Exploring the challenges of women taking anti-retroviral treatment during COVID-19 pandemic lockdown in peri-urban Harare, Zimbabwe.

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Abstract

Background

COVID-19 is a threat to both the welfare of the wider population and those who are living with chronic conditions like human immunodeficiency virus (HIV). People living with HIV need a robust supporting environment and a functioning health system. In response to COVID-19 all services were halted, and people were restricted indoors in an effort to prevent the spread of COVID-19. The restriction paused challenges to many vulnerable people living with chronic conditions. This study was set to explore the challenges of women taking anti-retroviral treatment during COVID-19 pandemic lockdown in a peri-urban area**.**

Methodology

This research employed an exploratory qualitative study (EQS) approach. Semi-structured questions were devised and used to elicit data on the on the impact of COVID-19 lockdown on women accessing HIV treatment. Twenty (20) women were interviewed through contacts from community and faith organisations in peri-urban Harare. All interviews were audio-recorded, transcribed verbatim and entered into NVivo for organisation to make analysis easy. The data were thematically analysed underpinned by the for phases of data analysis in the Silences Framework.

Results

The study found out that transport problems, confusing COVID-19 restrictions, abuse by police and soldiers at roadblocks, shortage of medication, lack of health check-up routines, involuntary ARVs default and shortage of Personal Protective Equipment (PPE) affected HIV positive women accessing anti-retroviral treatment during COVID-19 lockdown.

Conclusion

The study concluded that pandemic preparedness is important in keeping adequate supply of ARV treatment and responding to the needs of individuals on HIV treatment.

Key words: COVID-19, HIV, ARV treatment, Women, Pandemic

Background

COVID-19 epidemic pauses a disastrous situation for all affected populations, particularly vulnerable groups within communities, such as people with chronic diseases i.e., human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) [1]. These populations need functioning health care systems, sanitation and hygiene, safe water, and healthy food supply. Due to the epidemic, people cannot maintain their jobs, resulting in deterioration of the economy and public health services. Furthermore, important institutions, such as the health sector, were constantly under pressure and were unable to respond adequately to the health of population demands [2]. Communities and social networks fall apart, and individuals had difficulties in sustaining their livelihoods and living healthily. In responding to the challenges of COVID-19 outbreak all countries underwent a lockdown period as a strategy to arrest the spread of the infection [3]. Under lockdown all services were halted, and people were restricted indoors. Nutrition and access to health services for the wider population became a challenge in many low- and middle-income countries (LMICcs) during COVID-19.

HIV is one of the leading causes of preventable mortal infectious diseases globally, 37.9 million people have tested positive with the virus and two thirds of these people are living in sub-Sahara Africa [4]. Since the rollout of antiretroviral therapy (HAART) in sub-Saharan Africa (SSA) in the early 2000s, the life expectancy of people living with HIV has increased [5]. However, the gains made in reducing mortality from HIV-related complications are being threatened by the COVID-19 restrictions, implemented to curb the spread of the pandemic.

HIV/AIDS is still a persistent global health problem, particularly in low-income and middle-income countries (LMIc) [6]. Enormous steps have been undertaken to treat and prevent HIV such as the "90-90-90 targets" by the Joint United Nations Program on HIV/AIDS which means- 90% of people living with HIV(PLWH) know their status, 90% of PLWH who know their status are on treatment, and 90% of PLWH on treatment are virally suppressed by 2020 [7]. However, there is still much to be done to stop the spread of HIV and keep supply of antiretroviral drugs (ARVs) especially in the current situation of CVID-19 pandemic. HIV patients risk running out of life-saving drugs because of quarantines and lockdowns aimed at containing the COVID-19 pandemic. The lockdown makes it difficult to replenish vital medicine stocks for chronic conditions like HIV [8]. Most of the patients do not know where to collect their next antiretroviral therapy refill. Lockdowns and restrictions imposed by the government does not clearly explain how HIV patients are to collect their medications which means a lot of patients are going to run out of their HIV treatment with a possibility to relapse [9].

Some HIV patients fear letting other people know why they are desperate to get out of the cities, because they are afraid to be stigmatised by others. [10] believe that lockdowns in various cities have also meant that people with HIV who had travelled away from their hometowns have not been able to return home and access HIV services, including treatment, from their usual providers. Adherence to antiretroviral therapy (ART) is a key factor in ensuring optimal positive clinical health outcomes and is associated with improved survival rate among HIV and AIDS patients [11]. Sustained high levels of adherence (taking 95% or more of medication as prescribed) are essential for treatment success [12]. Suboptimal adherence to treatment has been associated with virologic, immunologic and clinical failure, and may increase the risk of resistance to first-line ART drugs. In light of the above discussion this research was set to explore the experiences of women taking anti-retroviral treatment during lockdown.

