessment and semi-structured qualitative interview exploring the impact of the COVID-19 pandemic on their lives. These interviews were conducted between December 2020 and April 2021, during the third wave of the COVID-19 pandemic in the US. For participants in Groups 4-5, the COVID-19-related qualitative interview questions were integrated into the existing qualitative exit interview conducted during the post-treatment assessment visit, which were held between May 2020 and November 2020, during the first and second waves of the pandemic (Fig. 1). All qualitative interviews across all groups were conducted from a secure location via audio-only Zoom and led by a trained study research assistant (GRG, AB, NK). Participants were financially compensated for their time via a reloadable debit card.

#### Measures

**Quantitative assessments.** Participants completed the Pandemic Stress Index, a 3-item quantitative measure of behavior changes and stressors experienced during the COVID-19 pandemic (see Table 1) [32]. These data were used to characterize the sample.

Qualitative interviews. Qualitative data was collected using semi-structured interview guide developed in accordance with interviewing guidelines outlined by Huberman and Miles [33] and Strauss and Corbin [34]. Interviews covered participants' perceptions of the impact of the COVID-19 pandemic on their perceived health risks, mental health and quality of life, social interactions and social distancing, concerns about contracting COVID-19, and use of coping strategies. Items were adapted from the Bennett and Elliott Qualitative Interview Guide and Gwadz Qualitative Interview Guide, which were retrieved in May 2020 from an open-source document compiled by The Center for Drug Use and HIV Research (CDUHR) [35, 36]. Sample

interview content areas, questions, and probes are provided in Table 2.

### **Analyses**

Descriptive statistics were calculated to characterize the sample and examine select quantitative variables from the assessment. Consistent with a multi-method approach, the quantitative questions were used to contextualize the sample and assess the number of participants in the sample who endorsed having experienced specific COVID-19-related challenges.

Qualitative interviews were digitally recorded and professionally transcribed. A rapid analysis approach was used [37]. Following this approach, transcripts were first independently reviewed by two study team members trained in qualitative methods (AS, GRG). The reviewers summarized each transcript using a template of neutral domain names (e.g., mental health, quality of life), which was created to align each interview question with a specific domain. The same two study team members iteratively reviewed and compared the data that was summarized within specific domains, resolving discrepancies throughout each stage of the process with oversight from the principal investigator (CP). The domains and corresponding interview summaries were then organized into a matrix, with the intent of creating a quick, accessible inventory of the data contents. Miles, Huberman, and Saldana have described this process as "condensing" the data through selection, simplification, and abstraction [38]. Key themes, defined as those appearing in at least three interview transcripts, were then extracted from the matrix by two team members (AS, GRG) and presented to the full study team (AB, NK, AKL, GKR, ERP) for discussion. Final themes were selected after consensus was reached.

Several steps were taken to ensure the quality of the qualitative data and the analytic process, following the eight criteria (worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, meaningful coherence) established by Tracy [39]. The topic was determined to be worthy based on its relevance and timeliness to the current COVID-19 public health crisis. Rigor during the interview process was achieved though appropriateness and breadth of the interview guide given the goals of the study, the high level of transcription detail, and the opportunities taken by the interviewers to confirm that participants' experiences were correctly understood and interpreted; rigor during the analysis process was ensured through independent tests and iterative refinement of the rapid analysis matrix by multiple reviewers, as well as by transparency among study team members during data summarization and organization. As a study team, we sought to achieve



