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ORIGINAL PAPER

"A Double Stress": The Mental Health Impacts of the COVID-19 Pandemic Among People Living with HIV in Rakai, Uganda

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Abstract

Mental health impacts of the COVID-19 pandemic for people living with HIV are poorly understood, especially in low-income settings. We conducted qualitative semi-structured in-depth interviews among people living with HIV (n = 16) and health workers (n = 10) in rural Rakai, southcentral Uganda. Data were analyzed thematically. We found mental stress during COVID-19 was compounded by worry about antiretroviral therapy (ART) access, distress over inadvertent disclosure of HIV status, fear that coronavirus infection would have more severe outcomes for immunocompromised individuals, and exacerbated poverty and economic stress. Mental health support for people living with HIV deserves greater attention during the COVID-19 pandemic and beyond.

Keywords Mental health · COVID-19 · HIV · Distress

Introduction

The COVID-19 pandemic presents complex, multidimensional challenges to maintaining the health and wellbeing of individuals worldwide. The emergence of COVID-19 and resulting mitigation measures have been shown to negatively affect the mental health of different populations.[1, 2]. Already at increased risk of poor mental health [3], people living with HIV may face an increased psychosocial burden due to stressors added or compounded by the COVID-19 pandemic. Unemployment from shrunken industries or business closures due to COVID-19 may put people living with HIV in need of antiretroviral therapy (ART) at particular risk for amplified distress [4]. However, the actual impact of the COVID-19 pandemic on the mental health of people living with HIV remains largely unknown—particularly in low-income, rural settings globally.

Uganda marked its first case of COVID-19 on March 21, 2020 and subsequently implemented policies to stem the spread of COVID-19, including closure of schools, restrictions on public gatherings, a country-wide curfew and stay-at-home-orders, restricted local travel, and a total travel ban into and out of the country (colloquially called "lockdown measures") [5]. Health facilities were able to continue providing ART at reduced staff capacity, and added additional services were subsequently implemented in the Rakai region. These services were primarily focused on assisting with ART access and included longer duration of ART refills, community-based ART distribution points with physical distancing measures in place, client-led distribution (having a single client or individual collect ART for multiple people), home-based peer health and para-social health worker ART distribution and adherence counselling, and allowing people living with HIV to collect ART refills at any health facility that was geographically convenient. Although the most stringent restrictions were relaxed in mid-May of 2020, the short- and long-term impacts are not well understood. We assessed how the COVID-19 pandemic has impacted the mental health of people living with HIV in Rakai southcentral, Uganda.

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Methods

We conducted a qualitative study among adults (ages 18–49) living with HIV and health workers in Rakai southcentral, Uganda from August-December 2020. People living with HIV (n = 16) were recruited from prior participants in the Rakai Community Cohort Study (RCCS) [6] who had agreed to be recontacted for future studies. Health workers who regularly provide care for people living with HIV (n = 10) were recruited from Rakai Health Sciences Program (RHSP) clinics based on recommendations from RHSP staff. All participants were purposively sampled, with people living with HIV selected for diversity in duration of time since HIV diagnosis (< 18 months or ≥ 18 months) and sex (male/female), and health workers selected for representation across type of care provider (nurse, HIV counselor, peer health worker). We also considered diversity in geographical location across the Rakai region (fishing, trading, and agrarian communities) in participant selection.

RHSP staff contacted potentially eligible individuals to assess their interest in participating in the study. For interested individuals, interviews were scheduled at a day and time of the participant's choosing. All interviews were conducted remotely via mobile phone. Emphasis was placed during recruitment on ensuring participants chose a time when they could be in a private location, with their mobile phone adequately charged. Interviews were conducted by experienced qualitative interviewers/research assistants. Verbal consent was provided by all participants via telephone and documented. Questions about the mental health impacts of COVID-19 were part of a larger study exploring how mental health manifests among people living with HIV in Rakai. Questions about COVID-19 focused on how the COVID-19 pandemic had impacted the emotions, feelings, and thinking of people living with HIV. For example, participants were asked to describe the impact of COVID-19 on mental health, emotions, feelings, and thinking specifically for people living with HIV. Participants were also asked to describe how COVID-19 impacted how people living with HIV experienced the mental health issues discussed earlier in the interview. Interviews among people living with HIV were conducted in Luganda, the local language, and health worker interviews were conducted in either Luganda or English. All interviews were audio recorded, transcribed, and translated to English as necessary.