Methodology

This research employed an exploratory qualitative study (EQS) approach. As the name suggests, an EQS is designed to explore the topic under consideration to better understand it rather than offer a final and conclusive solution to existing problems under investigation [13]. In doing so, an EQS may also identify possible areas for further investigations. As such, EQS is useful in understanding the overview of an existing issue from a new perspective and can provide key information for future interventions [14]. Semi-structured questions were devised and used to elicit experiences on the impact of COVID-19 lockdown on women accessing HIV treatment. The interview protocol was informed by the literature on access to sexual transmitted infections and HIV treatment among vulnerable groups from previous primary and secondary research studies. To test the appropriateness of the interview schedule four women accessing HIV treatment were interviewed. Following the completion of the pilot interviews the women were asked whether they felt that the interview schedule was suitable for the topic in question. None of the four women suggested any substantial changes to the interview schedule and was therefore adopted for use in the research study. However, where appropriate their comments were included to shape the final research interview schedule.

The Joint Research Ethics Committee (JREC) from the university of Zimbabwe granted the ethical approval for this study. 20 women were interviewed through contacts from community and faith organisations in peri-urban Harare. Letters and information sheets were sent to women organisations and faith groups inviting their members to take part in the research study. Only those women who agreed to take part in the research study had their names forwarded to the researchers to organise interview dates. The interviews were held at community and faith group centres where women normally meet for community and faith activities. This was to make sure that the research participants were comfortable and free to answer questions in an environment they are accustomed to. All the research participants signed a consent form which accorded them the right to with from the study without stating any reason. The interviews lasted for one hour each.

The inclusion criteria included women who were HIV positive and taking anti-retroviral treatment. The women were supposed to stay in peri-urban Harare prior to the lockdown. It was important to recruit a heterogeneous sample with respect to cut off time they started staying in peri-urban Harare to make sure that their experiences during lockdown were explored under a uniform situation. The interviews were conducted by two researchers who were both women. This was important to enhance openness and sharing of silences among women as opposed to when a male researcher is involved. All interviews were audio-recorded, transcribed verbatim and entered into NVivo for organisation to make analysis easy [15]. For the verification of accuracy all transcriptions were taken back to the research participants for confirmation. This is deemed important as it validates the data collected prior to analysis [16].

Following the organisation of data by NVivo, the analysis of the data started with coding of data into broad categories by the two researchers using the 4 phases of data analysis in The Silences Framework (TSF) [17]. At phase 2 of data analysis, the researchers took the categorised broad themes to the research participants for verification and confirmation as a true reflection of what they had said during the interviews. The research participants at this point had the opportunity to refute or confirm the constructed broad themes in line with their contribution at interview. At phase 3 of data analysis, the data from phase 2 was taken to a collective voice group for validation and verification. The collective voice group is a group of people who mirrored the research participants but did not participate in the research study. For example, this group was made up of HIV positive women receiving treatment and living in peri-urban Harare but did not take part in the research study. At this point the user voice group validated and verified the data coined in phase 2. This was meant to critique the data using an associative eye. Finally, in phase 4 the researchers analysed the data in line with the contributions made in each phase to form the final output of the research study. See Figure 1 below showing the four phases of analysis described above:

Fig 1 The 4 phases of The Silences Framework (STF) analysis phases.

Source: Serrant-Green, 2011

The research participants were given an information sheet to read and ask question prior to participating in the research study. Furthermore, all the research participants had to sign a consent form, which granted them the right to withdraw from the study at any time without giving reasons.

Results

Following analysis of the data on the impact of Covid-19 lockdown on HIV positive women, the seven themes identified included transport problems, confusing COVID-19 restrictions, abuse by police and soldiers at roadblocks, shortage of medication, lack of health check-up routines, involuntary ARVs default and shortage of Personal Protective Equipment (PPE).

Transport problems

All the research participants agreed that the travelling restrictions have made them miss appointments and/or sometimes made it difficult to travel to healthy facilities to collect their supply of ARVs because public transport was not allowed to move or take people from one place to another.

"*I live 60 kilometres from the health facility I get my ARVs supply and right now I do not know how I am going to go for my next appointment because of this pandemic……no transport is servicing our area"* (**A 46-year-old woman***)*

*"Even though I live 20kms away from the clinic I am not sure I am still fit to walk that long to get to the clinic…especially with this chronic condition that I have had for the past 10 years" (**A 50-year-old woman**).*

Confusing Covid-19 information

Research participants expressed that they all have a general idea of what Covid-19 is, although there was a lot of wrong information that was going around with no one to rectify it. They felt that there was no clear or strategic policy dealing with dissemination of information about the pandemic to the people.