Table 1 Pandemic Stress Index (PSI) quantitative questions

Sample Questions	Sample $(N=24)$	
	n	%
What are you doing/did you do during COVID-19?		
No changes to my life or behavior	1	4.2
Practicing social distancing	24	100.0
Isolating or quarantining yourself	9	37.5
Caring for someone at home	2	
A child or children	1	50.0
An elderly person	1	50.0
Working from home	6	25.0
Not working	13	54.2
A change in use of healthcare services (e.g., calling your healthcare provider, going to urgent care)	14	58.3
Increase in use of healthcare services	4	28.6
Decrease in use of healthcare services	10	71.4
How much is/did COVID-19 impacting/impact your daily life?		
Not at all	0	0
A little	6	25.0
Much	2	8.3
Very much	7	29.2
Extremely	9	37.5
Which of the following are you experiencing (or did you experience) during COVID-19?		
Fear of getting COVID-19	20	83.3
Fear of giving COVID-19 to someone else	12	50.0
Worrying about friends, family, partners, etc.	22	91.7
Stigma or discrimination from other people (e.g., people treating you differently because of your identity, having symptoms, or other factors related to COVID-19)	6	25.0
Personal financial loss	12	50.0
Frustration or boredom	18	75.0
Not having enough basic supplies (e.g., food, water, medications, a place to stay)	6	25.0
More anxiety	15	62.5
More depression	13	54.2
More sleep, less sleep, or other change to your normal sleep pattern	14	58.3
Increased alcohol or other substance use	1	4.2
A change in sexual activity	3	12.5
Loneliness	14	58.3
Confusion about what COVID-19 is or how to prevent it	2	8.3
Feeling that I was contributing to the greater good by preventing myself or others from getting COVID-19	21	87.5
Getting emotional or social support from family, friends, partners, a counselor, or someone else	16	66.7
Getting financial support from family, friends, partners, and organization or someone else	10	41.7
Other difficulties or challenges	5	20.8

sincerity throughout data collection and analysis by recognizing the ways in which our own biases and goals may shape and influence our interpretations. Credibility of the data and findings, which is earned through reliability and consistency, was achieved in part by triangulation such that multiple members of the study team converged on the same conclusions. Resonance, which Tracy defines as the ability of the research to meaningful reverberate and affect an audience, was reached through the selection of evocative quoted text and rich description of participant experiences. Given the lack of published data on the mental health and wellbeing of older WWH during the COVID-19 pandemic, the analyses were judged to significantly contribute to the

literature by extending existing knowledge and generating ample questions for ongoing research. The data collection and analysis process was deemed ethical procedurally (i.e., via IRB approval), situationally (i.e., via iterative reflection on our methods, the context of the pandemic, and the data worth exposing), and relationally (i.e., via ensuring respect and dignity between researchers and participants). Finally, we achieved meaningful coherence by accomplishing the stated purpose of the analyses, with face validity, and situating our findings in context.



Table 2 Sample interview content areas, questions, and probes

Content area: Impact of COVID-19 on	Sample questions and probes
Perceptions of risks to health	Which are the biggest risks to your health right now? Why do you feel that way? What would help you the most right now in terms of limiting those risks or feeling safer? What stands in the way of that?
Mental health and wellbeing	How has the coronavirus outbreak impacted your mental health and wellbeing? Which are the biggest risks to your mental health right now? Why do you feel that way? What would help you the most right now in terms of limiting those risks or feeling safer? What stands in the way of that?
Quality of life	Are you more or less socially connected? Are you more or less engaged in activities? Are you feeling more or less bored? How do these experiences or feelings affect your ability to manage your health?
Social interactions and social distancing	How have you changed how much you stay home or who you interact with as a result of the coronavirus? If so, please describe. If not, what have you heard about any recommendations about staying at home or "social distancing"?
Concerns about contracting COVID-19	How concerned are you about contracting coronavirus? Why or why not?

### Results

## **Sample Characteristics**

Twenty-four WWH completed quantitative assessments and qualitative interviews. The mean age of the sample was 58 years old (SD=5.7). Participants were primarily Black (62.5%) and non-Hispanic or Latina (87.5%). Most had less than a college degree (79.2%) and an annual income of \$40,000 or less (70.8%), and half were receiving disability payments or retired (50%). The majority of the sample identified as exclusively heterosexual (83.3%), half were single (50%), and all but one had been diagnosed with HIV more than 5 years prior to the assessment (95.8%). Full sociodemographic data are presented in Table 3.

Notably, 37.5% of participants (n=9) were recruited for the parent study through events or flyers at community organizations for people living with HIV, 54.2% (n=13) were recruited at medical appointments or via flyers at healthcare facilities, and 8.3% were recruited via word-of-mouth referrals from friends.

