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Access to HIV/AIDS or TB care among refugees in Kampala, Uganda: exploring the enablers and barriers during the COVID-19 pandemic

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ABSTRACT

The rapid spread of COVID-19 has overwhelmed the existing health care systems, finding it challenging to provide essential health services besides the COVID-19 response interventions. Refugees are disproportionately affected by the COVID-19 pandemic because of the barriers they face to access health care. However, there is limited research that investigates how access to HIV/AIDS or TB care services by urban refugees is affected during pandemics such as the COVID-19. This study adopted a cross-sectional survey utilizing quantitative (N=229) and qualitative data (26 in-depth interviews and 8 key informant interviews) held among urban refugees living in Kampala, Uganda. Results revealed that more females (75%) than males (25%) were able to access TB or HIV/AIDS services during COVID-19 related lockdowns. A decrease in queues, delivery of drugs through Village Health Teams (VHTs), proximity to health facilities, supply of necessities like food and the reception at the health facilities facilitated access to TB or HIV/AIDS services. On the other hand, restrictions on public transport, high transport costs, unemployment and subsequent poverty were barriers to access to TB or HIV/AIDS services. Results offer major insights into the effect of COVID-19 control measures on disruption of access to services particularly in relation to being able to access service points. The findings suggest that recognizing structural barriers to uninterrupted or continued access to HIV/AIDS or TB services during pandemics such as COVID-19 can go a long way in helping stakeholders to design measures that make it possible for more urban refugees to access HIV/AIDS or TB services.

Introduction

The rapid spread of the corona virus disease (COVID-19) has resulted in many health care systems finding it challenging to provide essential health services to citizens and non-citizens especially the ones that have previously been delivered at health facilities (Ahmed et al., 2020, Amimo, Lambert, and Magit, 2020, Bantebya, 2012). Restricted movements, exorbitant transport fares during and after the lifting of the lockdown, the stringent measures put in place to decongest the health facilities and to ensure adherence to social distancing, the fear of contracting COVID-19 and loss of livelihoods have been recognized as some of the impediments to access to health care during the COVID-19 pandemic (Berhe, Tegabu, and Alemayehu, 2013, Braun and Clarke, 2006). While

these challenges may be faced by all citizens and non-citizens, there are segments of the populations such as refugees that have been disproportionately affected by the COVID-19 pandemic events (Bryman, 2001, Bukuluki et al., 2021). Refugees like many other vulnerable groups are one of the groups that may be particularly affected by apparent and hidden barriers to healthcare access during the COVID-19 pandemic times (Berhe, Tegabu, and Alemayehu, 2013). This is because some measures put in place to adhere to the COVID-19 standard operating procedures were made tougher for refugees (living in Uganda) – making it harder for some refugees to access care (Bukuluki et al., 2021). In Uganda, this is likely to impact more on urban refugees especially those in informal settlements given the reinforced measures to ensure that the urban populace adheres to COVID-19 prevention.

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Uganda hosts the largest number of refugees in Africa with an estimated 1.5 million refugees as of November 2021 (Berhe, Tegabu, and Alemayehu, 2013). While many of these stay in zoned and protected refugee settlements, some reside in urban settings, with Kampala, the capital city hosting about 105,076 refugees (as at December 2021) (Bukuluki et al., 2020). Many of these come from Somalia, Democratic Republic of Congo, Eritrea, and Burundi (Centre for Disease Control (CDC) 2021). Recent estimates published in 2019 for Uganda, indicate the TB incidence to be 200 per 100,000 population and HIV prevalence (15-49 years) to be at 5.4% (De Paz et al., 2020). In Uganda, refugees are allowed to access health services from public health facilities and from non-government organizations that offer HIV/AIDS or Tuberculosis (TB) care free of charge (Crang and Cook, 2007). However, structural and social disparities escalated by the COVID-19 prevention and control strategies by the State and at health facilities, have led to refugees becoming disproportionately affected by failure to access services during the COVID-19 pandemic (Government of Uganda, United Nations High Commissioner for Refugees 2021). Refugees receiving health care services for chronic illnesses such as those enrolled on HIV/AIDS or Tuberculosis (TB) care may be greatly at risk of having deterioration with their health if they are affected by COVID-19 (Government of Uganda, United Nations High Commissioner for Refugees 2021). However, the enablers and deterrents to access to and use of HIV/AIDS or TB care among urban refugees during the COVID-19 pandemic are not well understood.

Overcoming the above deterrents to health care access is hampered by the current measures where much emphasis is being placed on addressing COVID-19 at the expense of other diseases (Government of Uganda, United Nations High Commissioner for Refugees 2022). However, to sustain the gains realized in the response to the HIV/AIDS pandemic and to improve the wellbeing of refugees in need of HIV/AIDS or TB care, there is need for health providers and other stakeholders to address the barriers to HIV/AIDS or TB care for refugees during the COVID-19 crisis (Grimm, 2010). It is also important to find out if there are refugees who have remained in care despite the challenges at hand (Government of Uganda, United Nations High Commissioner for Refugees 2022). Cognizance of the resilient mechanisms employed by refugees who continued to access HIV/AIDS or TB care during the pandemic will help stakeholders to design appropriate interventions to increase access to and use of HIV/AIDS or TB services and ensure optimization of health care for this special population.

