

# Lived experience of people on anti-retro viral therapy in the context of covid-19: a phenomenological study

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## Research Article

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# Abstract

**Introduction:** People living with human immune virus (HIV) are confronting multiple psychosocial and economic issues influenced by the illness. People on anti-retro viral drugs (ART) were at risk for discontinuation of medications during corona viral disease-2019 (COVID-19) pandemic. COVID-19 outbreak made people living with HIV (PLWH) to experience critical challenges and barriers to optimal care. The experience of people living with HIV such as stigma and discrimination, economic problem, psycho social problem before the emergency of COVID-19 was studied but there is lack of understanding on the lived experience of people living with HIV in the context of COVID-19 in Ethiopia particularly in Tach Gayint.

This study aimed to explore the lived experience of people on ART in context of COVID-19 in Tach Gayint district.

**Methods and materials:** Phenomenological study design was conducted with 16 study participants from March 12-April 12/2021. Data were collected using in-depth interview using interview guide and digital recorder. The investigator took note in addition to digital record. Interviews were transcribed word for word and translated conceptually. Analysis followed Reading of transcriptions, develop and apply coding, displaying data, data reduction and interpretation. Atlas.ti-7 software was used to facilitate analysis. The quality of data was assured by the principles of credibility, dependability, conformability and transferability.

**Result:** The study explored psychological experience, change in social interaction, and economic experience and ART drug interruption as the main themes including other sub-themes. Most participants perceived the severity of COVID-19 on them. Lack of participation in social activities due to fear of contracting and dying and loss of income were experienced by the participants. This extreme fear pushed some participants to interrupt their daily ART intake especially during lock down period. Personal, familial and community context contributed for these distressing experiences.

**Conclusion and recommendation:** This study reported participants' psychosocial, economic experiences including ART drug interruptions. It is recommended for the government to design policies and interventions to alleviate their personal, household and community problems which were the caused for the mentioned hostile experiences.

## Introduction

Anti-retroviral therapy (ART) involves taking a combination of HIV medicines called HIV treatment regimens every day and maximally suppressive ART regimens should be taken to obtain the best result (1). People living with HIV/AIDs are confronting multiple psychological issues influenced by the illness and social attitudes towards them. As 38 million people living with HIV (2), patients of COVID-19-HIV co-infection are likely to increase. COVID-19 brought different challenges to people on highly active anti-retro viral therapy (HAART) (3). People on ART were at risk for discontinuation of HAART and they did not know where to get ART drugs in the near future (4). By the end of 2019 only 67 percent were accessed to ART drugs (2). In Ethiopia it is estimated that the prevalence of HIV in 2017 was 1.16% and in the end of 2017 there were more than 41 hundred thousand adults on ART. And in 2020 the number of total people living with HIV is expected to be 745,719 (5).

Corona virus 2019 (COVID-19) is a family of severe acute respiratory syndrome (SARS) caused by a novel respiratory virus that mostly affect the respiratory system of human and was first originated in Wuhan, China in December 2019 (6). Globally the mortality rate of COVID-19 over time using a 14-day delay estimate was 5.7% (7). Globally up to 15 January 2021, there were more than 91 million confirmed cases of COVID-19, including two million deaths, and in Africa there were more than two million confirmed cases reported to world health organization (8). In Ethiopia the first COVID-19 case was detected in March 2020 and there were 120 hundred cases and 1,864 deaths reported until 23 December 2020 (9).