## **Quantitative Findings**

All participants reported engaging in social distancing since the onset of the COVID-19 pandemic, and over one-third (37.5%) reported isolating or quarantining. More than half

 Table 3 Participant demographic characteristics

Variable	Sample $(N=24)$	
	n	%
Age (in years)		
Mean (SD)	58 (5.7)	_
Range	50-71	_
Race		
Black/African American	15	62.5
White	7	29.2
Multiracial/Other	2	8.3
Ethnicity		
Hispanic or Latina	3	12.5
Not Hispanic or Latina	21	87.5
Education*		
Less than high school degree	7	30.4
High school graduate/GED	7	30.4
Some college/Associate degree/Technical school	5	21.7
College graduate	2	8.7
Master's degree	2	8.7
Employment		
Full-time	5	20.8
Part-time	5	20.8
Disabled/Retired	12	50.0
Other	2	8.3
Income (annual, USD)	_	0.5
\$10,000 or less	7	29.2
\$10,000 to \$20,000	8	33.3
\$20,001 to \$40,000	2	8.3
\$40,001 to \$60,000	4	16.7
\$60,001 to \$80,000	1	4.2
Over \$80,000	2	8.3
Sexual orientation	2	0.5
Exclusively heterosexual	20	83.3
Heterosexual with some same sex experience	4	16.7
Relationship status	4	10.7
Single	12	50.0
Married/Partnered	9	37.5
Separated/Divorced	1	4.2
1	2	8.3
Widowed	2	0.3
Years since HIV diagnosis	1	4.2
Less than 5 years	1 1	4.2
5 to 9 years		4.2
10 to 19 years	6	25.0
20 to 29 years	12	50.0
30 to 39 years	3	12.5
More than 40 years  Note: * Data missing from one participant. Per	1	4.2

Note: \* Data missing from one participant. Percentages may not total 100 due to rounding.

GED: General Educational Development test.

(54.2%) reported not working as a result of the pandemic, and 58.3% reported that COVID-19 had changed their use of healthcare services. Two-thirds (66.7%) reported that COVID-19 was impacting their daily lives "very much" or "extremely." Fear of COVID-19 infection was common



(83.3%), as was a reported COVID-19 related increase in anxiety (62.5%), depression (54.2%), and loneliness (58.3%).

# **Qualitative Findings**

Several themes emerged from the qualitative interviews. With respect to the overall impact of COVID-19 on participants' mental health and wellbeing, the four key themes included the following: (1) increased anxiety and depression; (2) a loss of social connectedness and associated isolation; (3) fear of unknown interactions among COVID-19, HIV, and other comorbidities; and (4) the use of predominantly healthy and adaptive strategies to cope with mental health challenges, isolation, and fear.

Increased anxiety and depression. Participants described increases in anxiety (e.g., daily worries, anxious thoughts about engaging in certain activities, fears of death, panic) and depression (e.g., low mood, anhedonia) following the onset of the COVID-19 pandemic. For some women, typical daily activities, like picking up medication or attending a medical appointment became associated with additional anxiety or different forms of anxiety (e.g., specific fears of contracting COVID-19, concerns about COVID-19 impacting concentration). One participant explained the ways in which her anxiety and depression, which existed prior to COVID-19, began to shift and grow throughout the pandemic:

I'm more anxious because places that you normally would go that would bring no anxiety to you, bring anxiety to you... I had anxiety and depression before this... [but] going to the supermarket never brought anxiety to me, or to CVS, or to the hospital. But now when I have to go... I had to have an upper endoscopy during this, and oh, my God, the anxiety I was feeling during that was just so, so much. I don't think I would have felt that anxiety under normal circumstances. (Age 50, White, COVID-19 wave 3)

Another participant described a decrease in her desire to engage in activities that she used to enjoy prior to the pandemic. When viewing news reports about the pandemic on television, she became depressed, experienced anhedonia, and felt her body move more slowly:

Just losing interest in most of the things... I'm at a slower pace. When I look on TV, you see people dying. You don't know what's going to happen next. (Age 50, Black/African American, COVID-19 wave 3)

For some women, fears of death due to COVID-19 were exacerbated by anxiety, creating a negative feedback loop. For example, the participant quoted below explained that her fear of acquiring COVID-19 led to heightened anxiety, which then increased negative physiological symptoms, leading to the perception that she had been infected with COVID-19, which then further increased her fear.