Understanding how access to HIV/AIDS or TB care by refugees is affected during pandemics such as COVID-19 is pertinent and has the potential to improve policy and programming for refugees (Gulliford, Figueroa-Munoz, and Morgan, 2002, Hermans, Castelnovo, and Katabira, 2012). Therefore, this study sought to identify the enablers and barriers to access to and use of HIV/AIDS or TB care in health systems, and at provider and individual levels among refugees living in Kampala during the COVID-19 pandemic. The findings are also aimed at generating evidence that could inform policy, preparedness and programming to overcome access barriers to HIV/AIDS or TB care as well as to facilitate current and future strategies to ensure continuity of chronic care for urban refugees during pandemics or crises such as COVID-19. The resilient mechanisms that enabled refugees to continue to access and receive HIV/AIDS or TB care can be leveraged on to support others who could not access the required services to stay in care and remain healthy during this COVID-19 crisis. Optimum health for refugees increases their productivity, self-reliance and economic and social development in low-income countries such as Uganda.

Data and methods

Study setting

Kampala district is the capital city of Uganda, located in the central region of the country. In December 2021, Kampala district was home

to 105,076 refugees (Bukuluki et al., 2020). An estimate provided by the Office of the Prime Minister on the 30th November 2021 shows that majority of refugees in Kampala Central division were from Somalia (26,702) (Hurst, Li, and Pugsley, 2014). Only 5.6% of the total refugees in Kampala are employed – with 473 working as tailors and dressmakers while 286 were engaged in crop and vegetable farming (Igoye, 2020). In terms of specific needs, 302 refugees have a serious medical condition and 354 had a form of disability (as at 31st January 2022) (Igoye, 2020).

Source of data and sample size

The data used in this paper is drawn from a cross-sectional survey that collected quantitative and qualitative data from 4 health centres (Kisenyi health center III, Kisugu health centre III, Kitebi health centre III and Kawaala health centre III) and 2 Non-Governmental Organizations (NGOs) (AIDS Information Centre) and Africa Humanitarian Action (AHA). The quantitative survey collected information from 229 refugees. In this paper, we define a refugee as a person forced to leave their home country because of reasons such as war, persecution or violence (Institute for Security Studies 2020). A qualitative approach was used to conduct in-depth and semi-structured interviews and key informant interviews (KIIs). In-depth interviews (IDIs) were used to collect information from refugees. Key-informant interviews were used to collect information from key stakeholders such as medical practitioners, Non-Governmental Organisations (NGOs), volunteers and village health team (VHT) members. In total, the study conducted 26 in-depth interviews (13 males and 13 female), and eight key informant interviews (KIIs).

Data collection and ethical clearance

Data were collected by 6 research assistants (RAs) who were well trained on how to ask questions and how to use the Computer Assisted Personal Interviewing (CAPI) technology. Interviews were conducted in English, Kiswahili, Juba Arabic, Kinyarwanda or Luganda. The use of CAPI technology enabled the investigators to access data in real time. Training of RAs took place on the 26th and 27th July 2021. A pre-test was done on the 28th July 2021 to test the suitability of the questions designed for the study. All comments arising from the pre-test were considered in the final revision of the final questions. The main data collection exercise took place between August 2021 and October 2021.

All the interviews were audio-recorded with permission from the participant. While conducting interviews, we followed the Standard Operating Procedures (SOPs), and in some instances, interviewers conducted phone-based interviews. This was done to minimize the spread of COVID-19.

Ethical clearance to conduct the study was obtained from the Ethics committee of the University of Edinburgh's School of Social and Political Science (281866) and the Mildmay Uganda Research Ethics Committee (MUREC – REC 0207-2021). Respondents were assured of utmost safety, privacy and confidentiality during the data collection exercise. All study participants verbally consented to participate in the study. Respondents who were found to be sick or at risk of illness were referred to a nearest health facility or counselor.

Study sampling

Purposive sampling was used to select both the health centres and participants who were included in the study. The health centres selected are the major healthcare providing institutions in the areas where the refugees lived. Similarly, purposive sampling was used to select participants for both quantitative and qualitative approaches. This was done to ensure we get rich information about the subject (International Federation of Red Cross and Red Crescent Society 2020). Recruitment of participants was purposively done to include the following categories:

young and old, educated and not educated, and receive TB or HIV/AIDS treatment – to allow depth and breadth in analysis.

Measurement of variables

Dependent variable

The main outcome variable was access to TB or HIV/AIDS services, and was assessed by asking the following question: How easy it was for you to access TB or HIV/AIDS services during the COVID-19 associated lockdown? Responses to this question were designed as: extremely difficult, fairly difficult, extremely easy, and fairly easy. Because of small frequencies within categories, we generated two categories: 'difficult' (extremely difficult and fairly difficult) and 'easy' (extremely easy and fairly easy). In this paper, access to TB or HIV/AIDS services imply being able to command appropriate TB or HIV/AIDS health services in order to improve the quality of life while utilisation refers to the actual use of TB or HIV/AIDS services (Inzaule et al., 2021).

