



# Symptoms, Stress, and HIV-Related Care Among Older People Living with HIV During the COVID-19 Pandemic, Miami, Florida

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On January 21, 2020, the Centers for Disease Control and Prevention (CDC) announced the first case of the Novel Coronavirus disease (COVID-19) in the United States [1]. COVID-19 is a severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) [2]. Despite reactive measures taken by the U.S. to prevent further infections, the country, ranks first in the number of COVID-19 cases [3]. Though there is limited information regarding the risk factors for severe disease, available information suggests older adults and those with serious underlying conditions (including HIV) are at higher risk [4]. The lack of current information on COVID-19 risk among PLWH may leave PLWH, especially those who are older and have advanced immune suppression, feeling under prepared in protecting themselves from acquiring COVID-19.

Before COVID-19, our research team had just begun a feasibility clinical trial of a mind–body intervention for older adults living with HIV in Miami, Florida. Participants were randomly assigned to one of three conditions: a tai chi/qigong intervention, a sham qigong, and a no treatment group. Both the tai chi/qigong intervention and sham qigong groups were in-person groups. On March 13, 2020, we suspended the trial due to COVID-19. Senior investigators

discussed the possibility of using Zoom videoconferencing to continue the intervention; however, after much discussion with investigators and staff, it was decided that this was not a viable option for our participants for the following reasons: limited data plan on smartphones, lack of computer in the home, lack of privacy to do the intervention, and lack of knowledge regarding videoconferencing. In addition, based on conversations with our program officer, it was also determined that videoconferencing the intervention would change the nature of the intervention itself. Although the clinical trial was temporarily suspended, we continued to contact our participants weekly via phone calls as per study protocol; however, we also used it as a ‘check-in’ and added a few questions, with IRB approval, regarding the coronavirus situation to track any possible adverse events. As part of the weekly calls during the COVID-19 social distancing period, participants are currently being asked a subset of 7 questions related to their potential symptoms of COVID-19, experiences in SARS-CoV-2 testing, the effects on their HIV care, and stress during the COVID-19 pandemic. This Note describes some of the preliminary information gathered from the first of these weekly ongoing calls.

## COVID-19 Related Information Collected

Of the 24 participants in the first cohort of the clinical trial, five participants were lost to follow up, and there were another 3 currently enrolled participants that were not able to be reached by phone during the first call. Sixteen of the 19 currently enrolled participants completed the COVID-19 related factors questionnaire. Demographic information can be found in Table 1.

We asked our participants about their potential COVID-19 symptoms based off of the CDC recommendations used to screen people into testing [5]. Among the sample, 3 participants experienced one potential symptom of COVID-19

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**Table 1** Sample characteristics and current COVID-19 outcomes among a sample of older people living with HIV

	N (%)	Mean $\pm$ std
Age		57.4 $\pm$ 6.0
Sex		
Male	6 (37.5%)	
Female	10 (62.5%)	
Race/ethnicity		
White, Non-Hispanic	0 (0.0%)	
Black, Non-Hispanic	13 (81.3%)	
Hispanic	3 (19.7%)	
Sexual Orientation		
Heterosexual	13 (81.3%)	
Homosexual/bisexual	3 (19.7%)	
Education		
< High School	5 (31.3%)	
High School	6 (37.5%)	
> High School	5 (31.3%)	
Presence of COVID-19 symptoms		
Fever	0 (0.0%)	
Dry cough	1 (6.3%)	
Productive cough	2 (12.5%)	
Shortness of breath	0 (0.0%)	
HIV care outcomes during COVID-19 social distancing		
Kept HIV care appointments <sup>a</sup>	10 (83.3%)	
Received antiretroviral therapy	16 (100.0%)	
Kept in contact with case manager <sup>b</sup>	10 (83.3%)	
Covid-19 Stress		4.4 $\pm$ 3.3