My God. Don't even mention. I feel like I'm going to die... I'm so scared of dying... And I'm very scared of being incapacitated... I'm germophobic. I fear germs... I have anxiety. And then I get anxiety, I stop breathing. So in case if somebody coughs, say, I go to an ATM and somebody coughs, to tell you the truth, I leave as if I'm sick. I start feeling funny. (Age 50, Black/African American, COVID-19 wave 3)

COVID-19-related stressors and associated anxiety also compromised one participant's ability to concentrate. For this woman, forgetting a planned activity or feeling unable to concentrate on a given task due to concerns about potentially failing to protect herself from COVID-19 contributed to functional impairment, confusion, and reduced quality of life:

I feel I'm not focused...Because I can see that I'm forgetting too much. On top of that, I can think about doing something... I can say, "Oh, I'm going to do this." And then I turn around. I forget what I'm going to do. (Age 50, Black/African American, COVID-19 wave 3)

#### Loss of social connectedness and associated isolation.

Most participants described a sense of loss surrounding the lack of family gatherings, community activities, and resources. These losses resulted in significant time spent in isolation and increased participants' feelings of frustration and loneliness related to the pandemic. For WWH, who often feel stigmatized by others in a range of contexts, the increased isolation and subsequent loneliness may have additional consequences for mental health and quality of life. One participant described the loneliness associated with separation from family and other sources of support as one of the most negative effects of the pandemic:

What affects me is just the time alone that you have because of the social distancing, and you can't have a lot of people around. That is what affects me, if anything, because you get tired of being by yourself. (Age 53, Black/African American, COVID-19 wave 3)



Another participant discussed weighing her desire to spend time with family against the possibility that she might be responsible for transmitting the virus to her loved ones, reminiscent of concerns that older WWH have likely experienced in the context of HIV transmission. Though engaging with others and participating in celebrations may have helped alleviate the loneliness described by most other participants, she ultimately decided to stay home:

When my grandchild was having birthday, I couldn't go there. I couldn't go with them. So... you want to go visit, but you don't know whether you have been going to these other places, you're taking the disease to somebody, so you're guilty. (Age 62, Black/African American, COVID-19 wave 2)

In addition to lamenting the loss of time spent with family, participants also noted the loss of community resources, many of which have been shuttered, temporarily cancelled, or reformatted. Many WWH rely on community centers and resources that cater to persons with HIV and offer specific activities (e.g., educational content on developments in HIV care and treatment, crafts, exercise classes), tangible support (e.g., meals and transportation vouchers), and emotional support. The participant below described the devastating closure of a monthly support group that had been an established resource for WWH for over 20 years:

I sit on the board of this group that we have... for women, by women, nurse-driven, and peer-led. And it started off only with women HIV-positive or living with AIDS, but we grew into women that are not positive, or may have positive family members, or are homeless, or getting clean from drugs... and COVID has now shut us down. We've lost women, we've cried with women, we've gone to funerals as a group. We go to hospitals to visit women, or their homes if they're sick, as groups...So a lot of our women are isolated now... Even if they weren't positive, that was their monthly place to come. They had an opportunity, for two and a half hours, to feel wonderful. And COVID has taken that from us, on top of COVID infecting us. (Age 58, Black/African American, COVID-19 wave 3)

The cancellation of community programing has also had negative indirect effects on shared connections with others, including among larger social circles, and on overall community stability. For example, one participant explained that the general negative impact of the COVID-19 pandemic, combined with the specific consequences of its management in her neighborhood, including the closure of her gym, has

led some of her friends to move to more rural areas of the state that they perceive to be safer.

Not being able to connect with resources that I used to. All my groups that I used to go with. Going to the gym is a big one. Because that was part of my social life, going to the gym—connecting with people who were interested in the same kind of thing as me exercise-wise...A good friend of mine that used to do a lot of stuff together—gym and shopping and stuff like that—she's hibernating...[and] because of the pandemic, and also because of what's going on where I live, several good friends have moved. (Age 66, White, COVID-19 wave 3)

In some cases, community programming was adjusted to serve WWH during the pandemic. Although many group-based resources for people with HIV were cancelled, compromising social connectedness and increasing loneliness, some programs were modified and brought directly to women in their homes. In one case, this shift in program format was associated with a strong sense of appreciation:

I used to go to the day program, and that's closed down...[so] they came to us. They brought our arts and crafts so we could do it for the week. They gave us hand sanitizer and talked to us, kept taking our weight and that thermometer, make sure we were all okay. It was like they really cared. No other program went and did that. (Age 63, White, COVID-19 wave 3)

In another case, one participant described how, even though her HIV support group has resumed following an initial closure during the early phases of the pandemic, attending the groups now feels "different." The participant mentioned the physical distance created by masks as a factor that influenced her decision to stay home alone:

I used to go to my HIV support groups every Friday, but I don't go as much as I used to because before the pandemic... most of the days I don't even go because I feel like it's different. We've got to keep our masks on at all times... This Friday we have a group, but I'm not going. (Age 50, Black/African American, COVID-19 wave 3)

Fear of unknown interactions among COVID-19, HIV, and other comorbidities. Mental health challenges and social isolation occurred alongside fears of acquiring COVID-19, lack of certainty around the physiological effects of the virus, and its potential interactions with HIV and other HIV-related comorbidities. The majority of women



in the sample described uncertainty about COVID-19, their already compromised immune systems, and the increased possibility of death given their health status. One participant highlighted concern about the unknown interaction effects of HIV, ongoing cancer treatment, and COVID-19:

I'm very concerned about that because I'm one of those people. I'm in treatment for chemo... I'm a double triple compromised immune system. So I get up and I go out, but I'm in protective gear... If someone's close to me, not only will I give you the eye, but I will vocally say, "I'm six feet." I'm concerned because I don't want to get it, because I don't know how it would affect me. I've known people that have had it, and they're doing much better. But everyone's situation is different, and my situation is different. (Age 53, Black/African American, COVID-19 wave 2)

The participant below expressed a similar sentiment:

My immune system will not take it as well as a healthy person... So yeah, it gets frustrating, it gets nerve wracking when you go out, if you have to go out... If I get it, I'm done, to be honest. I don't want to go in an incubator, and I don't want to be resuscitated. So I'm in a spot where it's do or die. (Age 59, Race not reported, COVID-19 wave 3)

Although some women were less concerned about a potential increased likelihood of death in the event that they contracted COVID-19, they still expressed uncertainty about how COVID-19 would interact with HIV, which led to significant health concerns. One participant ruminated about these potential interactions in "little moments" over time:

I think the fear of the unknown was one of the biggest [challenges] in the beginning... And then the number one reason would be, I didn't know it interacted with HIV. And if I catch it with HIV, am I a complete goner? Those type of things, or just little moments, would happen... That part was very, very, very, very, very touchy for me. (Age 52, Black/African American, COVID-19 wave 3)

Use of generally adaptive strategies to cope with mental health challenges, isolation, and fear. In spite of the many pandemic-related difficulties described above, women also reported using a range of strategies, some highly adaptive, to cope with and remain resilient in the face of these challenges. One commonly reported combination of strategies was prayer and meditation. The two participants quoted

below described the calming effects of pausing to pray and/ or meditate:

I get up every day, and I'm grateful, and I thank God every day that I get up. And I sit with self, and I meditate and have my quiet time... There's nothing I can do about the coronavirus. The only thing I can do is just to make sure I keep myself mentally sane and keep myself protected and pay attention to what I'm doing. (Age 53, Black/African American, COVID-19 wave 2)

I pray. That's one thing I do is I pray, and then, the next thing I do is, I have a rock collection. May sound silly... I'm 55 years old, and I have a rock collection. I put them in my hand and just roll them around in my hand, and it makes me feel better. And I look out my window. I have two beautiful trees that I look at all the time, and they also calm me too. (Age 53, Black/African American, COVID-19 wave 3)

Other participants described approaching the COVID-19 pandemic with mindfulness, which helped them to stay focused on the present moment, rather than looking to the future to anticipate negative events. One woman noted that her consistent, long-term engagement with mental health services and continued support from her provider and community, as well as her experience living with HIV, have helped her to remain mindful during the pandemic:

I've had a psychiatrist that I've worked with for 30 years...I have the support of neighbors and friends and family. I don't feel any isolation, or I don't feel any psychological negative impact from [COVID-19]...I tend to live in the moment. That was another thing about living with HIV. You very much learn some of the Buddhist practices about living in the moment. And I've been living in the moment for a very long time. (Age 61, White, COVID-19 wave 3)