Independent variables

Background characteristics of respondents included age, sex, education, income and living condition. Age was collected in complete years, with the minimum age being 18 years and maximum 73 years. We created five age groups 18-27, 28-37, 38-47, 48-57 and 58 years or more. Education attainment is either no education, primary, secondary or post-secondary. Monthly income was categorized into two categories: less than 100 dollars and 100-300 dollars. Respondents were either living in a rental or non-rental living arrangement, either belonged to a social support group or not. Participants either obtained medical health services for free or paid. Respondents living with HIV/AIDS had either received HIV/AIDS treatment for less than or equal to a year or more

than a year. Duration of receiving TB treatment had three categories: less than 2 months, 2-6 months or more than 6 months. Respondents were asked whether they took the initiative to find out how to access services during lockdown, whether service providers conducted community outreaches, whether respondents were informed by health workers where to obtain services during lockdown or how to continue getting services, whether they got all health workers they needed or whether they got all the services they needed. A response to each of these questions was either 'Yes' or 'No'. Respondents were also asked to mention whether services were provided timely: waiting time appropriate, waiting time longer or waiting time unusually longer.

Data analysis

Descriptive quantitative analysis was performed using the Stata software version 15 (Johnson and Stoll, 2008). The distribution of respondents was presented by gender (female and male). Data analysis for the qualitative data started during fieldwork (Kansiime et al., 2021). Qualitative data was first transcribed from local languages (Juba Arabic, Kinyarwanda, Luganda and Swahili) to English. We used thematic analysis to analyse the transcripts. Qualitative data were organized into codes and themes (Khan, Rego, and Rajal, 2021). We considered quotes in the results that resonate with key themes and sub-themes.

Results

Background characteristics

Table 1 shows the distribution of the respondents by gender. Majority of the respondents were female (72%) compared to male (28%).

Table 1.
Background characteristics

Variable	Sex of the respondent		Total (N)	Chi-square
	Female	Male		
Age				0.023*
18-27	66.7	33.3	21	
28-37	81.3	18.7	48	
38-47	79.2	20.8	77	
48-57	65.6	34.4	64	
58+	47.4	52.6	19	
Education				0.001**
No education	71.7	28.3	46	
Primary	80.6	19.4	98	
Secondary	69.7	30.3	66	
Post-Secondary	36.8	63.2	19	
Income				0.534
Less than 100 dollars	72.7	27.3	205	
100-300 dollars	66.7	33.3	24	
Financial means to access services				0.151
Free	73.3	26.7	210	
Pay	57.9	42.1	19	
Duration of receiving HIV/AIDS treatment				0.665
Less than or equal to a year	66.7	33.3	24	
More than a year	73.1	26.9	197	
Not applicable	62.5	37.5	8	
Duration of receiving TB treatment				0.129
Less than 2 months	81.6	18.4	38	
2-6 months	68.0	32.0	25	
More than 6 months	61.4	38.6	57	
Not applicable	75.2	24.8	109	
Living environment				0.298
Rental	70.9	29.1	199	
Non-rental	80.0	20.0	30	
Social support				0.621
Belong to a social support group	76.4	23.6	55	
Do not belong to any social support group	72.9	27.1	144	
Total (N)	165	64	229	
Total (%)	72.1	27.9	100	

Note: *p<0.05; **p<0.01

Table 2.
Ease in accessing TB or HIV/AIDS services during COVID-19 lockdown by background factors

Variable	How easy to access services during lockdown		Total (N)	Chi-square
	Difficult	Easy		
Age				0.885
18-27	42.9	57.1	21	
28-37	37.5	62.5	48	
38-47	39.0	61.0	77	
48-57	32.8	67.2	64	
58+	31.6	68.4	19	
Education				0.726
No education	39.1	60.9	46	
Primary	34.7	65.3	98	
Secondary	34.8	65.2	66	
Post-Secondary	47.4	52.6	19	
Income				0.152
Less than 100 dollars	35.1	64.9	205	
100-300 dollars	50.0	50.0	24	
Financial means to access services				0.313
Free	35.7	64.3	210	
Pay	47.4	52.6	19	
Duration of receiving HIV/AIDS treatment				0.058
Less than or equal to a year	41.7	58.3	24	
More than a year	34.5	65.5	197	
Not applicable	75.0	25.0	8	
Duration of receiving TB treatment				0.000**
Less than 2 months	2.6	97.4	38	
2-6 months	24.0	76.0	25	
More than 6 months	31.6	68.4	57	
Not applicable	54.1	45.9	109	
Living environment				0.223
Rental	35.2	64.8	199	
Non-rental	46.7	53.3	30	
Social support				0.726
Belong to a social support group	34.6	65.4	55	
Do not belong to any social support group	31.9	68.1	144	
Total (N)	84	145	229	
Total (%)	36.7	63.3	100	

Note: **p<0.01

Slightly more than half of males (53%) were 58 years or older. More females had no education (72%), primary education (81%), and secondary (70%) except post-secondary – where there were more males (63%) than females (37%).

