Impact of the COVID-19 Pandemic on Persons Living with HIV in Western Washington:

Examining Lived Experiences of Social Distancing Stress, Personal Buffers, and Mental Health

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Abstract

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Background: People with pre-existing mental health conditions may be more susceptible to stressors associated with COVID-19. Understanding the psychosocial impacts of the pandemic for people living with HIV (PLWH) is critical, as they are already disproportionately at risk for common mental disorders such as depression and anxiety, and poor mental health is a predictor of negative HIV-related outcomes. We explored how PLWH in Western Washington State are coping with the COVID-19 pandemic.

Methods: Stratified, purposive sampling was used to recruit 24 patients from the University of Washington HIV patient registry, who had participated in a quantitative survey on COVID-19 experiences, to participate in semi-structured individual interviews (IDIs). IDIs were conducted by Zoom, were audio recorded and transcribed. Thematic analysis, including a combination of inductive and deductive coding approaches, was used to develop an adapted stress-coping model to holistically capture participants' experiences during the first year of the pandemic.

Results: Although fear of acquiring COVID-19 was not a major stressor in their lives, participants felt acute stress following exposure events and symptoms compatible with COVID-19. Participants described experiencing longer term stress as a result of social distancing guidelines, which increased isolation and feelings of loneliness. Participants employed adaptive coping strategies, including cognitive coping techniques and physical exercise, to combat prolonged stressors and promote mental health. Participants who experienced multiple stressors simultaneously were less likely to be able to adopt positive coping behaviors, and increasingly engaged in maladaptive coping strategies. Healthcare providers were an important avenue of social support for PLWH, providing consistency in care, and referral and provision of mental health and social services.

Conclusion: Our qualitative evaluation of lived experiences of PLWH in Western Washington suggests that social isolation and job loss are linked to higher levels of stress during the COVID-19 pandemic. PLWH should be encouraged to practice cognitive coping techniques and physical exercise while following social distancing guidelines. Likewise, maintaining social ties by providing and receiving social support is recommended. Healthcare providers and social workers ought to continue making concerted efforts to connect with their patients to address both HIV and non-HIV related needs, as the pandemic influenced numerous facets of daily life.

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INTRODUCTION

The first case of COVID-19 in the United States was reported in Western Washington in January 2020.[1] The World Health Organization declared COVID-19 a global pandemic in March 2020 and shortly thereafter, Washington State implemented a wide range of social distancing measures.[1,2] The COVID-19 pandemic has since laid bare social and health inequities throughout the United States, including in Washington State. Numerous published reports have indicated that COVID-19 has disproportionately impacted vulnerable populations such as racial and ethnic minorities, individuals experiencing homelessness, and other marginalized groups.[3,4,5,6] Prior evidence also suggests these same communities are most vulnerable to and affected by HIV.[6,7,8,9]

At the same time, a growing body of literature posits that people with pre-existing mental health conditions may be more susceptible to stressors associated with COVID-19 relative to the general population.[10] As such, gaining an improved understanding of the psychosocial impacts of the pandemic for people living with HIV (PLWH) is critical, as they are already disproportionately at risk for common mental disorders such as depression and anxiety,[11,12,13] and poor mental health is often a predictor of substance use, poor treatment adherence, and negative HIV-related outcomes.[14]

According to a scoping review published in May 2021, nearly 70% of research investigating the impacts of COVID-19 on PLWH were focused on clinical outcomes, with less than 8% involving qualitative research.[13] While these contributions are invaluable, it is equally if not more important, to understand the social impacts of the pandemic, and in what ways the mental health of PLWH was affected given disruptions in service delivery, socioeconomic concerns, and the establishment of social distancing protocols. Qualitative methods provide powerful analytical approaches that complement epidemiological studies,[15] and may offer important insight regarding mental health and other determinants of clinical outcomes. Without addressing these gaps in knowledge, clinicians and social service providers may not fully understand *how* PLWH responded to and made meaning of the COVID-19 pandemic,[15] and in what ways adaptive and maladaptive coping strategies were adopted.

To address this gap in knowledge, our team conducted a qualitative study to explore the lived experiences of PLWH in Western Washington during the first year of the pandemic. Our study aimed to better understand how the pandemic impacted daily life, and identify factors that prevented individuals from experiencing symptoms of anxiety and depression. Participant experiences were used to develop an adapted stress-coping model, which identifies causes and effects of COVID-19 related stress, as well as factors which promoted successful coping. Research findings will add to emerging evidence regarding stress and coping during the pandemic, and can inform future research and service provision taking a strengths-based and resiliency perspective.[16,17]

My aims in conducting this study were two-fold: (a) to explore the ways in which COVID-19 has impacted PLWH in Western Washington and how personal protective factors or “buffers” helped cope with challenges; and (b) to develop a tailored stress-coping model to reflect PLWH’s experiences during the COVID-19 pandemic that 1) articulates common mechanisms through which COVID-19 impacted mental health and 2) identifies factors that led to successful coping or promoted resilience.

METHODS

Study Design and Population

As part of the University of Washington HIV and COVID Study, in-depth interviews (IDIs) were conducted with a subset of patients from the University of Washington HIV patient registry who participated in a cross-sectional, online survey to evaluate experiences with and impacts of COVID-19 social distancing on a range of health outcomes. Individuals were eligible to participate in the survey if they were ≥18 years and had internet access. Survey recruitment was done via email and text message. After consenting, participants were asked a series of questions related to sociodemographic characteristics, COVID-19 impact, personal buffers, mental health, substance use, sexual health, and HIV treatment outcomes. Individuals who participated in the survey were asked if they would be willing to participate in an IDI. Participants who completed the survey by November 6, 2020, and who consented to being invited to an interview, were eligible to participate in this qualitative study.

For each eligible participant, we used survey response data to calculate a COVID stress score, a 7-item composite measure with scores ranging from 0 (no impact) to 28 (high impact). All eligible participants were then categorized as belonging to one of three tertiles: “Low Stress” (2-11), “Medium Stress” (12-16) or “High Stress” (17-24). As of November 6, 2020, 277 participants had completed the RedCap survey and consented to being invited to an IDI: 103 participants scored as having “Low Stress”, 95 as “Medium Stress”, and 79 as “High Stress.”