In March 2020, the Centers for Disease Control and Prevention (CDC) warned that people living with HIV (PLWH) as a population may be at heightened risk for severe physical health illness from COVID-19 compared to the general population (10). The prevalence of COVID-19 on people living with HIV infection was 4.5% (11). COVID-19 has potential interference with HIV care and treatments, and high rates of socially-produced burdens in the form of violence, stigma, discrimination, isolation, and hate on ART people (12). People on ART obligated to uphold the lockdown and prevent transmission of COVID-19 which cause tension and anxiety on them; these combined effects resulted in delays accessing HIV care, missing clinic appointments and poor medication adherence. The rate of hospital admission of people HIV infection due to COVID-19 is higher compared to those who have no HIV infection (13). In China people on ART missed their HIV medication and there was disruption of medical care as the health system was overburdened by high COVID-19 patients. To address this concern the government designed mailing ART to people living with HIV (PLWH) and this service made unwanted exposure of their status to their family (14). In Europe there was no closure of ART clinic but they give only ART drugs and other service related to HIV care were not given and health professionals reported as there was shortage of ART medication and they may stop ART drug procurement for the future as a result of COVID-19 (15). During COVID-19 pandemic in Wisconsin, United State people on ART miss their medication more than one time per a week has 7% increment than that was before COVID-19 (16).. Physical distance that was taken as a measure of COVID - 19 prevention mechanism affect the interaction between ART providers and ART users as a result ART adherence is reduced (17).. The current measures to control COVID-19 epidemic neglected the economic, social and health care service of people taking ART drugs (18). In China, COVID-19 outbreak made people living with HIV (PLWH) to experience critical challenges and barriers to optimal care outcomes and due to the growing number of COVID-19 cases and the shortage of medical resources, (14). People living with HIV expressed feelings of anxiety, fear, unhappiness and hopelessness to the future which are related to their illness during COVID-19 epidemic (19, 20). In Belgium and Brazil during COVID-19-epidemic among people living with HIV 23.3% were positive for major depressive disorders, whereas 22.7% had generalized anxiety disorders (21). During COVID-19, people on ART faced psychosocial problems like food insecurity due to lose of job opportunity severe depressive and anxiety symptoms in Kenya (22). In Ethiopia youth people on ART assumed as there was no any service in health institutions and they feared to go clinic to bring ART medication as a result they stopped taking their ART medications (23). There are researches done on the experience of people on ART such as stigma and discrimination, economic problem, psychosocial problem before the emergency of COVID-19. So far the mortality rate and hospital admission rate of people on ART with COVID-19 was studied. But the lived experience of people on ART in context of COVID-19 pandemic is not explored and there is lack of understanding on the lived experience of people on ART in context of this pandemic in Ethiopia particularly in Tach Gayint district and qualitative study may be suitable to explore it. The purpose of this phenomenological study is to explore the lived experience of people on ART in context of COVID-19.

## Methods

### Study settings and period

This study was conducted in Tach Gayint district, South Gondar zone; Amhara regional state, Ethiopia from March 12-April 12/2021. There were six health centers, one primary hospital and two private clinics in the district. The government in the district was not doing any special activities which supported people on ART in relating to COVID-19 to reduce the impact of COVID-19 on them. There were two ART trained health professionals, one ART adherence counselor and one data clerk working in ART outpatient department in the health center.

### Study design

Descriptive phenomenological design was applied to describe the experience of people on ART in context of COVID-19 pandemic from March 12-April 12/2021.

### Study participants

Study participants were those people who were on ART at the time of data collection and were on ART before the emergency of COVID-19. Participants who have appointment time for ART, who come for different services in the health facilities during data collection period were included in the study. The reason why the principal investigator selected participants who were on ART before COVID-19 pandemic and on ART in data collection period was that they could tell their experience by comparing what their experience looked like before COVID-19 and at the time of COVID-19 pandemic. All study participants with age 18 years or more were selected purposely and seriously ill participants who were unable to communicate and unable to give full information at the time of data collection were excluded. Participants were selected purposely through heterogeneous method to attain maximum variation of experience in context of COVID-19 in terms of different background characteristics.

### Sample size determination

The sample size was determined based on data saturation. For this study, sixteen participants, aged between 25 and 65 years were interviewed.

### Sampling technique and participants requirement procedure

To select participants, meeting was made with care providers in the health center. At the meeting, the principal investigator explained the aim and objective of the study and the participants of the study. Two health care providers were assigned to arrange and contact study participants with principal investigator. These care providers were the instrumental in facilitating a meeting between the principal investigator and study participants. The principal investigator explained the aim and objective of the study to people on ART. He also

informed them taking part in the study would mean they would be interviewed about their personal experience taking ART drug in context of COVID-19 and the interview would be audio recorded with their permission. With those who volunteered to participate, an agreement on convenient time and place was made for the interview.

## **Data collection tools**

In-depth Interview Guide and digital recorder were used to explore the lived experience of people on ART in context of COVID-19.