Relationship between background factors and ease in accessing TB or HIV/AIDS services during COVID-19 lockdown

The results in [Table 2](#) indicate that most of the respondents (63%) found it easy to access TB or HIV/AIDS services during COVID-19 lockdown. There was significant difference among respondents regarding ease in accessing TB or HIV/AIDS services when compared by duration of receiving TB treatment (p<0.01).

Approachability towards services

The results in [Table 3](#) show that there was significant difference among respondents while accessing outreach services for TB or HIV/AIDS during COVID-19 lockdown (p<0.01). As reported in [Table 2](#), most respondents reported to have found it easy to access TB or HIV/AIDS services during COVID-19 lockdown (63% vs 37%). More respondents with no access to community outreach (52%) found it difficult to access TB or HIV/AIDS services during COVID-19 lockdown.

Availability and appropriateness of services

The results presented in [Table 4](#) indicate that respondents were significantly different by access to health facilities (p<0.01), timely provision of services (p<0.01), getting all the needed health workers (p<0.01) and getting all the needed services (p<0.01). More respondents (87%)

who did not find it easy to access health facilities found it difficult at the same time to access TB or HIV/AIDS services during COVID-19 lockdown. The same pattern is observed among respondents who did not get all the health workers (65%) or services (63%).

Effects of COVID-19 on refugee's health and wellbeing

The majority of the refugees described their quality of life during the pandemic as adequate possibly because the pandemic occurred when most of them had fully settled in communities and were familiar with existing services. However, they reported effects on their survival, social and emotional wellbeing.

Survival

The commonest survival concern was the loss of livelihood. Many refugees lost jobs (as hawkers) which affected their subsistence in terms of purchasing necessities such as food and paying for their accommodation (rent, personal care and maintenance). This was also aggravated by the fact that refugees did not receive social support (relief food) as nationals. This was a great challenge because they need proper nutrition for their long-term treatment, without which their immunity deteriorates.

COVID-19 has affected us because before COVID-19, we were working, because you cannot survive in Uganda without working and because of the pandemic, we have lost jobs, and getting what to eat has become a problem (36-year female, Rwandese).

We are no longer working and when the government supplied the COVID-19 relief food to the vulnerable groups during the lockdown, refugees were left out. (57-year-old Congolese).

First and foremost, the transport was a challenge and patients on chronic care like HIV/AIDS or TB were affected so much which led to

Table 3.
Approachability towards services and ease to access TB or HIV/AIDS during COVID-19 lockdown

Variable	How easy to access services during lockdown		Total (N)	Chi-square
	Difficult	Easy		
Taken initiative to find out how to access services during lockdown				
No	48.6	51.4	37	0.099
Yes	34.4	65.6	192	
Whether service providers conducted community outreaches				
No	51.9	48.1	79	0.001**
Yes	28.7	71.3	150	
Informed by health workers where to obtain services during lockdown				
No	43.3	56.7	60	0.213
Yes	34.3	65.7	169	
Informed by health workers on how to continue getting services				
No	40.7	59.3	59	0.460
Yes	35.3	64.7	170	
Total (N)	84	145	229	
Total (%)	36.7	63.3	100	

Note: **p<0.01

Table 4.
Availability and appropriateness

Variable	How easy to access services during lockdown		Total (N)	Chi-square
	Difficult	Easy		
Whether health facilities are easy to access when needed				
Not easy	87.5	12.5	8	0.002**
Easy	34.8	65.2	221	
Whether services were provided timely				
Waiting time appropriate	86.4	13.6	22	0.000**
Waiting time longer	57.5	42.5	47	
Waiting unusually longer	23.7	76.3	160	
Whether got all health workers needed				
No	65.0	35.0	40	0.000**
Yes	30.7	69.3	189	
Whether got all services needed				
No	63.2	36.8	38	0.000**
Yes	31.4	68.6	191	
Total (N)	84	145	229	
Total (%)	36.7	63.3	100	

Note: **p<0.01

defaulting because people could not go to the nearby health facilities to access treatment and waited to go to Kisenyi health center after lifting the lockdown (Health worker, Kisenyi Health Center IV).

Social

The participants reported an increase in discrimination against them. They complained of being discriminated against by government programmes (such as during the distribution of relief food) and also at the health facilities. Others complained of being ignored when they needed other services which should complement treatment for HIV/AIDS such as treatment for hypertension as well as COVID-19 vaccination.

COVID-19 has affected us in a way that some services have only been provided to nationals and refugees have been left out, for example when they were distributing COVID-19 relief food to the vulnerable poor in Kalangala, we as refugees were left out (34-year-old female Rwandese).

Social isolation was also reported due to misrepresentation of refugee status as people who are supported by various agencies and thus being financially stable. This is also due to underlying tendencies for corruption that affect the quality of service provision.