To capture a wide range of experiences, we used a stratified purposive sampling approach to select an equal number of high and low stress participants, and reflect underlying demographics of the patient population related to gender and age.

Positionality

As a young researcher and the lead author of this study, it is important to acknowledge my positionality. Though I have lived in Washington State nearly all my life, and in the Seattle area for 10 years, I do not have prior experience working with PLWH in this context. In addition, I do not have personal experience managing a chronic illness; and, as a white, cis-gender heterosexual female, my identity differs from many of the study participants’. I am currently a full-time master’s student at the University of Washington, Department of Global Health, where I hold a bachelor’s degree in Medical Anthroppology and Global Health. Acknowledging my positionality, I work closely with my study team, who collectively have several decades of experience working with PLWH in clinical care and research, both locally and globally.

Relationships between interviewers and participants were not established prior to study commencement. Likewise, the only information or personal characteristics participants knew about the interviewers was that they were members of the University of Washington CFAR HIV and COVID Study team.

Data Collection

This study, as well as the larger research project, was guided by an adapted version of the “Indigenist Stress-Coping Model (ISCM)” developed by Walters et al.[17] and earlier work on theories of stress and coping by Dinges and Joos, and Krieger.[18,19] To date, stress-coping models have been applied to a wide array of health topics such as diabetes, mental illness and substance use, as well as other chronic conditions and health-risk behaviors among vulnerable populations.[19,20,21] The stress-coping model, as adapted for this study (Figure 1), proposes that each individual’s COVID-19 experience (illness, social distancing stress, job loss, housing

challenges and reduced quality of life) is the stressful/traumatic life event, and personal buffers such as knowledge, technology access and related skills, social support, and other adaptive coping strategies act as protective factors (i.e., buffers) between the negative effects of COVID-19 on mental health and substance use outcomes.

Based on this model, we developed a four-part semi-structured discussion guide that captured 1) participants' knowledge of COVID-19, 2) their personal experiences and beliefs about COVID-19, 3) how social distancing measures have influenced daily life, and 4) how the pandemic has impacted their desire and ability to access health related services, including those related to mental health and substance use treatment. Before recruitment for IDIs began, the topic guide was piloted by members of the research team and revised accordingly.

Recruitment for IDIs was carried out via email by the lead author and another member of the study team (Dr. Murugi Micheni). All IDIs were conducted using the UW HIPAA-compliant version of online Zoom or the phone-to Zoom option. Study participants who completed an interview received $40 for their time. After the first 5 interviews were completed, the study team added several probing questions to more fully capture participants' experiences and perspectives. The final version of the interview guide can be found in Appendix A.

All IDIs were conducted in English by the lead author and another member of the research team (Dr. Murugi Micheni). All interviews were audio recorded via Zoom with participants' consent. The average length of IDIs was 55 minutes, ranging from 35 minutes to 1 hour and 33 minutes. After each interview was completed, a debrief report was written to capture general observations as well as a summary of the responses provided by the study participant. Audio recordings were uploaded to Otter.com, where AI software provided first-draft transcriptions. Draft transcripts were reviewed and revised to ensure accuracy and quality by the lead author or an undergraduate student in Anthropology (Nikki Bhatia).

The study protocol, consent form, and interview topic guide were reviewed and approved the Human Subjects Division at the University of Washington. All study participants provided written informed consent, with oral confirmation as the interview started.

Data Analysis

We conducted thematic analysis, grounded in our adapted COVID-19 Stress and Coping Model, to identify stressful impacts of COVID-19, personal buffers that act as protective factors mitigating these negative effects, and reflections on personal mental health during COVID-19 social distancing. All transcripts were coded using the qualitative analysis software ATLAS.ti 8 Windows (ATLAS.ti Scientific Software Development GmbH, Berlin, 2020). A preliminary codebook was developed deductively based on the domains found in the conceptual model in Figure 1, and further revised through open coding and identification of data-driven codes through transcript review. The codebook was further refined during multiple rounds of consensus coding, conducted to ensure consistency in text segmentation and code application between coders. During consensus coding, discrepancies in code application were resolved through group discussion with the larger analysis team, until a final codebook and coding strategy was agreed upon. Following consensus coding, remaining transcripts were divided between two analysts and imported into Atlas.ti for independent coding.

A modified Framework analysis approach[21, 22] was used to extract data from coded transcripts around each conceptual area (stressors, buffers, mental health) into a matrix for evaluation of within and between case comparisons. This Framework Method[21] served as an analytical tool to

support early thematic analysis and provided an audit trail of how segments of texts were coded within the context of an individual's experiences and perspectives. Data interpretation and identification of salient themes were further developed through additional queries to explore concepts emerging through review of matrix data. Finally, a data display was developed to include illustrative quotes which correspond to strategies that enabled participants to cope with stresses brought on by the pandemic.

RESULTS

A total of 24 IDIs were conducted, including 11 with people who had low COVID stress scores and 13 who had high COVID stress scores. The mean age of participants was 47 years (range, 28–67 years), and 18 (75%) identified as male. Sixteen (67%) identified as white, and 16 (67%) identified as gay, homosexual or lesbian. The majority (80%) had at least some college, an associate's degree, or technical school training. Notably, while many lived in low-income housing, no participants experienced homelessness during the pandemic, although two younger participants reported housing instability.

Most participants expressed having felt some level of anxiety and depression throughout the pandemic. However, the degree to which they experienced mental health challenges was related to their specific stressors and ability to adopt positive coping strategies. Overall, six main themes emerged as participants described their experiences.

Exposure events and symptoms compatible with COVID-19 acted as powerful short-term stressors

On the individual level, stressors included exposure events, onset of symptoms compatible with COVID-19 and COVID-19 illness. Many participants described being fearful of COVID-19, stemming from the uncertainty of how COVID-19 may affect their health and from their personal experiences living with a chronic viral infection. However, out of the 24 participants, only four (one younger adult and three older adults) had been diagnosed with COVID-19 prior to their interview. As such, most participants, though they may have been tested for COVID-19, did not experience stress related to illness, treatment, or long-term complications. The experiences of the four individuals who were treated for COVID-19 varied. Though they have all since recovered, each expressed fear of contracting it again in the future.