## **Data collection method and procedure**

Before conducting in-depth interview agreement was made with respondents about the convenient time and place of the in-depth interview. After explaining the purpose, risks and benefits of the study, and the length of the interview, the participants were asked to sign the consent in order to participate in the study. Digital recorder was used at the time of data collection. Sixteen In-depth Interviews were done by principal investigator. Fifteen in-depth interviews were held in consultation room provided by the health center based on their choice. The room provided by the health center was private, familiar and comfortable to the study participants. One in-depth interview was held in the participant's house. The principal investigator conducted two in-depth interviews per day. Face to face interview was done which allowed the researcher an opportunity to write memos. The interviewer requested permission to start the interview and digital recording to ensure verbatim transcription. Interviews were conducted until conceptual saturation (to the point no further new information was gained any more). Data collector used probing technique, by using how and why, to get adequate data on the point of interest. Participants were coded as P1, P2, P3.....respectively based on the order of interview. Interviews were conducted using Amharic (local language). A total of 16 in-depth interviews (IDI) were conducted and each IDI lasted an average of 65 minutes.

## **Trustworthiness**

The credibility of this study was ensured by involving in research assistance. This assistance was candidate graduate master of public health in health promotion and behavioral science. Descriptions of theme categories and supportive quotations add value for credibility in context of relationships. To assure credibility peer debriefing was done.

Dependability was attained through accurate documentation by minimizing spelling errors through frequently observing data including all documents in the final report. It incorporates including the notes written during the interview and ensuring that the details of the procedures were described to allow the readers to see the bases upon which conclusions were made.

An audit trail which means the researcher detailed the process of data collection, data analysis, and interpretations of the data were made for conformability of data. The principal investigator assured conformability in a way that his background should not bias the process of selecting the topic, choosing the methodology, analyzing the data, interpreting the results, and presenting the conclusions.

The researcher ensured transferability by providing evidence, detailed description of the study starting from sampling to data analysis

## Data processing and analysis .

Data were analyzed by the following steps:

**1. Reading for the content:** The transcribed data were read and reread until full understanding of the meanings of what participants said were gained to detect emerged themes and sub-themes.

**2. Coding:** coding consists of reviewing transcript line by line to isolate key words and phrases to generate emerging sub-themes and themes.

**3. Displaying of data:** themes were identified and the variation or richness of each themes were explored.

**4. Data reduction:** less broad themes were put together to form more broad themes and essential themes were separated from none essentials.

**5. Interpretation of data:** Finally, the principal investigator interpreted the reduced themes and formed themes to show the core meanings of the experiences. Quotes were used to highlight each category and show association with each theme. Atlas.ti qualitative data analysis software version 7 was used to facilitate data analysis.

## Results

**Sixteen study participants were participated in the study. Their age ranges from 25-65 years. (See table 1 for detail sociodemographic variables of the study participants)**

Table 1 Socio-Demographic characteristics of the study participant (N=16) who are on ART in Tach Gayint district in 2021

Code	Sex	Age	Years with HIV	ART year	Educational status	Religion	Occupational status	Marital status	Resident
P1	F	37	4	4	Did not attend	Orthodox	Alcohol cashier	Divorced	Urban
P2	M	41	8	8	Degree	Orthodox	Civil servant	Married	Urban
P3	F	25	3	2	elementary	Orthodox	Housewife	Married	Urban
P4	F	65	10	10	Did not attend	Protestant	no work	Widowed	Urban
P5	F	40	12	10	Did not attend	Orthodox	no work	Divorced	Urban
P6	F	30	12	6	Did not attend	Orthodox	Housewife	Married	Urban
P7	F	37	8	8	Did not attend	Orthodox	Shopkeeper	Divorced	Urban
P8	F	30	4	4	Secondary	Orthodox	Farmer	Married	Urban
P9	M	44	8	8	Elementary	Orthodox	Farmer	Married	Rural
P10	M	30	2.5	2.5	Diploma	Orthodox	Teacher	Married	Urban
P11	F	45	7	7	Did not attend	Orthodox	Alcohol cashier	Divorced	Urban
P12	Me	42	10	10	Secondary	Orthodox	Barber	Married	Urban
P13	M	43	9	7	Did not attend	Orthodox	Carpenter	Married	Urban
P14	M	55	5	5	Secondary	Orthodox	Merchant	Married	Urban
P15	M	50	6	6	Elementary	Orthodox	Farmer	Married	Urban
P16	M	40	11	8	Secondary	Orthodox	Merchant	Married	Urban

Note: M=MALE

F=female

Years=number years living with HIV since diagnosis

## Participants experience

The following main themes were explored with sub-themes: psychological experience, social experience, economical experience and anti-retroviral treatment interruption.