Local people sometimes do not want to share with us because they believe that we refugees have money which is not true (53-year old female Congolese).

In Uganda, if you want something to be done your way, you have to pay something (bribe) to someone (53-year old male Burundian).

Refugee status sometimes was associated with the transmission of COVID-19. This became complicated when the individual was also living with TB or HIV/AIDS.

Sometimes people discriminate against us saying that we are the ones spreading COVID-19 (51-year-old-male Congolese).

Local people also discriminate against us because we are refugees and at the same time HIV/AIDS patients (36-year-old female Rwandese).

However, those who easily related and with social connections within the communities and at the health facilities had differing accounts.

We also have a health worker whom we can easily go to in case of any problem (40-year old female Rwandese).

Most of the local people treat me so well although there are still some Ugandans who discriminate against us as Eritreans (47 years –old male Eritrean).

Local people have been so friendly and I appreciate this effort from them. (53-year old male Burundian)

Contrastingly, one participant insisted that even where positive social relations exist, they are often uncaring and exploitative and uncompassionate:

People just associate with refugees because of the services they provide like cheap labour but not in the human aspect (49-year-old male Rwandese).

Emotional

Heightened anxieties among our participants were sparked by closures and restrictions on border crossing during the COVID-19 pandemic. Poor emotional health was also intensified by deteriorating social relations within host communities because refugees were labeled COVID-19 carriers:

Community members think that refugees are the ones spreading the virus and they are the reason behind the lockdowns. We are being told every day (56-year-old female Congolese).

People suspected refugees to be having the virus. They (refugees) even used to fear coming to the health facility and receive services freely (Health worker, Kisenyi Health Center).

The enablers and barriers to accessing HIV/AIDS or TB care among refugees

The participants reported access and utilization concerns although some were satisfied with the adjustments that were made during the Pandemic.

Significant changes/ enablers

Various adjustments have been initiated to cope with COVID-19 and the evolving restrictions. The respondents were grateful because of improvements such as a decrease in queues, waiting for hours and delivery of drugs through VHTs. Others were content with the extended dosage regimens which is also an adjustment aimed at reducing journeys for treatment during the COVID-19 Pandemic.

Before the pandemic, we had to wait for long hours but now, I receive my treatment in time (36-year female, Rwandese)

Before COVID-19 we used to collect the treatment ourselves but during the COVID-19 period, VHTs are the ones bringing it to us (44-year-old female Rwandese).

Before COVID-19, we used to be given medication lasting for a month, but during COVID-19, we now receive medication that lasts for six months (40-year old female Rwandese).

Access and utilization barriers

While health facilities maintained continuity and quality of ART and TB services, the participants experienced difficulties in accessing their medication during the COVID-19 pandemic due to restrictions on public transport and high transport costs each time these restrictions were eased. This affected both the refugees as they missed schedules and the health workers because they could hardly trace/ follow up their patients.

Before COVID-19, people could access the health facilities using any means and they could receive treatment but during COVID-19, patients have failed to receive the required medication. We do not know whether it is because of discrimination or the medication is just inadequate and people have been negatively affected (49-year-old male Rwandese).

In this COVID-19 period, we have had issues to do with transport whereby public transport was banned and when the ban was lifted, the costs became too high which made it hard for us to go for treatment (39-year-old female Rwandese).

With COVID-19, everything became affected in that even health workers got challenges in movement (Health worker, Kisenyi Health Center IV).

Other refugees experienced difficulties in using TB or HIV/AIDS medication due to lack of basic provisions such as food to supplement their medication:

Feeding has become a problem because you cannot take the medication on an empty stomach (53-year old male Burundian).

The quality of services provided is good but the challenge comes with feeding yet we are being advised not to take medication on an empty stomach and during this COVID-19 pandemic, getting what to eat is a problem because we do not have money and I can spend two days without food yet I have to take the medication daily (56-year-old female Congolese).

Scarcity of basic provisions also contributed to non-adherence to HIV/AIDS or TB treatments

Some patients have failed to adhere to ART or TB treatment because of improper feeding and as Rwandese, we have very weak body immunity systems (35-year-old female Rwandese).

Adhering to ART or TB treatment has been so hard on my side because I am no longer working, providing for myself is also hard and my children also need support (60-year-old female Rwandese).

Adherence to ART or TB treatment among refugees during COVID-19 pandemic (enablers and barriers)

Adherence or non-adherence to ART or TB treatment depended on proximity to health facilities, access to public transport, ability to reach the facilities, access to necessities such as food and the reception at the health facilities.

Distance to health facilities (enabler and barrier)

The distance to health facilities both facilitated and disabled adherence to ART or TB treatment. Refugees who lived close to health facilities did not experience major issues in receiving and adhering to their medical routines as they would tread to health facilities.

I try and walk to the health facility to get my treatment even during lockdown (53-year –old female Congolese).

On the other hand, majority failed to get medication on time and adhere to medication schedule due to long distances to health facilities, physical disabilities and lack of public transport during the lockdown.