Participants' living and/or working environments, along with any co-morbidities they had, informed personal perceptions of their risk of contracting COVID-19 and developing severe complications. Those who perceived their risk to be high felt they would likely die from COVID-19 if they were to contract it. For most participants, COVID-19-related fear and stress were manageable on a day-to-day basis, provided they could follow social distancing guidelines, practice regular hygiene routines, and limit their frequency of going to the store and using public transportation. At the same time, most participants felt people in their broader communities were not taking the pandemic and social distancing guidelines as seriously as they ought to, which brought about feelings of anger and frustration. On occasions when outbreaks occurred in their living or working environments, or participants experienced cold or flu-like symptoms, participants' level of worry and stress intensified.

> *"I mean, I'm probably like 80- or 90-pounds overweight, and the smoking, and then who knows what it would really do with the HIV?... like I said, on a daily basis, it doesn't scare me. But whenever I've had to go in for a test, I mean, that's when all those thoughts are going on. It's like, Oh, my God, I'll probably die if I get it. And then like right now, like, today, with the ICU so overloaded and stuff, it's like, I wonder if they had to like triage me, where they would put me, right? Am I just at more of a risk of dying, so they're not going*

to treat me? You know what I mean? If they have to start treating people that they think will survive? So, I mean, that sort of bothers me." – 44-year-old white man, high COVID stress

When experiencing symptoms, worry and heightened levels of stress were felt even by participants who perceived their overall risk of contracting COVID-19 and developing complications to be low.

> *"I've never been that concerned about it because my doctors have always made me feel like I'm healthy enough that my immune system is fine to handle something like that…the only time I was worried about COVID was…I had a no-strings-attached encounter where I kissed the dude. And then I got really sick. And that's when I thought I had COVID."* – 32-year-old white man, low COVID stress

When these acute stressors arose, participants did not report difficulties in accessing COVID-19 tests. In fact, participants described receiving tests at a wide variety of locations including the same clinic where they receive HIV care, county public health testing sites, social service organizations, workplaces, and low-income housing facilities. After having tested negative for COVID-19, participants maintained or increased their adherence to social distancing guidelines. In addition to modulating personal behavior throughout the pandemic, several participants reported avoiding medical facilities and delaying in-person appointments to further reduce their risk of exposure.

Social distancing and concern for others were sources of chronic stress, regardless of fears about COVID-19 illness

Nearly all participants expressed their support for, and followed, social distancing guidelines established in Western Washington. Stress resulting from implementing social distancing practices (e.g., social isolation and loneliness) was often described as a profound challenge at the interpersonal level. Participants expressed varying degrees of distress from having limited face-to-face interaction with family and friends, lack of social gatherings and recreational activities, and reduced opportunities to support loved ones who were not doing well.

> *"I am a very social person. So like, not being able to get out or do anything is really damping my spirit. When I said I'm a hugger, I'm the person that my friends and family tend to call when they want that hug or when they need that good cry, and we haven't been able to do that. So I spend a lot of my time on video calls, zoom calls, and things like that, trying to keep the connection open, but this has been very hard, you know, not seeing my nephew has been very, very, very hard."* – 37-year-old Black woman, high COVID stress

Moreover, social distancing guidelines severely limited participants' ability to engage in activities that brought them joy in pre-COVID times. Shopping, traveling, going to movie theatres, or simply getting a cup of coffee, were frequently noted as activities participants enjoyed doing, both independently and with others, before the pandemic began. This led some participants to have "too much time on their hands," and promoted a more sedentary and isolated lifestyle.

While technology access and skills helped most participants feel less lonely and, in some ways, more socially connected, calling, texting or video-chatting were not comparable to seeing loved ones in person. Furthermore, many found it challenging to know how to best express concern and provide support for family members and friends who were not in good health or were struggling in other aspects of their lives. For some, this element of social distancing brought on added feelings of sadness and helplessness.

> *"But it is sad, cuz I do see a lot of my friends who are out in those situations that do have predisposed mental illnesses. Those have all been inflamed. Extremely. Due to the pandemic. I've had multiple friends, you know, try to commit suicide, other friends that just, you know, lay in bed all day and want to die but don't even have the energy to try to commit suicide. You know, and that's where my sadness comes in is seeing that for them."* – 41-year-old white woman, low COVID stress

In addition to feeling lonely, sad, or having "down" days by not being able to engage in pre-COVID activities or social gatherings, some participants experienced added stress after communicating their wishes to limit in-person contact with extended family members.

> *"…we ended up fighting. And then, I said, 'It's your belief, let's agree to disagree and just respect my wish not to see each other until COVID ends'…I mean, it's stressing, because every time I call it's like there is this discussion about when you're gonna see us and it depends on COVID. Then they say, 'Oh, COVID is not gonna end in two years maybe or whatever.'…I mean, it's every time that we call each other and it's once a week or twice a week. And it's the same conversation."* – 29-year-old white man, high COVID stress

Disruption in medical services, changes in insurance, and accessing unemployment benefits and other social services were common system navigation challenges

In addition to experiencing pandemic-related stress on the individual, inter-personal and community levels, system navigation was as an additional source of stress. Challenges scheduling medical appointments, understanding insurance policies following changes in employment status, as well as accessing unemployment, DSHS and other social services were described by several participants.