# Theme1: Psychological experiences

Experience of boredom, fear of being infected and Feeling of uncertainty about future ART drug availability were shared by most study participants. People whose family members were in foreign countries seemed to be more terrified and anxious. Most study participants reported COVID-19 brought negative psychological experience on them. They expressed feeling of anxiety, worried, depression, fear, tension, sadness and hopelessness. Three sub-themes namely fear of dying, feeling of uncertainty about future ART drug availability in the nearby health institutions and perception on severity of COVID-19 were identified.

## Fear of dying

Participants explained that COVID-19 made them to experience fear of dying in their future life. They heard the severity of COVID-19 is more in people with immune compromised patient and this made them to be in extreme fear. Due to fear of dying participants were exposed to psychological problem and they reported as they were not spending normal life due to the existence of the new virus called COVID-19.

“People said to me “HIV patients will die first if corona infects them (yibilagnlachihu)...” when I hear this; I worry for myself and feel depressed. Internally I was demoralized at that time.” A 43 years old male participant stated

Especially at the initial stage of the pandemic in our country, study participants mentioned that they were in extreme tension and lack of hopefulness in their future lives. They were assuming as they will die immediately if they were contracted by the new virus.

In contrast to the above stated response of participants, few participants narrated that they did not feel anything related to the pandemic of COVID-19. Among of these one female participant explained as she did not know the severity of COVID -19 on people living with HIV/AIDS.

## Feeling of uncertainty about future ART drug accessibility and availability

Participants narrated that they were uncertain what happened to their drug for the future. Most of them worried about the future availability of anti-retroviral therapy (ART) due to COVID-19. They mentioned shortage of drug for the future was their major concern. They stated as they knew ART drug is imported from abroad and if exchanging of goods and services stopped with other countries, ART medication would not be easily available to them and this condition made them to be uncertain for their medication.

“I worry for the future about the availability of drug [ART]. If the drug is interrupted, we will not stay even for one day. This was my... [Stress]” 40 years female participant

## Perception on severity of COVID-19

Almost all participants explained as they heard and accept the severity of COVID-19 on them. When they asked about severity of COVID19 on people living with HIV, most of the participants mentioned as it affect more in people having chronic disease including HIV.

Participants narrated that they would be severely affected by COVID-19 if they were infected. All most all interviewed participants except one knew the severity of the virus on them. They mentioned that people with low immunity including them were more risky than that of healthy individuals.

“Ehha ... I do not tolerate the double burden of the two diseases. I will not cure if two and three virus infects me. When I meet with friends [PLWHA], I worried about the new virus as it kills us before HIV kills us but some people [PLWHV] said “No! No! It [corona] will not kill us”. I said people without HIV can resist corona but I and other people who take drug [ART] will not survive.”40 years female participant

## Contexts (factors) related to psychological experience

**Personal contexts:** knowledge on severity of disease and their immune status; Participants knew that their immunity status lead them for easily susceptibility for COVID-19. Occupational status of participant: merchants always move from place to place due to the nature of their work and this made them to fear of contracting and dying. Barber has many contacts with their customers and this cause to be fear of dying because they are easily at risk for contracting COVID-19.

**Familial contexts:** low socioeconomic status of the households made them not to stay at home. Participants move here and there to win breads; this made them to be at risk for contracting COVID-19 and faced distressing psychological experiences.

**Contexts related to community and governments:** lack of psychosocial and financial support, the information heard from the community about the myth and misconception about COVID-19 on people with living with HIV.

## theme 2: Social experience

More than half of the study participant faced negative social relation in context of COVID-19 due to their HIV status. Some isolated themselves from social activities and the rest were isolated by others. COVID-19 made them to isolate themselves from participating in social activities like wedding ceremony and funeral ceremony because they worried about the contracting of COVID-19. Two sub themes emerged under this main theme:- Isolating themselves from social activities and and Isolated by others

## Isolating themselves from social activities

Participants stated that they had isolated themselves from social activities especially during the initial stage of the pandemic in the country. Restricting themselves in social activities was explored due to fear of contracting the new virus called COVID-19.

“As I tried to explain to you earlier, as soon as corona emerges and distributed throughout the country, we isolated ourselves from social life like absenting from funeral ceremony and people had not good attitude on me because I only know my health status and people do not know the reason why I absent from that social life. I was afraid to go to a place where people gather together” 30 years male participant

## Isolated by others

Few of the study participants reported as other people afraid them and they were isolated by others especially during the lock down period. They were assumed by others as they are infected with COVID-19. As a result other people become far away from them and the normal relation that was in pre-COVID-19 was reduced.