"Most of the information we heard was through social media and some of the information is not as clear as one would want it to be, I have a lot of questions which are unanswered" (**A 29-year-old woman).**

"This is the most difficult time to survive. We are afraid so much information, scary information……. We need clear communication from those in authority in future to avoid this unnecessary fear" (**A 36-year-old woman**)

Abuse by Police and Soldiers at roadblock

Encounters with the authorities in most cases, in Zimbabwe is not a pleasant experience especially the police and soldiers at roadblocks. With the introduction of these travelling restrictions a lot of roadblocks were established to help enforce these restrictions.

"Police are the most unreasonable people I have ever met; they act like they will never fall sick or they do not have relatives who are on this ARVs programme…..imagine I had to spend more than two hours pleading with them to pass " (**A 48 year-old man**)

"Everyone knows that the police are very unreasonable, they asked to see my hospital cards, violating my confidentiality in the process, I was not happy at all." (**A 36-year-old woman***)*.

Shortage of medication
Some of the research participants acknowledged that some of the clinics ran short of ARVs due to people being given supplies for three to six months. They reported that those who had got to the clinics first got enough supplies for three to six months.

"By the time that I made it to my local clinic where I normally collect my ARVs the nurse told me that I was late, and I could only get supply for one month and I am now wondering where I will get my next supply" (**A 42-year-old woman**).

"I could only get supply for two months because the clinic had been giving out three to six months' supply on the first come first serve basis…I am thinking of going to big hospitals to get more supply" (**A 28-year-old woman**).

Lack of health check-up routines
The research participants reported that there were no regular checks i.e., BP, temperature, blood glucose and general check-ups. They also found it challenging to communicate with the nurse through a window just to drop their medical cards and sit as far as possible waiting to collect their medication. Although this was part of enforcing social distancing for individuals, they found it difficult to understand and acknowledge.

"It is exceedingly difficult to be treated like someone with leprosy but anyways I do understand the fear this disease has instilled in us. It is difficult to understand still… more of concern I could not get any regular check-ups which I normally get as a person living with a chronic condition" (**A 33-year-old woman**).

"*Remember we have HIV, and our health depends on regular checks and some of us have developed other conditions like Bp and with no checks we do not know how we are doing right now."* (**A 43-year-old woman**).

Involuntary default
Most of the research participants reported involuntary medication default due to their medication running out while being locked down in a different location far from their homes. The research participants reported difficulties in getting supplies at health facilities where they are not registered.

"*I spend two weeks without taking medication as I was locked down in Bubi where I had visited my sister the local clinic told me that they had supplies for their registered patients only and advised me to go to my registered clinic which was impossible due to lockdown"* (**A 49-year - old woman**).

"I had visited my brother in Bocha when the lockdown happened, I could not make my way back to Gweru until after three weeks… The local clinic could not give me any supplies, so I had to default for one week until I returned to my Gweru" (**A 37-year-old woman**).

Shortage of Personal Protective Equipment (PPE)
The research participants reported difficulties in acquiring PPE for themselves as it was very expensive and sometimes out of stock. They reported improvisation of PPE to protect themselves but sometimes the improvisation was not fit for purpose.

"With fear of infection everyone wanted to get PPE, but it was very expensive I ended up covering my mouth using an old cloth and I don't know whether it works or not… Honestly we needed help as with PPE as vulnerable people" (**A 49year-old woman**).

"I went round all shops and I could not get any PPE to cover myself… I ended up moving around with nothing on my mouth…. You don't even know when you will be infected" (**A 42-year-old woman**).

Discussion

Transport problems affect many health systems in low- and middle-income countries owing to poor infrastructure [18,19]. During COVID-19, the Zimbabwean government effected restrictions on unnecessary travel including public transport [20]. Many research participants reported difficulties in travelling to local clinics for ARVs collection because of COVID-19 lockdown. They also missed some clinical appointments pertinent for their HIV treatment. In future pandemics there is need for the government to make provision for people living with chronic diseases to be ferried to different health facilities to collect their ARVs and attend pertinent clinical appointments during the lockdown periods.

It is important that when there is a pandemic like COVID-19 the affected communities need to be educated about it [21]. In doing so, it enables effective control of the pandemic through behaviour change informed by the information provided. Most of the research participants reported ever changing information about COVID-19 leaving them in fear. It is important that during a pandemic the government establishes effective communication channels understood and available to all the population [22]. It is also important that information is managed and disseminated by qualified health practitioners. More importantly, information needs to be simplified to make sure that it is free of technical jargon and easily understood by the lay members of the communities [23,24]. This is more important when dealing with people accessing ARV treatment to ensure that their medication uptake is not interrupted.