Some receive their treatment in health facilities that are very far from where they stay and there was no way they could reach those facilities when public transport was banned. So, many people failed to take the medication in time (53-year old male Burundian).

Some of us are disabled and aged. So, walking from home to the health facility sometimes is hard (36-year female, Rwandese).

Many patients have defaulted because they had run out of pills and they couldn't access the health facilities (Health worker, Kisenyi Health Center IV).

Poor reception at health facilities

The attitude of health providers also discouraged the participants from visiting these facilities. Some refugees reported the negative attitude and discrimination from health service providers as a reason for not committing to their treatment regimens.

Most of our fellow refugees who do not have any connections in the health system have died because of discrimination in the health facilities and my life was saved by my boss who is a "Muganda" by tribe and a national (39-year-old female Rwandese).

Social-cultural barriers

The social-cultural issues are related to the absence of social support, stigma and lack of disclosure. This means that patients would not receive essential support from family and relatives as implied in these accounts.

Sometimes I fail to pick the medication because I do not have enough transport and there is no one to run to for support and I no longer work (40-year-old –female Rwandese).

I have not disclosed my health status to my husband. So, sometimes I fail to get transport fees because I cannot ask my husband (37-year-old female Rwandese)

Shortage of other essential medicine and care

Respondents reported inability to access medication for other comorbidities associated with TB or HIV/AIDS at health facilities which put their lives at risk.

HIV/AIDS is associated with other diseases like hypertension, cancer among others. But when you request medication for those other diseases, the doctors tell us to buy it yet we do not have money (46-year old female Congolese)

Not being able to receive treatment for other diseases like diabetes, hypertension and others not until you pay for that treatment (56-year-old female Congolese).

I only receive treatment for HIV/AIDS and not for other sicknesses yet they also affect my life (51-year-old-male Congolese).

Not receiving the proper treatment, and health workers want to make decisions over my life of which their decisions are putting my life in danger (60-year-old female Rwandese).

Discussion

The findings of this study revealed that a decrease in queues, waiting for hours, delivery of drugs through VHTs, proximity to health facilities, access to public transport, ability to reach the facilities, access to necessities like food and the reception at the health facilities facilitated access to TB or HIV/AIDS services. It is important to note that during the pre-COVID-19 period, long queues and waiting hours were articulated by some studies as negatively affecting access to ART care (Knipper, Sedas, and Keshavjee, 2021/03/26/2021, Lupieri, 2021). On the other hand, restrictions on public transport, high transport costs, unemployment and subsequent poverty were barriers to access to TB or HIV/AIDS services. During the COVID-19 pandemic, the costs for transport significantly increased amidst loss of livelihoods particularly for people involved in the informal sector that employs most of the urban refugees (Maroko, Nash, and Pavilonis, 2020). Our results underscore the detrimental effect of COVID-19 and its control measures including curfews, lockdowns and restrictions in movements, the stern measures put in place to decongest the health facilities and to ensure adherence to social distancing on continued access to the essential services (Berhe, Tegabu, and Alemayehu, 2013, Braun and Clarke, 2006) particularly among urban refugees in Kampala receiving HIV/AIDS or TB care services.

Our results reveal differentials between female and male urban refugees (75% female vs 25% male) in demonstrating agency and self-efficacy to take initiative to find out how to access TB or HIV/AIDS care services during COVID-19 related lockdowns. Female urban refugees were more agile than their male counterparts in initiating or engaging relevant actors in the health care system to find out how they could ensure continuity of care during the COVID-19 pandemic. Similarly, they were more likely to report that service providers conducted community outreaches and that they were informed by health workers where to obtain or continue getting HIV/AIDS or TB services. In this case our results tend to project female urban refugees as exhibiting more agency and self-efficacy than their male counterparts in navigating the challenges posed by COVID-19 and its containment measures (Berhe, Tegabu, and Alemayehu, 2013) in relation to continuity of access to services.

Furthermore, more females (72%) reported that accessing health services when needed was easy and they got the health workers they needed to provide HIV/AIDS or TB care services. This also shows that females demonstrated relatively more self-efficacy in adapting and coping with the COVID-19 pandemic restrictions (Braun and Clarke, 2006) by exhibiting ability to continue accessing HIV/AIDS or TB services in comparison to their male counterparts.

Women were likely to report that waiting time (which is an indication of perceived quality of care or satisfaction with services) was appropriate compared to their male counterparts. This further demonstrates that female refugees living with HIV/AIDS or accessing TB care services seemed to cope and adjust relatively better in coping with COVID-19 and its containment measures (Berhe, Tegabu, and Alemayehu, 2013, Braun and Clarke, 2006) in order to continue to receive TB or HIV/AIDS care services than males. It could be that their male counterparts had several competing priorities related to being traditionally socialized to be the bread winners of their households and this made them to perceive the waiting time as less appropriate compared to their female counterparts. Even when livelihood options became more limited generally, men could have been more anxious to try and find alternative livelihoods to fulfill their gender roles related to being bread winners (Ministry of Health 12 December 2021, Ministry of Health 2021). This underscores the need for gender sensitive engagement strategies to re-

spond to any unique and dynamic needs of women and men in urban refugee contexts.