Data were analyzed using thematic analysis. Themes were identified through an iterative process of familiarization with the transcripts and the generation and application of codes. Themes were reviewed and discussed among study investigators for consensus and completeness. Illustrative quotes were chosen to exemplify salient themes.

This study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board, Uganda Virus Research Institute Research and Ethics Committee, and the Uganda National Council for Science and Technology.

Results

Among the participants living with HIV (n = 16), seven were women and nine were men. Nine had been diagnosed with HIV ≤ 18 months ago, and 7 had been diagnosed > 18 months ago. Of the health workers (n = 10), 5 were nurses, 3 were HIV counsellors, and 2 were peer health workers. Themes were consistent across stratifications, therefore are presented together. Table 1 presents the four key themes we identified and exemplary quotations.

Worry Over ART Access

Many participants said that people living with HIV often obtain ART from clinics outside of their own communities to avoid being identified as HIV-positive and stigmatized by others in their community. Even when individuals collect ART from the clinic within their community, it is often not possible to get to the clinic by walking. During the early days of the COVID-19 pandemic, transportation restrictions impacted clinic access, causing a great deal of anxiety and worry in anticipation of running out of ART. Following the lifting of lockdown measures, most participants reported that transport costs were inflated and that many people had lost their employment and could not afford the cost to travel to the clinic, which led to continued stress.

Distress over Inadvertent HIV Status Disclosure

Half of health care providers and some participants living with HIV said that the COVID-19 pandemic made it difficult for some people living with HIV to conceal their HIV status as they had previously done, causing them distress. In particular, being confined inside of the home with family members who were not aware of their HIV status resulted in a loss of normally utilized ways of taking or collecting ART. Some participants also said that people living with HIV were worried that if they became ill with COVID-19 this would force them or the health workers taking care of them to reveal their HIV status to family members.

Fear of Death from COVID-19

Many participants discussed fear over the double burden stressor of getting COVID-19 while being HIV-positive and noted that this fear is particularly salient for people living

Table 1 Key themes and quotations

Themes	Quotations
Worry over ART access	*One in Kalisizo [may get] HIV treatment from Mbarara because he/she does not want to be seen by people in Kalisizo at the ART clinic in Kalisizo. You find that person stressed not knowing what to do after his/her treatment is finished* – female, age 21 *Some people were still in villages, and they were not prepared [for lockdown measures]. Therefore, time came when some patients had finished their medication, and they stopped taking ART. This led the patients to get worried or experience apprehension [okweraliikirira]. Indeed, COVID has strongly affected people living with HIV.* -Nurse *COVID-19 caused a lot of problem to our side—the people living with HIV. We were so worried about how to access medicine from the clinic during the quarantine period. You could worry about getting a refill in case your medicine was about to get finished. Personally, this was so worrying a situation.* – male, age 40
Distress over inadvertent HIV status disclosure	*The lock down restrictions on travel started to be enforced when some people living with HIV had gone to visit family members or friends. This caused fear as a result of wondering what to do next because you cannot disclose your status to those people.* – female, 32 *Sometimes the husband was taking the medicine from work but they are now at home. This greatly affected people living with HIV especially those who had never disclosed to the people that they stay with at home that they take HIV medicine.* – male, 40
Fear of death from COVID-19	*They used to say: "I am HIV positive, if I get infected with 'corona will I even spend a minute [alive]."* – female, age 27 *As we are experiencing this here now, it's giving a double stress. Now you [people living with HIV] have HIV and COVID you have had a very deep fear of dying because COVID is worse for you.* – Nurse
Poverty and economic stress	*But the money is the problem now, the transport [following COVID-related restrictions] …they [people living with HIV] don't get their medicine. Then you [people living with HIV] start thinking, overthinking. It affects someone psychologically. The kids are many at home. They are poor. They have no job now. So, they overthink. And they automatically become psychologically affected.* -Nurse *Currently, we have the COVID pandemic, I do not have the money and most of the businesses were shut down. Where I used to spend about ten thousand Uganda shillings for my transport, I am now spending about forty thousand Uganda shillings. Therefore, in all these ways I must experience worry or apprehension [okweraliikirira].*—male, age 41

with HIV due to their immunocompromised status. A number of participants also mentioned that misinformation circulating in communities included the idea that individuals with HIV could not survive COVID-19. This caused compounded feelings of fear of COVID-19 for people living with HIV.