> *"Not being able to collect unemployment and being broke. That's been probably the main cause of everything. So, unemployment's totally let me down, even though I got a job. And I almost kind of gave up."* – 32-year-old white man, low COVID stress

For one participant, having limited access to bus tickets was not only stressful, but it also exacerbated pre-existing health conditions:

> *"Imagine that my social worker, my case manager was yelling and screaming at me, just because I have a little bit more appointments that I have to go to every week that I wanted to get some more help for bus tickets…And they refuse me for this, that and those services…That is extremely stressful. And now, I am having to walk to my physical therapy. And do you know what happened? When I walked more? I have a gait problem now. It is not just my shoulder, it's not just the elbows, now it's the knee. Now it's the hip."* – 64-year-old Asian man, high COVID stress

Adaptive coping techniques were helpful in alleviating stress from COVID-19 and building resilience to get through the pandemic

Participants frequently drew parallels between when they were first diagnosed with HIV and the current COVID-19 pandemic. Most felt they were in the process of continuing to build resilience since their HIV diagnosis, and in so doing, had developed an array of techniques to help them manage their physical and mental health. As such, several participants felt their years of experience managing HIV, in addition to other chronic conditions, enabled them to be more prepared for the COVID-19 pandemic. In both low and high COVID stress categories, participants described using four major adaptive coping strategies: *cognitive coping techniques*, *staying active or exercising*, *social support* (e.g., emotional, instrumental, informational), and *engaging in*

meaningful activities at home (e.g., working on projects, making art, reading). Illustrative quotes capturing these coping strategies can be found in Table 2.

Cognitive coping techniques and emotion-focused strategies (e.g., meditation, positive reframing, mindfulness) in particular were useful for stressors that were perceived to be out of one's personal control. For example, while waiting for test results or when experiencing potential COVID-19 symptoms, cognitive coping techniques improved several participants' ability to remain calm.

> *"And it always goes back to HIV, with those of us that have HIV, it's that same anxiety you feel and fears that you feel when you've taken the test that, back then we had to wait seven days, and fortunately with this, we only had to wait 24 hours. And so, there was a lot of high anxiety, but I just started doing my self-meditation and thinking that, you know, there's no sense in stressing about it until you hear."* – 67-year-old American Indian man, high COVID stress

Moreover, emotion-focused strategies were also helpful for coping with the open-endedness of the pandemic. Many participants spoke about the early months of the pandemic as being some of the most difficult, especially when there was limited information on how long it would last. Meditation, mindfulness, and positive-reframing were frequently cited by participants, which helped them practice gratitude and positive thinking over time. This type of positive reframing, leavened with a sense of humor, was possible even for a participant who experienced multiple forms of adversity in the beginning of the pandemic.

> *"Well, my mood in the beginning, it went from not noticing it, to fear, fear and panic, to a little bit of lacksy-daisy, and now it's kind of like I am, I mean, as far as like losing my job and having to move, that was like my greatest fears, and now that those have all happened, eh, I'm kind of fine about it. I mean, I don't really know what else COVID is gonna throw at us, but I feel like we can take it. I feel like it's like the Boogey Man came out of my closet and turns out he's just a hairy guy who likes to dance. So, it's not that big of a deal, you know?"* – 30-year-old Black man, low COVID stress

Staying active appeared to be the one of the most impactful coping strategies for combatting prolonged stress and building resilience. Participants who remained active, either in or outside their homes, often reported improvements in depressive and anxiety symptoms. Several participants stayed active by working out in home-based gyms, while others went for scenic drives or engaged in camping, hiking, or skiing. Exercise provided more than physical and mental health benefits, serving as a distraction and means of keeping busy.

> *"My husband and I decided that instead of just, you know, numbing ourselves by eating whatever treat we wanted, or, you know, by having wine in the evening, you know, while we watch TV, we decided that we, you know, once we looked at the scale, and our COVID weights, our stress eating and stress drinking, we decided, this is ridiculous, we've had enough… it's been really nice, because we've had a little bit more socialization in kind of like little bite size interactions at the gym. But it's all still very what we feel is controlled within reason…And, you know, also just losing some of, you know, losing my COVID weight, and now I'm, you know, chipping away at the baby weight that I didn't lose. It feels really good to be able to focus on something other than COVID."* – 39-year-old white woman, high COVID stress

Likewise, participants who worked during the pandemic, and especially those who had the ability to work outside their homes, expressed less social distancing stress than those who spent the majority of time at home. One participant noted that walking to work not only enabled him to

maintain separate working and living environments, but provided a certain level of social interaction.

> *"Well, I think I really have tried to keep [fit], like I try to walk to work every day. And I think that's been one nice thing, because in the morning, there's not a lot of people out. And it's been a way to one, get my heart rate up a little bit, because you could, it would be very easy to do nothing and be around no one… I don't like that whole 'you work where you live.' So I've continued to go to the office, and that's my choice. But in a sense, I think it's really helped me manage the anxiety part of it."* – 56-year-old white man, high COVID stress

Nearly all participants in this study relied upon their friends, family or neighbors for various forms of social support, including: emotional (e.g., physical or virtual presence), instrumental (e.g., food deliveries, financial assistance), and informational (e.g., sharing COVID-19 information and advice). Importantly, most participants who described losing their jobs in the beginning of the pandemic had spouses or family members who assisted them financially. This financial security enabled them to continue accessing food, media services (e.g., phone, internet, TV), and other necessities. Moreover, those who limited in-person contact with extended family and friends, technology was crucial in maintaining social connection.

> *"I still spend a lot of time on the telephone…I spend a lot of time having long conversations with people, especially those nearest and dearest, you know…And it's just kind of that thing that sometimes that call out of the blue, that interaction you weren't planning for is the thing that really lifts your spirits."* – 53-year-old white man, high COVID stress

Finally, working on projects around the house, making art, reading, watching TV, and cooking new recipes are just a few examples of how participants engaged in meaningful activities at home. Many of these activities served as important elements of self-care, which helped promote physical and mental health. For some, spending more time at home also provided important opportunities for self-reflection and personal growth.

> *"I think, in a weird way, this isolation at home alone has given me a really long time to recover on my own in a way that has helped me specifically, gathering my own thoughts and look back on things, and, what's the word I'm looking for, a chance to review things long term and come to some, like, really important life decisions and choices that have helped me in a tremendous way."* – 52-year-old white man, high COVID stress

Job loss and social distancing stress exacerbated pre-existing tendencies to engage in maladaptive coping strategies

Most participants stated that they have either been sober for many years or their consumption of alcohol, tobacco, marijuana, or illicit substances had not increased during the pandemic. However, several participants who engaged in maladaptive coping strategies prior to the pandemic (e.g., alcohol consumption, substance use, gambling) noted that stressors (e.g., job loss or persistent unemployment, social distancing, inter-personal conflict) exacerbated or increased the frequency of engaging in unhealthy habits. For some participants, it was the combination of stressors acting together that contributed to reaching unhealthy consumption levels.