Acceptance – a practice that is distinct from but related to mindfulness – also featured prominently in participants' descriptions of their coping strategies. For some, acceptance was defined by learning how to live during the pandemic and using COVID-19 as a "teaching tool" for learning how to "get back to life":

We need to learn to live with it now, and not hide. For me, we just have to get over it and get back to life. But it's not as easy for some people, and I have to respect that, as well. So COVID is just not a good friend. But it's a teaching tool, that's for sure. (Age 58, Black/African American, COVID-19 wave 3)



For others, acceptance may involve finding a careful balance between attempts to eliminate risk (i.e., "living in a bubble") and embracing all of the opportunities that life offers, without being controlled by fear:

I'm not living in a bubble. I want to be able to go and travel. I do. I just want to be able to be careful, mindful, and successful at living. I cannot allow myself to continue to be afraid or anxious because I might get it. (Age 52, Black/African American, COVID-19 wave 3)

For a few women, helping others functioned as a coping strategy. For example, one participant's low mood and increased anxiety led her to reach out to individuals in her life whom she described as being "really alone" and in need of support. She described calling friends and family members whom she felt had more needs or were perhaps more isolated than she was:

It's definitely made me more depressed, more anxious, more sad... whereas, before this, I wasn't crying at the drop of a dime in a bucket, but now I am. But it's also made me, on the flip side of things, want to reach out more to those people that are really alone... friends, family members, that are literally alone, that go food shopping, maybe, if they have to – but alone. (Age 50, White, COVID-19 wave 3)

A few participants described the use of maladaptive coping strategies when faced with COVID-19-related depression, anxiety, and isolation. One participant recognized that her main coping strategy – eating – was likely unhelpful, noting that she has not yet been able to effectively navigate COVID-19-related concerns in the same ways that she had approached previous challenges.

I definitely have gained 15 pounds. Because instead of dealing with the things I used to—how I would deal with things, I'm eating. Emotional eating. It's not going to kill me. But it's not the best thing to do either. (Age 66, White, COVID-19 wave 3)

For another participant, the sadness and low mood associated with the pandemic and efforts to manage COVID-19 transmission led to increased alcohol use. Indeed, for the participant quoted below, COVID-19-related stressors, a lack of usually available coping strategies (e.g., Alcoholics Anonymous meetings), and a perceived lack of additional actions that she herself could take made it challenging to maintain her sobriety:

I be depressed, then I find myself drinking more... Just sitting home alone, drinking. And I told myself today I'm not drinking anything... I already am a recovering alcoholic, practicing recovery. So I find myself getting more depressed... I done did everything in my home I could do... I made masks. I helped my neighbors. I don't know what else to do... I just watch the news, and I break out crying sometimes. (Age 59, Black/African American, COVID-19 wave 2)

#### Discussion

In this analysis of multi-method data collected from a subset of older WWH who participated in a pilot RCT assessing the feasibility and acceptability of a group-based resiliency intervention, the majority of participants quantitatively reported that the COVID-19 pandemic was significantly impacting their daily lives. Most were living in fear of COVID-19 infection, and had experienced increases in anxiety, depression, and loneliness during the pandemic. With respect to the qualitative interviews, four themes related to the impact of COVID-19 on psychosocial wellbeing and quality of life emerged. Though recent studies have documented negative, COVID-related impacts on engagement in HIV care and HIV prevention services at different phases of the pandemic, both in the US [40] and in other contexts [41], relatively little attention has been paid to the psychosocial sequelae of the pandemic across HIV-affected populations, including older adults. The few papers that have addressed wellbeing and mental health among older individuals with HIV are commentaries [42] or sampled primarily White, gay men [43]. Older WWH, and specifically older Black/ African American WWH (who comprise the majority of our sample), have therefore not been the focus of previous work, even though they face disproportionate risk for comorbid medical conditions, increased pain and fatigue, and lower health-related quality of life relative to men with HIV [12, 13, 44, 45].