Poverty and Economic Stress

All participants said that lockdowns impacted people's ability to work, throwing many into dire economic situations where they struggled to afford food and pay for transport to collect ART, even once lockdown measures were relaxed. Participants noted that specific industries (such as fishing or selling goods) did not rebound after lockdowns were lifted because so many people lacked money. Responses to this stress varied, including worsening depression, "deep thoughts", worry/apprehension, and thoughts of death or suicide.

Discussion

These findings demonstrate the compounded stressors and mental health impacts of the COVID-19 pandemic that are specific to people living with HIV in rural Rakai, Uganda. People living with HIV experienced worry about how to access ART, concern about inadvertent disclosure of their HIV-status in living situations impacted by COVID-19 lockdowns, and fear of dying if they contracted COVID-19 because of their immunocompromised status. Already tenuous economic conditions were exacerbated by COVID-19 mitigation measures, causing added mental health stressors for people living with HIV.

Literature is emerging around the negative impacts of fear of contracting COVID-19 on mental health generally [7, 8], and our findings suggest this fear is even more prominent among people living with HIV. The perceived negative outcomes of having one's HIV status disclosed have been well documented as having psychological ramifications [9]. Specifically, concerns over HIV disclosure are commonly associated with anxiety, fear and worry. From our data, COVID-19 curfew and travel restrictions placed people living with HIV who had not disclosed their status in situations where they had to newly contend with concealing their HIV status, thus impacting their mental health by adding fear and anxiety over the possibility of inadvertent disclosure. The COVID-19 pandemic has intensified poverty worldwide [10], and poverty is a risk factor of poor mental health, with low socio-economic status shown to be associated with increased prevalence of depression and suicide attempts [11]. With a critical need to regularly access HIV services, the mental health impacts of deepening states of poverty may be more pronounced for people living with HIV, and was a significant point of distress in our study. Furthermore, poor mental health has been shown to impact engagement and retention in HIV care [12], suggesting that prompt attention to added or exacerbated mental health due to the COVID-19 pandemic is critical.

Although in the Rakai region additional measures were put into place to increase access to ART, adherence counselling, and HIV care early in the COVID-19 pandemic, participants in this study were asked to talk about the challenges and impacts of the COVID-19 pandemic on the mental health and wellbeing of people living with HIV, and thus did not touch upon these particular services. Many participants in this study focused on the hardships experienced during lockdowns and in the early weeks after the lifting of lockdown measures. However, these innovative ways of delivering ART and counselling to reach people living with HIV may have positive impacts on the mental health of people living with HIV during the on-going COVID-19 pandemic, and are worth consideration by ART service providers across sub-Saharan African settings. As countries in this region implemented various COVID-19 mitigation procedure that specifically impacted people living with HIV, our findings may be transferable to other settings.

Conclusions

These findings suggest that the COVID-19 pandemic and measures taken to curb the pandemic may have exacerbated or contributed to mental stressors unique to people living with HIV. Mental health services for people living with HIV in low-income settings are already lacking. Given the implications of the COVID-19 pandemic on the mental health of people living with HIV, and the potential downstream impacts on engagement and retention in HIV care, as governments and the health system continue to develop responses to the pandemic, additional attention must be paid to addressing the psychosocial and mental health support needs of people living with HIV. In addition, it may be beneficial to consider how peer-led counselling and psychosocial support beyond just adherence counselling might benefit the mental well-being of people living with HIV and could be integrated into modified ART delivery models that have been implemented as a result of the ongoing COVID-19 pandemic.

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Author Contributions NSW developed the interview guides and sampling scheme, with input from CEK, WD, NN, FN, and JK. NSW, WD, CEK and NN trained study staff on data collection and study procedures. DI, RN, and NSW conducted interviews. NSW coded all transcripts and performed data analysis. DI, RN, WD, CEK and NN gave feedback on the themes from the analysis. NSW developed the first draft of the manuscript. CEK supervised all writing of the manuscript. All authors read and commented on a draft of the manuscript and approved the final manuscript.

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Data Availability The dataset generated and analyzed during the study is not publicly available to protect the confidentiality of the participants. Reasonable requests for data access will be considered by the corresponding author. Relevant interview guide questions will be made available upon request to the corresponding author.

Code Availability A copy of the codebook will be made available upon request to the corresponding author.

Declarations

Conflict of interest The authors declare no conflicts of interest or competing interests relevant to this report.

Ethical Approval This study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB 00009695), Uganda Virus Research Institute Research and Ethics Committee (GC/127/19/12/744), and the Uganda National Council for Science and Technology (SS408ES).

Informed Consent Informed consent was obtained from all participants included in the study.

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