> *"[W]hen COVID started, it took away my new job, and then it closed down my gym, and then it closed down all the trails that I was hiking at. So it took away not only my job, but took away like, everything that I could do for fun. So. I had already drank a lot. So COVID turned drinking*

into like, a full-time hobby, which was not healthy for me… Not seeing my boyfriend for about half a year, that was really hard." – 32-year-old white man, low COVID stress

"I took on a really intense job from around like October, November, as a peer support specialist and mental health case manager… it was intense…And on the other side of that, my partner at home is just suffering from all the stuff that mental health and isolation and it was too much…"
Interviewer: *"How were you able to manage?"*
"Ha, with lots of drugs!" – 31-year-old Black gender-queer/gender non-conforming, low COVID stress

Fortunately, several individuals who engaged in such maladaptive coping strategies were connected to, or increased their participation in, mental health counseling, AA, or other social and rehabilitative services. Having access to in-person and virtual appointments was critical in helping them manage stress and engage in healthier habits.

Healthcare provider check-ins and mental health services provided critical assistance for anxiety and depressive symptoms

For most study participants, the shift to telemedicine services brought about many positive changes. Some participants found it much easier to meet with their HIV providers via Zoom or over the phone because it eliminated the commute time, paying for parking, finding childcare, and interrupting work schedules. Participants who expressed anxiety about going to medical facilities for fear of exposure to COVID-19 felt that telemedicine provided a convenient alternative that allowed continuity of care.

Engagement in virtual mental health services, specifically, was mixed among study participants. However, those who regularly attended virtual counseling sessions were often provided with valuable coping tools or practices. In many cases, medication was prescribed to or restarted for patients who had pre-existing mental illness and experienced heightened depressive or anxiety symptoms during the pandemic.

"I have a really fantastic therapist that I see once a week online. And I feel so fortunate. So I have a great thing with her, and she's really helpful for me… it's one of those things where, after going to therapy for a long time, you get a really good toolbox of tools that you can use emotionally." – 39-year-old white woman, high COVID stress

Several participants underscored the importance of healthcare providers maintaining relationships with patients during the pandemic. For some, their HIV providers or mental health therapists had either quit, not contacted them during the pandemic, or had limited availability to schedule appointments. Not having prior rapport with new providers diminished trust and engagement in services.

"Well, I had a really awesome doctor, and then she left too. And so I kind of just don't care, like, not that I don't care. But it's really important to me to develop relationships with your providers, and then when they dip out like that, it's kinda like, I don't really have time to invest in getting to know someone else no more....And plus, I had a really awesome therapist, and they moved. So the new one I have, I pretty much just use her for, like, when I need resources as far as like, 'Can you write this letter for this? Or this?' Because like, I mean, they don't know me, I don't know them. It's odd. And it's like, the human connection lags. With this online stuff." – 31-year-old Black gender-queer/gender non-conforming, low COVID stress

Many participants expressed gratitude and increased trust in healthcare providers and social workers who called and checked in on them during the pandemic. These phone calls provided much-needed support for participants who were experiencing system navigation challenges, or were unwilling or felt uncomfortable participating in formal counseling services or talking to family and friends.

Updated Stress-Coping Conceptual Model

Lived experiences of participants were used to expand our initial stress-coping model (Figure 1) to accommodate the socio-ecological complexity and interaction between individual stressors, coping strategies, and mental health outcomes among PLWH in our study population (Figure 2). Our adapted model includes four primary sources of stress grouped into the following socio-ecological levels: individual (e.g., feelings of anxiety associated with acquiring COVID-19), interpersonal (e.g., social distancing stress from confinement or anxiety and depressive symptoms stemming from how others were affected by the COVID-19 pandemic), community level (e.g., limited social gatherings and activities) and systems level (stress attributable to system navigation challenges). These stressors acted in either acute/short-term or chronic/long-term manners. Adaptive coping strategies helped most participants cope with these stressors in positive ways and reduced the negative impacts of COVID-19 on mental health.

DISCUSSION

Our qualitative evaluation of lived experiences of PLWH in Western Washington suggests that social isolation and job loss are linked to higher levels of stress during the COVID-19 pandemic. Exposure events and symptoms compatible with COVID-19 were associated with short-term stress, while most participants described prolonged stress stemming from adhering to social distancing guidelines, and feeling concern for others with limited ability to offer adequate support. Participants who experienced multiple stressors in addition to job loss, were less likely to be able to adopt positive coping behaviors, and increasingly engaged in maladaptive coping strategies. Healthcare providers played a critical role in supporting PLWH, by providing continuity in care as well as referrals to mental health and social services.

Nearly all participants in this study relied upon their friends, family or neighbors for various forms of social support during the pandemic, including: emotional, instrumental, and informational support. These findings align with previous research suggesting emotion-focused coping resources, such as finding gratitude via mindfulness and having a supportive social network, promoted well-being during the COVID-19 pandemic.[24,25,26] To date, there are limited data available which examine possible threshold effects of emotion-focused coping resources during the pandemic. This merits further exploration and may be particularly relevant for individuals who experienced multiple forms of adversity. If for example, increasing levels of social support are associated with progressively less benefit, identifying and adopting additional strategies for successful coping may be warranted.

Notably, while several participants remained physically active during the pandemic, many participants did not describe physical activity as part of their daily routines. This finding is supported by a recent study conducted by Wion et al., which found that aspects of HIV self-management that have been made the most difficult by the COVID-19 pandemic are the ability to exercise, ability to manage affective symptoms, and ability to maintain social support networks, among others.[27] This is cause for concern, as a growing body of literature suggests exercise improves depressive and anxiety symptoms, increases quality of life and ART adherence among PLWH.[27,28, 29] Equitable access to physical activity, including outdoor recreation opportunities, should be further explored for PLWH who either do not have access or feel safe exercising outside of their homes. Likewise, additional research is needed to evaluate the clinical effectiveness of

virtual physical therapy sessions, as well as patient barriers to using these services,[30,31,32] particularly for populations living with HIV and other chronic conditions.