n = 16

<sup>a</sup>Denominator was among those who had appointments (n = 12)<sup>b</sup>Denominator among those who knew they had a case manager (n = 12)

which were a productive cough (n = 2) and a dry cough (n = 1). However, the participants who listed productive cough as a symptom said that the cough preceded the COVID-19 pandemic. Four participants sought SARS-CoV-2 testing, but interestingly none of the participants who reported symptoms were those who sought testing. Three of those who sought testing received a test. Two tested negative and 1 participant was awaiting results. The participant who was unable to receive testing indicated that it was due to being unaware that an appointment was necessary to receive a test. These findings could highlight potential barriers in educating older PLWH in COVID-19 symptoms and testing; particularly as it pertains to (1) identifying symptoms of COVID-19, (2) knowing who should be tested for SARS-CoV-2, (3) the appropriate protocol to procure a test depending on location (i.e. drive through testing vs appointment driven testing).

When looking at the effects of COVID-19 on HIV care, we found among participants who had HIV care appointments since the initiation of social distancing (n = 12), ten participants were able to keep their HIV health care appointments. Among those who made their appointments, two mentioned their visit transitioning to ‘telehealth’. All participants were able to receive their HIV antiretrovirals (n = 16). Among those who were aware they had a case manager (n = 12), two were not able to keep in contact with their case manager, but mentioned difficulty even before social distancing.

We were also interested in the stress that participants were feeling during this period of COVID-19 and social distancing. We asked participants to rank their stress since social distancing from 1 to 10 with higher scores indicative of greater stress. The average level of stress reported by our sample due to COVID-19 was 4.4  $\pm$  3.3 with scores ranging from 1 to 10. Among the most stressful things participants reported were potential exposures to SARS-CoV-2, adjusting to social distancing, and issues related to finances. One participant reported a perceived benefit, noting that the connection to an emergent social support system had decreased their perceived loneliness.

## Insights and Implications

Preliminary findings from our weekly calls to older people living with HIV suggest that most of our participants continue to receive HIV care in person, although telehealth was reported by some and could be an important alternative to in-person care in the future. One participant did report not being able to get a SARS-CoV-2 test because they did not have an appointment. It is unclear why this was the case. Clinics should prioritize certain vulnerable populations such as older PLWH for testing, or perhaps provide testing during a routine care visit if available. Stress levels do seem to be impacted by COVID-19, and for our participants, stress revolved around its impact on their health, on their sense of social isolation, and their economic situation. For example, one participant asked if they could receive the study incentive even if the trial was suspended. Researchers should consider how suspension of studies may financially affect their target population. We did not ask about social isolation directly; however, anecdotally, our research interviewer has observed how happy our participants are to receive his phone calls and to talk to someone. One participant was so grateful, he states, she cried during the phone call. Social isolation and mental health should be assessed and addressed during such a crisis event.

Several policy implications should be considered. Previous guidelines have been composed to address the deleterious effects of natural disasters on HIV care. However, these

guidelines seem to be geared mostly towards resource limited scenarios such as absence of electricity, potable water, and/or shelter. New guidelines should be constructed that address HIV care during epidemics which typically occur in the presence of necessary resources. Our findings imply the need for future guidelines to include the following information: when should clinics begin using telehealth methods to maintain client appointments?; how often should HIV providers check in with their clients, and should check-ins include mental health assessments?; what else can researchers do to help participants get through difficult periods of uncertainty?; and what actions can researchers take to educate their participants on emerging pandemics?

Moving forward, we will continue to conduct weekly calls to our participants; and once the trial begins again, this first cohort will complete the intervention. However, their pre- and post-data has been impacted by COVID-19. To address this, and if approved, we will add another cohort of participants. In sum, weekly phone calls can help researchers maintain contact with participants and provides an option for further data collection. We also believe that our weekly phone calls to all our participants are helping them stay connected and puts us in a position to help them in the case an emergency arises.

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