First, participants described increases in anxiety and depression over the course of the COVID-19 pandemic, with different manifestations of worry and sadness but shared concerns about acquiring COVID-19 and common experiences of low mood. These findings align with those of other studies that documented increased mental health concerns among populations with existing conditions, such as Parkinson's disease [46] and different types of cancer [47], during the pandemic. Similar reports that broadly assess mental health challenges in populations with HIV have been published, with one reporting prevalence rates of 22.7% and 23.3% for anxiety and depression, respectively [48]; the



authors noted that, though differences in methodology preclude direct comparison, the prevalence rates for depression during the pandemic are higher than corresponding prepandemic levels, whereas anxiety rates appear to be similar prior to and during the pandemic. However, in our sample, the majority of women who reported anxiety during the pandemic expressed that their anxiety was different or more intense than their anxiety pre-pandemic. These descriptions suggest an exacerbation of existing challenges—potentially related to existing physical health problems and comorbid conditions but also to ageism, sexism, and racism [26, 49], among the Black/African American women who participated—that are not accounted for in analyses that only assess mental health disorder prevalence rates. Although none of the participants in the current study explicitly drew a connection between experiences of racism and poor mental health during the height of the pandemic, racism may have been a contributing factor to the high levels of anxiety described by participants, especially in the context of several high-profile police killings of Black Americans and widespread antiracism protests in 2020. Indeed, the impact of these events on the mental health of Black Americans has been documented elsewhere [50]. Increased awareness of the unique ways in which COVID-related anxiety and depression interact with pre-existing mental health issues and pose new challenges for older WWH will inform the development of innovative approaches to mental health treatment and service delivery for this population during future outbreaks.

The second theme that emerged from the data was a loss of social connectedness and associated isolation, which likely comes at a particularly high cost for older adults [51], who are often functionally dependent on family members or community services. Much like most individuals, women in this sample reported a strong sense of loss due to a lack of family connectedness, gatherings, and social interactions during the pandemic. These losses may have been particularly challenging for older adults, as they are less likely to be familiar with new video communication technologies that have enabled people to stay connected during the pandemic, and these video interaction styles may not effectively serve their emotional needs [51]. But, more so relevant to older WWH, participants described the loss of critical community resources and gathering spaces when local agencies that serve populations with HIV shuttered their doors. Community programming acts as lifelines for many older WWH; without these resources, spaces to gather, and access to HIV-related information and services, women were left feeling isolated and lonely, which is not only distressing [52, 53] but has negative implications for health and wellness. Among older adults with HIV, there are documented pre-COVID-19 associations among loneliness, depression,

and substance use, and loneliness is a strong predictor of functional impairment and poor health-related quality of life [54]. Loneliness and isolation may also increase risk for cognitive impairment [55]. Much like ensuring that mental health services can continue via telehealth and/or other strategies during public health crises, the centrality and importance of community programming for older WWH suggests that adjustments to the delivery of these resources will also need to be made to prepare for future crises.

Third, women described a fear of the unknown and discomfort with uncertainty, especially with respect to as yet unidentified or inconclusive data on potential interactions between COVID-19 and HIV. An uncertain and continuous threat, like the threat of COVID-19 acquisition, can become chronic and highly burdensome [56]. Moreover, with a high number of asymptomatic individuals and inconsistencies in the availability of at-home and community-based testing, reports on current infection and fatality rates are likely inaccurate. Therefore, participants could not be certain that those around them were not infected (or that they themselves were not infected), nor could they predict the emergence of new variants or peaks in infection rates. This host of unknown variables, combined with a lack of longitudinal data on long-term interaction effects of COVID-19 and HIV, led to heightened concerns about what the future and the "new normal" might actually look like for individuals who are already immunocompromised. Fear of the unknown, though a core component of anxiety [57, 58], is worthy of individual attention for populations with HIV, HIV-related comorbidities, and other conditions that compromise the immune system. With older WWH more likely than men to experience certain HIV-related comorbidities [12] and HIV-related mortality, they may be at risk for heightened anxiety around situations that are unpredictable or impossible to control.