To our knowledge, this is one of the first research studies to provide a stress-coping model that articulates common mechanisms through which the COVID-19 pandemic impacted the mental health of PLWH. While our model is similar to the ecological model published by Cowan et. al. illustrating individual, network, community, and structural features of the pandemic impacting the health of individuals with opioid use disorder,[33] this and other models published in the literature do not include factors which promote resilience or successful coping strategies.[34]

Finally, it is important to note that the COVID stress score that we used for purposive sampling was not a proxy for having experienced job loss, housing and system navigation challenges, or other traumatizing events such as domestic violence. In fact, many participants who were categorized as having "low COVID stress" had indeed experienced many of these difficulties, but these experiences did not necessarily exacerbate how they perceived their personal risk of contracting COVID-19 or developing complications.

We acknowledge several limitations to this study. Our data reflect the experiences of individuals who had access to and were willing to use email, Zoom and telephone throughout the study process. This sampling bias was, in part, unavoidable due to COVID-19 social distancing restrictions, wherein in-person recruitment and data collection were not possible. Additionally, we likely under sampled individuals who had experienced homelessness or extreme mental health and substance use challenges during the pandemic. However, our study draws on the experiences of individuals who reflect the sociodemographic profile of many UW HIV clinic patients, particularly in terms of age, race/ethnicity, gender identification, and sexual orientation. Finally, of the twenty-four participants, only four (three older adults and one younger adult) had been diagnosed with COVID-19 prior to being interviewed. As such, we cannot provide generalizable findings regarding experiences with illness, stigma, or other adverse outcomes for those diagnosed with COVID-19.

Conclusion

In summary, we collected interview data from 24 individuals who receive their HIV care at UW clinics in Western Washington. Cognitive techniques, physical activity, and social support appeared to be the most impactful coping strategies for participants during the first year of the pandemic. As the vaccine rollout continues and social distancing guidelines are lifted, it will be critical for healthcare providers to connect with their patients to better understand how they can best address HIV and non-HIV related needs.

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Table 1: Sociodemographic Characteristics of Participants

	Low Stress (n=11)	High Stress (n=13)	Combined (n=24)
Age			
Mean age in years (range)	46 (30-64)	48 (28-67)	47 (28-67)
Gender Identification			
Male	8 (72.7%)	10 (77.0%)	18 (75.0%)
Female	2 (18.2%)	3 (23.1%)	5 (21.0%)
Gender Non-Conforming	1 (9.1%)	0 (0.0%)	1 (4.2%)
Sexual Orientation			
Gay, Homosexual, or Lesbian	7 (63.6%)	9 (69.2%)	16 (66.7%)
Straight or Heterosexual	2 (18.2%)	4 (30.8%)	6 (25.0%)
Bisexual	1 (9.1%)	0 (0.0%)	1 (4.2%)
Don't know	1 (9.1%)	0 (0.0%)	1 (4.2%)
Race			
White	7 (64.0%)	9 (69.2%)	16 (66.7%)
Black	2 (18.2%)	1 (7.7%)	3 (12.5%)
American Indian	2 (18.2%)	2 (15.4%)	4 (16.7%)
Asian	0 (0.0%)	1 (7.7%)	1 (4.2%)
High Level of Education			
12th grade or less	0 (0.0%)	2 (15.4%)	2 (8.3%)
High school graduate or GED	1 (9.1%)	2 (15.4%)	3 (12.5%)
Some college/AA degree/Technical school training	8 (72.7%)	4 (30.8%)	12 (50.0%)
College graduate (BA or BS)	1 (9.1%)	2 (15.4%)	3 (12.5%)
Graduate school degree: Master's or Doctorate degree (MD, PhD, JD)	**1 (9.1%)**	**3 (23.1%)**	**4 (16.7%)**
Country of Origin			
USA	11 (100.0%)	11 (84.6%)	22 (92.0%)
Brazil	0 (0.0%)	1 (7.7%))	1 (4.2%)
Lebanon	0 (0.0%)	1 (7.7%)	1 (4.2%)

Table 2: Adaptive Coping Strategies and Illustrative Quotes

Adaptive Coping Strategies	Illustrative Quotes from Low COVID Stress Participants	Illustrative Quotes from High COVID Stress Participants
Cognitive Coping Strategies	"I mean, take a couple of deep breaths and get aware. Like, Okay, what, like, get really tuned into what's really in front of me. Like, What's really happening here? What's just like, what's and what's, as opposed to what I'm afraid of, or what some perception is. And often it's like, Oh, actually, I started coughing a little bit. I've been sneezing. It feels like I have a cold. I will go get tested. And I don't have a result yet. And there's nothing I can do about it until I know and I'll know, one way or another and if it is COVID, I will be able to accept. So it kind of Yeah, I mean, I think that's how I usually deal with things like that. It's like, Okay, what's true, and what's made up? And what's unknown? And if, if it is COVID, then are the things for me to do?" 54-year-old white man, low COVID stress	"Well I think it's, for me, personally, it's just been this finite balance of trying to be at peace with what's going on, but not like, you know, if I were to, like, look at every little pain or discomfort I'm having, I could, you know, link it to COVID, I guess. It would cause me so much anxiety." 44-year-old white man, high COVID stress
Physical Exercise	"Oh, whenever I get that little feeling in your tummy that, you know, you're like, Oh, I'm depressed, oh. I try to knock it out. I mean, it's how do you make a fire grow, you feed it? So I just kind of would go and be more active." 37-year-old American Indian man, low COVID stress "I like to go fishing or in the summer I'll play golf or something. But that's pretty much naturally social distance. Or if I'm fishing with somebody, it's somebody I've known I know and I know they take their precautions. But you know, I'm not gonna let this dictate how I live my life either. I'm gonna still enjoy my life. I'm not gonna sit at home and and put myself in a bubble until I die or until this is over. It's just not me, I'm not gonna do that." 64-year-old white man, low COVID stress	"I was diagnosed when I was 19. I have spent the last however many years, 30 plus years, doing just about everything I could think of to stay healthy. You know, I'm super adherent with my, with my medication. I exercise, I eat right, I, you know, do my best to manage my stress, all of those things. Honestly, outside of anything that might happen, you know, as far as the cytokine storm and all that kind of stuff that goes with, with COVID infection, I think my, my ability, my opportunity to get it is probably standard. It's just like everybody else's." 52-year-old white man, high COVID stress
Social Support	"But we do have a little COVID pod where my one friend, she takes care of five grandkids. And they're all with her. And my other friend that has two kids. And so we just made our own little pod. So it feels like a little party when we hang out. Because we scored with the five kids in the one family." 41-year-old white woman, low COVID stress	"You asked me the question earlier, do I get outside support. And I think that that there two or three of us from, you know, from this particular environment situation, have been, you know, in touch with each other, so to speak…And we try to understand how to navigate the healthcare system." 64-year-old Asian man, high COVID stress "He texts me regularly. I have a cousin in Alaska who emails me regularly. And so, I do hear from them.