Our qualitative findings also shed light on the perceptions of adequacy of TB or HIV/AIDS care services during COVID-19. Many of the refugees interviewed described the quality of care during their interactions with service providers as adequate. The main reason cited was that they received what they perceived as fair treatment by service providers more or less like the nationals. In other words, they did not see manifestations of discrimination based on nationality or refugee status. However, notwithstanding these positive perceptions of quality of care in respect to fair and equitable treatment by health workers, several urban refugees expressed feelings and experiences of resentment and discrimination during the process of seeking TB or HIV/AIDS care services. They highlighted issues related to not getting services that meet their expectations, some health workers refusing to provide comprehensive care or providing treatment without first undertaking the required investigations that would facilitate correct diagnosis and prescription.

Similarly, some felt that nationals were being given priority to the discontentment of the refugees seeking the same HIV/AIDS or TB care services. Maltreatment and discrimination by service providers was perceived as one of the reasons for failure of some urban refugees to adhere to their treatment regimens. Our participants noted that those who did not have informal networks and connections with service providers at health facilities were susceptible to discrimination and maltreatment by service providers.

Our results further showed that the feelings of discrimination and lack of equity in access to the care services were compounded and should be understood in the overall context of the effects of COVID-19 on the socio-economic and psychosocial wellbeing of refugees. Results from our study identify physiological, psychosocial and economic effects of the COVID-19 pandemic on wellbeing of the urban refugees (Bryman, 2001) living with HIV/AIDS or TB. These were perceived by urban refugees to have affected their ability to cope and adapt to the COVID-19 pandemic and particularly their continued access to care and adherence to ART or TB treatment. The commonest concern was the loss of livelihood especially informal sector jobs that constituted a major source of livelihood for the urban refugees under care (Bryman, 2001, Nathan and Benon, 2020). This affected their ability to meet basic needs as well as paying for their accommodation (Grimm, 2010). This was happening in the context of reduced support from their social support networks whose capacity to support them had also been diminished by COVID-19 and its control measures. Urban refugees in particular lost contact during this time with their relations in neighboring countries particularly Rwanda, DRC and South Sudan due to border closures or restrictions on border crossing (Bukuluki et al., 2021, Nathan and Benon, 2020). Similarly, remittances from their relations abroad had reduced during the pandemic that affected the livelihoods of their relatives who used to send them remittances (Nathan and Benon, 2020, Office of the Prime Minister, UNHCR, Government of Uganda 2021). This is critical given that for patients on ARVs, food and nutrition security is paramount for their adherence to ART and overall health outcomes (Office of the Prime Minister 2021). This was further exacerbated by the fact that urban refugees did not at least formally benefit from social protection packages offered by the Uganda government to the nationals categorized as vulnerable during the COVID-19 pandemic (Government of Uganda, United Nations High Commissioner for Refugees 2022, Nathan and Benon, 2020). These packages included food relief and in some cases cash transfers intended to help people cope with the effects of the pandemic and its control measures (Grimm, 2010).

Our results offer major insights into the effects of COVID-19 control measures on the disruption of access to services particularly in relation to refugee's ability to access the service delivery points. While the availability of services at the facilities remained quite good because they remained open, our study reveals several barriers to access particularly from the demand side during the lockdown and early curfew time. Refugees seeking HIV/AIDS or TB care services experienced

challenges related to restrictions on public transport and high transport costs (O’Laughlin, Greenwald, and Rahman, 2021). This affected timely access to ART and other HIV/AIDS or TB care services. Therefore, for many urban refugees, their adherence to ART or TB treatment depended on proximity to health facilities, access to public transport, ability to reach the facilities, access to necessities taking medication such as food (O’Laughlin et al., 2013, O’Laughlin, Rouhani, and Kasozi, 2018, Parker and Aggleton, 2003). Physical barriers were significant particularly for urban refugees who reported having a disability or who were based in locations that they perceived to be far from where they access treatment. It is also plausible that some study participants have specific facilities of preference to seek services due to possible self and external stigma and discrimination associated with TB or HIV/AIDS (Rustein and Johnson, 2004).

Taking cognizance of these structural barriers to uninterrupted or continued access of refugees living in urban areas outside designated refugee settlements during pandemics such as COVID-19 will help policy makers and humanitarian practitioners to design measures that make it possible for more urban refugees (Schulz, 2018) to access the needed HIV/AIDS or TB services in order to ensure that no one is left behind (Gulliford, Figueroa-Munoz, and Morgan, 2002, Hermans, Castelnovo, and Katabira, 2012). Although this study did not interview rural refugees, previous studies (Sharpe and Namusoby, 2012) (Smith et al., 2021) have highlighted barriers in accessing HIV/AIDS and TB services in rural settings or refugee settlements. These include staffing gaps for critical cadres (generally refugee settlements are in areas with low level health facilities (Stata statistical software: release 15 2017) that do not offer comprehensive health services) (Tang and Li, 2021), difficulties in accessing treatment centres (due to poor roads infrastructure), stock shortages of medicines and other health supplies and food insecurity. These factors have an effect on adherence to treatment and viral suppression. Additionally, rural health facilities used by refugees in settlements are more susceptible to chronic shortages of PPEs alongside other infection prevention control supplies (The World Bank 2020) that may increase the patient-to-staff or staff-to-patient transmissions with a heavy death toll on medical staff and the patients seeking health services including HIV/AIDS or TB care services (UNAIDS 2020).