Finally, the last theme that emerged from these interviews was the use of largely adaptive coping strategies, though a minority of women noted that they relied on relatively maladaptive or unhealthy strategies. Adaptive strategies included prayer, meditation, staying mindful and present, acceptance-based approaches, and helping others perceived to be in greater need, whereas the maladaptive strategies mentioned were eating and substance use to manage negative affect. Resilient coping is known to buffer the negative impact of stressors on mental health. For example, seeking social support, one form of resilient coping, has been shown to help people with HIV cope with the negative impacts of the COVID-19 pandemic [59]. Other strategies, like mindfulness- and acceptance-based coping have not been widely discussed in the context of the pandemic, though mindfulness-based interventions that include these strategies have been demonstrated to be acceptable/feasible among older



women with HIV [60]. Outside of the pandemic context, older WWH have described making meaning of their diagnoses by providing service to others living with HIV and by joining community groups to support those who were recently diagnosed [52]. These findings align with participants' descriptions of reaching out to friends who they perceived to be "more alone" or have comparatively less resources than they did during the COVID-19 pandemic. The use of unhealthy coping strategies, like drinking alcohol and eating to manage distress, suggests that additional telehealth supports, particularly for substance use, need to be consistently available and offered to older WWH, even if they do not volunteer their need for such services to their providers.

These findings provide insights that can be taken into consideration when developing or adjusting service delivery models for WWH to prepare for the emergence of new COVID-19 variants or other future health crises. WWH who are actively engaged in HIV care have relatively frequent contact with their HIV care providers. These providers need to proactively ask their patients about anxiety, low mood, and isolation rather than waiting for their patients to communicate these challenges. Integrating exercises or strategies that increase tolerance of uncertainty into mental health treatment models or community programming may benefit WWH, who continue to face many "unknowns" about longterm interactions between COVID-19 and HIV. Uncertainty tolerance has been associated with emotional wellbeing and other positive patient health outcomes [46], and interventions and curricula have successfully reduced the perceived threat of ambiguity among populations that face significant uncertainty (e.g., medical students, individuals with multiple sclerosis or other conditions for which disease course is not certain) [61, 62]. In addition, increased flexibility of format and delivery method (i.e., continuation of telehealth services, expansion of options for virtual gatherings and interactions) for community-based and other social support resources should be a priority for older WWH. This suggests the importance of implementation science-based research that assesses innovative models for the provision of resources on which older WWH rely.

Several limitations of the current study should be noted. Small sample sizes are typical of qualitative work, but the size of our sample limited our ability to separate the data by phase of the COVID-19 pandemic. Therefore, we could not draw conclusions about psychosocial challenges that may have been unique to specific time points over the ongoing pandemic's duration. Though there were no notable differences in theme invocation by group modality, it is possible that women who participated in the in-person vs. audio-only Zoom groups had different levels of comfort disclosing their experiences or revealing their COVID-related concerns

to the interviewer. In addition, participants who were not included in this qualitative sub-study either withdrew from the parent study, did not participate in group sessions, were unreachable or lost to follow-up, or declined to complete the additional COVID-19 assessment. These women may have had different or worse experiences than those who participated in the qualitative interviews. Similarly, participants were recruited from the parent study from community organizations for persons with HIV and healthcare facilities, and as such, they were already linked to community resources and engaged in care. There may therefore have been a selection bias towards a more resilient sample, with the understanding that WWH who are not connected to community supports or healthcare providers may also have had different or worse experiences than those who participated in the qualitative interviews. The phrasing of certain items on the Pandemic Stress Index (e.g., "more depression", "more anxiety") may have resulted in more endorsements that might have occurred otherwise if more balanced language had been used. Finally, it is possible that the intervention tested in the parent study contributed to participants' use of adaptive coping strategies, as intervention content included guidance on meditation, mindfulness, and acceptance-based strategies [60]. However, both women randomized to the control condition, a supportive psychotherapy group that did not teach coping strategies, and women randomized to the intervention group were included in this analysis, decreasing the risk that this finding was driven by the intervention content. Given the nature of the analyses and the size of the sample, the data were not analyzed by condition.

In conclusion, older WWH have faced significant psychosocial challenges during the COVID-19 pandemic, above and beyond their pre-existing stressors. As the pandemic persists and as other public health crises emerge, providers and community agencies that serve this population should (1) be aware of potential increases in anxiety, depression, isolation, and fear of the unknown and (2) proactively address these concerns at both an individual and systems-level.

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#### **Declarations**

Competing Interests All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

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