Meanwhile, although it is important that a lockdown should be enforced by law enforcement agents like police and soldiers, it is very essential that the enforcement does not infringe on the rights of citizens especially those who are vulnerable and accessing medication for chronic conditions like HIV [25]. Most of the research participants reported abuse by police and soldiers at roadblocks while on their way to collect their ARV treatment. They also reported breach of their right to confidentiality when the police and soldiers demanded to see their hospital cards. It is important that during pandemic periods police and soldiers are educated about their role during the pandemic, clearly articulating their roles and boundaries to avoid misuse of power which can impact negatively on vulnerable people accessing ARV treatment. There is need for all law enforcement agents to have a clear knowledge and understanding on the laws governing confidentiality and sharing of information to protect vulnerable individuals accessing ARV treatment from being abused [26]. This is crucial in protecting the rights of the patients while upholding their dignity when accessing medication for chronic conditions.

Shortage of medication in low- and middle-income countries is one of the long-standing health problems affecting many countries in this economic group [27]. This is normally caused by weak health systems and infrastructure. Most of the research participants reported shortage of ARV treatment during the lockdown period owing to some patients being given treatment supplies for three to six months. There is need for the government to stay with reserve ARV treatment in case of any pandemic coming. This will prevent individual patients from taking medication errands during the lockdown period and possibly expose themselves to infections. There is need to measure an affordable amount of medication that each patient can get before exhausting supply in reserve [28]. For example, instead of giving up to five months medication supply, all patients can be given medication equivalent to three months to avoid shortage. This would ensure that every patient will get the medication for the first three months and give health facilities time to prepare supply for the next three months again.

Regular check-ups for people taking HIV treatment is important to prevent co-morbidity and other complications [29]. They participants also reported that it was challenging to communicate with the nurse through a window just to drop their medical cards and sit as far as possible waiting to collect their medication. There is need to maintain the regular care of individuals on HIV treatment. Health professionals need to be provided with PPE to make sure that they carry out regular checks for vulnerable patients like those on HIV treatment. This would enable medication to be regularly monitored and replenished. There is also need for health facilities to clearly explain to the patients on the changes in patient care in a more empathetic way to maintain a therapeutic relationship with the patients and avoid despondence.

Medication default whether voluntary or involuntary has dire impact on the health and well-being of the patient [30]. Most of the research participants reported involuntary medication default due to their medication running out while being locked down in a different location far from their homes. The research participants reported difficulties in getting supplies at health facilities where they are not registered, and this led to involuntary default of their ARV treatment. With the advent of COVID-19 pandemic, they were now at risk of interruption in their HIV treatment [31]. There is need for the central government to make it easy for individuals accessing ARV treatment to access their medication from any health facility in the country rather than referring them back where they are registered. This will circumvent the problem of defaulting on treatment and enhance positive outcomes for individuals on HIV treatment.

PPE is one of the most important requirements when fighting an infectious pandemic like COVID-19 [32]. Shortage of PPE posed a threat of COVID-19 infection to individuals in receipt of HIV care or on ARV treatment. Nearly all the research participants in this study reported a severe shortage of PPE. The research participants reported difficulties in acquiring PPE for themselves as it was very expensive and sometimes out of stock. They reported improvisation of PPE to protect themselves as they travelled to get their supply of HIV medication. The shortage of PPEs also affected the health workers in many health care settings that also exposed them to possible infection of COVID-19. The shortage of PPE undoubtedly brought fear and anxiety among the participants. This was also compounded by the fact that COVID-19 is untreatable [33]. There is need for the central government to have a clear policy on procurement of PPE. This will ensure adequate stock of PPE and access by vulnerable groups like people on ARV treatment. More importantly subsidy on PPE price is needed to make it affordable especially to women accessing ARV treatment who are usually unemployed [34]. This will ensure affordability of PPE in times of pandemics like COVID-19.

Implication for professionals working with people living with HIV.

There is need for professionals working with individuals living with HIV to raise awareness among government departments to enlighten other professionals like the police and soldiers to understand the importance of treating HIV positive individuals with dignity. Furthermore, professionals working in sexual health and HIV need to carry out a more robust situational analysis to improve pandemic preparedness when delivering services.

Limitations of the study

This research was carried out in Harare peri-urban area. A research encompassing more regions may be necessary to understand the generic impact of COVID-19 lockdown on individuals accessing ARV treatment. The research utilised a qualitative paradigm, another research utilising mixed methods may be necessary to enable exploration of issues affecting HIV positive women from different epistemological and ontological positions.

Concluding comments

Pandemic preparedness is important in keeping adequate supply of ARV treatment available to people accessing it. More importantly robust policies supporting HIV education and awareness are needed to make sure that the public are aware of the need to support individuals affected by HIV.

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Author contributions

(1) Substantial contributions to the conception and design of the work (Dr Mathew Nyashanu)
(2) Drafting the work and revising it critically for important intellectual content (Ms RumbidzaiChireshe)
(3) Final approval of the version to be published (Ms Fungisai Mushawa)
(4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy are appropriately investigated and resolved (Dr Mandu Stephen Ekpenyong)

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Figures

i Fig 1 The four phases of data analysis in The Silences Framework