Conclusion and recommendations

The African continent supports the second largest proportion of refugees and migrants in the world and services for these peoples have always been problematic, not the least because in general, indigenous populations have come first in terms of food, health and welfare services with refugees and migrants occupying a provisional and precarious status in their country of (temporary) settlement. This is and was the position before the advent of COVID-19. The pandemic has presented many challenges for all peoples, governments and states. Those with the least resources have felt the consequences worse. Throughout Africa, compared with the minority world, governments have disproportionately experienced struggles to combat the spread of the various versions of the COVID-19 virus. The combination of existent structural poverty, the disparities felt by refugees and migrants in relation to services and now the challenges of the pandemic mean that at the same time as the COVID-19 related needs of refugees and migrants are the same as everyone, the threadbare nature of the existing provision has worsened terribly. Our research documents some of the ways in which this is most keenly felt. These include the decisions by resource-pressed governments to prioritize dealing with the virus to the detriment of other more chronic diseases that are rife among migrant and refugee communities such as HIV/AIDS or TB. Also, with the understanding that many in these communities already live lives on the edge (economically, socially and in health and welfare terms), then the least additional pressure on the societies in which they live is likely to affect them disproportionately. As we have shown, jobs on the margins, in which many migrants gained some income, have dried up, transport to health facilitates – already

as struggle – has become more difficult because of COVID-19 related restrictions, and hand-outs from governments have tended not to designate refugees as a vulnerable group. Other COVID-19 related problems keenly felt by refugees and migrants include restrictions on the ability to maintain social networks in the face of reductions in travel and social networking. Though not evident from our research, it might also be speculated that in terms of severe social crises such as those posed by COVID-19, societies have been known to divide between those that see themselves as the indigenous population (and therefore more worthy of help) and the ‘outsiders’ in the midst such as refugees. Thus the already precarious position of refugees and migrants can be worsened by a phenomenon such as the COVID-19 pandemic.

The study provides important insights into measures that can be adopted by the government, KCCA and NGOs to improve refugee’s access to TB or HIV/AIDS treatment services as well as COVID-19 vaccination. These include sensitization, advocacy and representation, equal treatment, translation and language training services, basic needs, support community awareness, comprehensive treatments and economic empowerment programmes. Refugees must be given priority to access social protection services that facilitate consumption, smoothing, access to alternative forms of livelihoods to meet their basic financial needs that enable them to adhere to their daily medication. Given their TB or HIV/AIDS status, they are another high-risk group for the contraction of COVID-19, thus, it is important for them to be prioritized in strategies to increase access to vaccines. Information concerning the availability of similar services in other locations should be provided to urban refugees through appropriate channels and languages that are effective in reaching out to them to ensure continuity of care.

In the absence of any world-wide effort to ensure parity in access to COVID-19 vaccines, the presence of widespread poverty among African nations, and the relatively even worse conditions of migrants and refugees within Africa, then recommendations for policy and practice are necessarily relative and contingent. However, our research has pointed to some reforms that could be achievable. These involve the need for an authoritative, consistent and reliable – and indigenous – voice for migrants – someone or group of people that will champion their needs but combine this with lobbying for better services for all. A concerted effort to improve language and communication skills could also help minimize any local feelings of resentment and make for better employment opportunities. We recommend programmes that integrate both TB and HIV/AIDS services due to the similar risk factors between the two (United Nations High Commissioner for Refugees 25 December 2021). This can go a long way in saving resources such as time and money on transport for patients among others.

Limitations

As with any other study, this paper has four key limitations. First, this study investigated issues that are sensitive or private in nature, i.e. HIV/AIDS or TB. Thus, the data used in this study could have suffered from social-desirability bias (Williams, Maier, and Scarpetti, 2020) – where respondents choose to respond to questions they deem fit or will be viewed as favorable. Second, a significant proportion of people are less likely to report their true income – either they do not know or they are hiding or suspect interviewers to come from a government institution (World Bank 2018). The situation gets worse among respondents engaged in self-employment or home production of goods and services (similar to our study population) (World Health Organization 2019). In such a case, the estimates about income that we report may not be a true reflection of what we measure but can provide an indication of household income. Third, there is a likelihood of underreporting as the study could have missed out on responses from eligible but undocumented refugees or those that cannot be traced. Last, the enablers and barriers are different based on the programme that the participant is enrolled in – implying that our findings may not be generally representative.

Declaration of Competing Interest

None

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