“People afraid I because they have information as I am easily susceptible to the disease and assumed as I have already infected by the disease [COVID-19]. They afraid me and said be far away from us: living with hearing such type of sayings was difficult for me. So corona made my social life to be difficult.” A 55 years old male

Amazingly in contrast to the above mentioned study participants, one female participant stated that as her social interaction with her neighbors increased. They assumed them themselves as they will die soon and stop fighting each other.

“Yes before corona we have no good relation as there was (beletishign beletihugsh) type of thinking but after corona everything was changed. We said for this short period of time why we made sinful activities.” A 37 female .

## Contexts for social experiences

For the occurrence of these hostile social experiences there were different reasons; these reasons classified as personal, familial and community; participants’ knowledge on the severity of disease on them. Household contexts such as free moving of their family members in everywhere made them to face distressing experiences. Negative perception of community toward PLWHA, traditional activities of the community such as collecting together in traditional activities of the community made some participants to face unsmooth relationships with people.

## Theme 3: Economic experience

Majority of the participant had varied experience of economic lose as a result of lockdown and isolation in COVID-19 pandemic.. All participants reported that they were unable to get any financial support from the government and from the community in this COVID-19 pandemic period and their household income was reduced due to COVID-19. Under this two sub-themes were identified 1) disruption of economic activity due to COVID-19 and 2) absence of financial support.

## Disruption of economic activity

Some participants brought their concern of significant loss in their business as a result of the closed market. In this study some people on ART reported as they stopped doing their work due to fear of the effect of COVID-19 on them. Two merchant participants express as they stopped shopping because they fear contracting of COVID-19. They mentioned their customers afraid them especially during the lockdown period and do not buy goods and service from them and this led to decrease their household income.

“When corona virus emerges, market was closed at that time I unable to gain money because I stopped working and I stayed at home; in this case the household income decreased in some extent. For example I was buying onion from farmers and selling it to urban residence but the market closed and I unable to gain any profit from the onion and I used the deposited money which was deposited for other purpose. As a result my household economy decreased.” A 25 years old female

“Most of the time I did not work because being hungry is somewhat better than death. I always feared corona because my activities as I told you made me at risk of corona. I stop cashiering and my income decreased.” A 45 years female

## **.Absence of financial support**

Participants stated that people living with HIV including them were economically disadvantaged group of population. But they were not getting any financial support from anybody. The government, community and other social institution were not giving special financial support to people on ART in the study area.

“Only god supports me. I am not getting any special support without God. In the last summer I have got one sack of wheat but this was given to all people [including those without HIV]. I did not gain any special support from anybody in this corona period. Few years back we were going to Debre Tabor and train different things and there was different support for us. But now a day everything is stopped. I have one daughter at home and she did not support me because she is not mature to support me and she did not remember corona. Only God supports me.” A 65 years female

All participants were not gaining any financial support from the government and the community as a result they were living in extreme poverty and the emergency of COVID-19 pandemic made double burden on their financial problem.

## **Contexts related to economic experience**

Government context like lack of concern for people on ART in context of COVID-19 was their main reason for the above experience. Their occupation was the other factors for this distressing experience. Merchant participants experienced decrement household income but civil servants and farmers did not.

## **Theme 4: ART drug interruption**

Four participants explained that they had stopped collecting and taking ART drug though this was for a short period of time at the initial stage of the pandemic in our country (at the lockdown period). As they narrated they

were disturbed by the information about the disease (COVID-19) and they considered health institutions were shifted giving routine service including ART to COVID-19 patients. They also feared and stopped going to health institution because they were thinking as there were COVID-19 infected patients in the health center and going and making contact with them was the risk of contracting the virus. As a result they stopped taking ART drugs though this was for short period of time.

“I feared to come to this health center to take my drug as a result I interrupted drug intake for about one week because what I have brought is finished and when corona emerges I fear to go and brought. I assumed the health center was only giving for seriously ill patients and if I go to health center to brought drug, corona will infect me and I stopped coming to this health center.” A 41 years old male participant

But study participants highlighted that due to negative effect of poor ART drug adherence, they were taking ART drug appropriately because ART is a lifesaving medication. They were collecting and taking their medication according to their appointment time even in the lockdown period. They preferred to take their ART medication and desired to continue healthy with HIV.