		And I have a couple friends in the building that email me and so, you know, I feel that's enough. I don't feel deprived, or feel so isolated and alone." 67-year-old American Indian man, high COVID stress
Engaging in meaningful activities at home	"Well, I'm kind of artistic. So I just dwell on that a lot. So I'll just like, I'll jump into an art project. And that's a good release of, you know, for me…" 44-year-old white man, low COVID stress "Well, there's not really much that I can do. But I pretty much tried to divert from baking and go more just like cooking, because a lot of baked goods have a lot of carbs and sugars, and I'm trying to get more into the proteins and the grains. So now like, I guess, like having to make that gravitation is giving me something to do. And pretty much just bettering my life is the only thing I've been trying do during this pandemic." 30-year-old Black man, low COVID stress	"Yeah, we have a patio. So, we'll go and we'll sit on the patio together. I've talked her [participant's wife] into learning how to fix simple meals, so we'll do that together. Or, you know, watch TV, watch movies, things like that. She's a gamer, so I'll sit and watch her play her Xbox." 37-year-old Black woman, high COVID stress "My weekends are when I have to get caught up on my housework and cleaning stuff type of thing. But I always try to organize it so that I have a few hours of downtime to myself to recuperate." 59-year-old white man, high COVID stress

Figure 1: COVID-19 Stress-Coping Model for Mental Health Outcomes

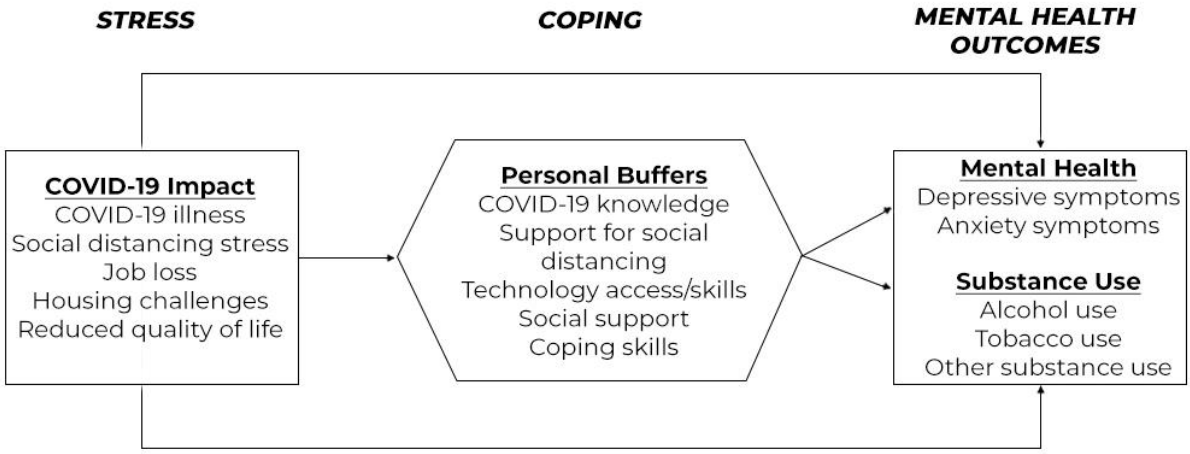
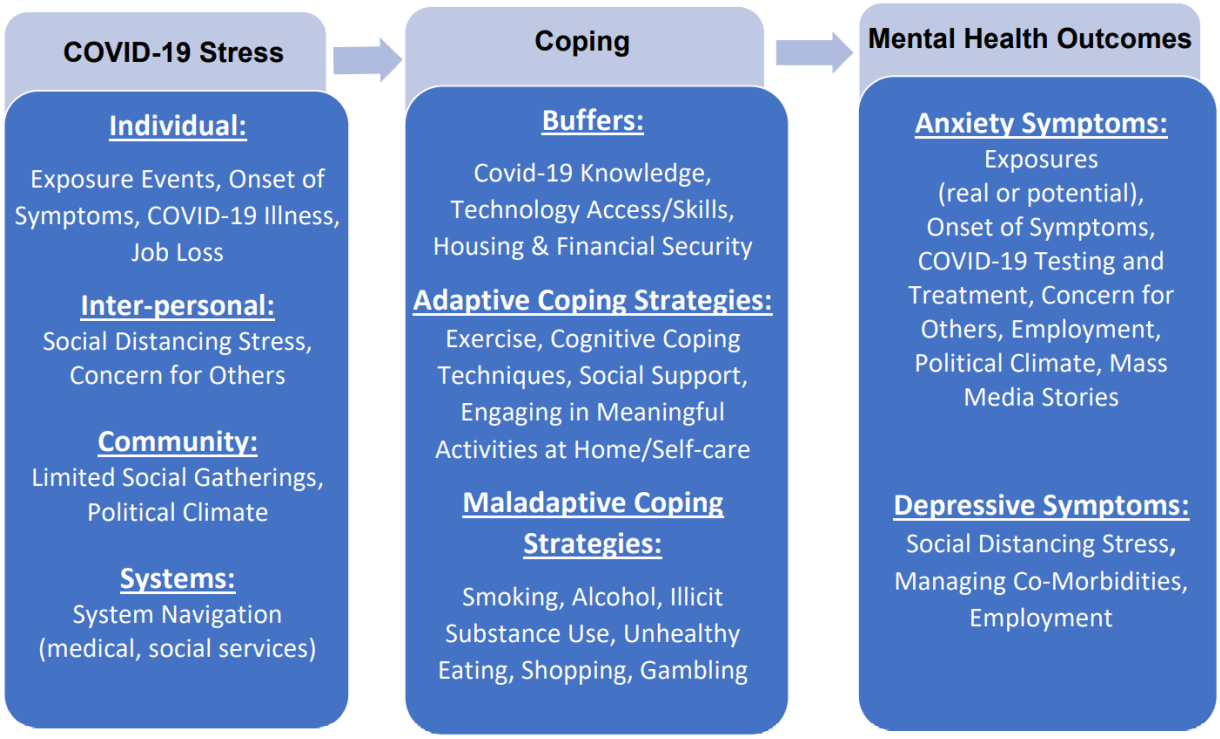


Figure 2: Updated Stress-Coping Model Depicting Stressors, Personal Protective Factors or "Buffers," Coping Strategies, and Mental Health Outcomes Expressed by Participants



Appendix A: Interview Guide for In-Depth Interviews

KNOWLEDGE OF COVID 19:

1. First, I'd like to learn a little more about what you know about COVID-19.

- What have you heard about the new coronavirus, also called COVID-19 or SARS-CoV-2?
- Who or where do you get your information on COVID-19 from?
    - What do you think about the accuracy of what you have heard? (probe if not mentioned above)
    - What sources of information do you trust? (probe if not mentioned above)
- Have you received and/or asked for any guidance from any of your health care providers about the new corona virus? Did you get enough information? Why or why not?

BELIEFS/PERSONAL EXPERIENCE OF COVID 19:

2. Now, I'd like to talk with you about your beliefs about your risk of getting COVID-19.

- Who is at risk of COVID (lead in question)
- Do you think people living with HIV are more at risk or less at risk for the new corona virus than people not living with HIV?
- What do you think about your own risk of getting COVID?
    - If you were to get COVID, what do you think about your own risk of having complications?
    - How concerned are you about your getting (that is, contracting) the new corona virus? (How worried are you about getting COVID)
    - Why do you feel that way?
    - Has your concern changed over time? Why or why not?
- What is your attitude towards masking?
- Are people around you wearing masks (for example: people in your family/social network, near where you live, when you go outside)? Is this a cause of stress?
- Did you ever have any symptoms or situations that made you think that you might have had COVID-19?
- Did anyone you know have COVID-19?
    - Please tell me about your experience (or the experience of someone you know) having COVID-19?
    - What was your experience with symptoms?
    - Did you get tested? (If yes, what was it like to get tested for COVID-19?)- probe emotional experience, and the process: waiting for a test, waiting for the result, getting the result
    - How did you or healthcare providers manage your (your loved one's) illness? - probe for kind of treatment given, experience of care
    - What could healthcare workers have done better to improve your experience?
    - Have you (or someone you know) experienced any longer lasting health effects from COVID-19?
    - Are you scared about getting COVID-19 again? Why or why not?
- Do you think there is support from the community for people who have had COVID e.g. wanting to take care of those affected, or is there stigma?

SOCIAL DISTANCING:

3. Now, I'd like to talk with you about your experiences with social distancing and how that has influenced what your life is like.

- Overall, how has your quality of life changed since coronavirus? Probes: Do you feel more or less socially connected? More or less engaged in activities? More or less bored?
- How has your mood been since the COVID epidemic start?
    - Have you experienced depression, sadness, or grief?
    - Have you experienced anxiety or additional stress?
- Have you had social support from your family, friends, or partner?
- How do these experiences or feelings affect your life?
- How has the coronavirus and/or social distancing affected other parts of your life?
    - How has your job or how you get money changed?
    - How has your ability to see friends and family changed?
    - Have there been any changes in your sexual life? Has it been difficult to meet people?
    - How has your sexual behavior, sexual health, or relationships changed?
    - How has your ability to get food or stay housed changed?
    - Has anything changed about your use of alcohol, tobacco, marijuana, or other drugs?
- What has been the most challenging part of the social distancing guidelines?
- What have you done to stay connected with friends and family? How do you feel that's been working for you?
- What else have you done to cope during corona virus?

HEALTH CARE ACCESS:

4. Next I'd like to hear more about how COVID-19 has affected your desire or ability to access HIV care.

- What was working well for HIV care before COVID-19?
- What were some of the challenges with your HIV care before COVID-19?
- How has your HIV care changed since COVID-19?
    - How has COVID-19 changed how you access medications? What has been hard/easy about these changes?
    - How has COVID-19 changed your adherence to medications? Why?
    - How regularly do you have lab appointments? Have you experienced any problems accessing and/or scheduling your lab appointments since COVID-19?
    - Have you had a clinic visit during this pandemic?
    - Do you feel comfortable having in-person clinic visits? Do you feel that COVID protocols (masking, distance between patients) have been followed where you receive your HIV and non-HIV care?
    - What do your clinic visits look like during COVID-19? Have you used telemedicine? Why/why not? What did you like/not like about that?
    - How has getting to clinic changed since COVID-19? How have you liked or not liked those changes?
    - In your opinion, has your risk of contracting an STI increased, decreased, or not changed during the COVID-19 Pandemic?
    - Have you had trouble getting tested for sexually transmitted infections (syphilis, gonorrhea or chlamydia) since COVID-19 began?
    - What has been different about your ability to get social services? What about insurance? What about counseling and support? What has been working well with these changes? What has not been working well?
- How has COVID affected your desire or ability to access other types of health care for conditions other than HIV?

- What do you and members of your community need to manage life during the corona virus outbreak that you are not getting? Are there any other concerns that you would like the Madison Clinic to know about or address?