**Contexts:** fear of contracting COVID-19 in the health facility, their personal perception about the health institution where they collected drug were factors for their drug interruption. Lack of full information about the routine service of the health center was one an additional reason for their drug intake interruption. Among the sixteen interviewed participants twelve study participants did not interrupted their ART drug and they were taking to increase their immune status. One female study participant reported as she was in intension to stop going and taking the drug during the lockdown period.

## Discussion

According to the findings in this research, study participants had perceived the severity of COVID-19 on people with low immunity including them. As reports from studies in Indonesia and south Africa showed people living with HIV and on ART experienced feeling of hopelessness, stress and anxiety due to their HIV status alone (19, 24). The current study revealed that COVID-19 created extra psychosocial problem in addition to HIV on people living with HIV. So these findings indicated that people on ART confronted double psychosocial problems because people living with HIV/AIDS and taking ART has other concern in addition to COVID-19 when compared to normal population (25). Their extreme worried and tension was due to fear of contracting COVID-19 because of the severity of disease on chronic patient including people living with HIV. Physical distancing or social isolation recommended by center of disease control (CDC) to lower the spread of COVID-19 may added additional burden to already highly burdened lives. This finding is also supported by a qualitative study done in Ethiopia on adolescent people living with HIV that narrated as they stopped attending medias due to fear of information transmitted about the huge burden of COVID-19 (23). Fear of dying if they were infected by COVID-19 and uncertainty about future ART drug availability and accessibility was the major concern of this research finding. This is in lined with following two researches done in Belgium and Brazil (21, 26). Some study participants in this study and study participants mentioned from the above heard about the severity of COVID-19. This was the reason why they faced psychosocial problems. In contrast to this few participants in this study do not feel any negative psychological problem related to COVID-19. When they asked the reason why not they felt anything they explained the reason and this reason highlight as they do not have deep information about COVID-19. The other reason why not they fell any psychosocial problem was they have been already

hopelessness as a result of HIV infection. Study participants in this research worried about future ART drug accessibility and availability. This finding is similar with the finding of the study done in Europe (central and eastern), Uganda and Ghana on people living with HIV (15, 27, 28). Few participants in the study reported that they feared to go to health institute and stopped taking ART drug for short period of time during the lock down period. This finding is nearly similar with study done in other study which showed poor HIV clinic attendance, poor ART adherence (29). ART drug intake and consistent adherence has improved the long-term health outcomes among PLWH, but they are vulnerable to severe health problems if interruptions in treatment occur due to the COVID-19 pandemic. If people living with HIV did not take ART their viral load is more likely to increase (30), leading to lower CD4-count and an increase the risk of developing opportunistic infection (31). As such, it is imperative people living with HIV infection need to engaged and health care providers amidst COVID - 19 pandemic to insure consistent in HIV related care and treatment. This ART drug interruption due to COVID-19 pandemic may be absence of different support by the government and community to PLWHA. In this COVID-19 pandemic period, people infected with HIV need special psychosocial support because they have other health problem (HIV) which pushed them to different psychosocial problems like tension, anxiety, depression and lose of hopefulness.

Study participants in this study explained the disease and its consequences exacerbated their economic crisis. This finding is in lined with the study done in Argentina (32). This showed that people ON ART are living in low socio-economic status and the economic burden of COVID-19 severe in these groups of population because these populations are disproportionately affected by COVID-19. They fear feared contracting the new virus and restricted their economic activities and stayed at home especially during the lockdown period made an additional factor for their decrement of household income. However, COVID-19 did not reported to bring considerable change in their economic changes on some people on ART especially who are rural dwellers and civil servants in this research. The reason for this is that people on ART did not restrict in different income generating activities. According to the study findings in western Kenya and Zimbabwe losing employment, not being able to get access their job, unable to pay money for food and slowdown of any business activities were the common problems among people on ART (22, 33). Some of these problems like difficulty of paying money for goods and service were highlighted among people on ART in COVID-19 pandemic and this research area and the finding was in lined with the result done in the above researches. This similarity may be due to the fact that COVID-19 brought difficulty of exchanging goods between countries and the production of these goods were decreased. The other reason for this is that people living with HIV are not economically supported by the government, other non-government organizations including the community. However, losing of employment and unable to get job opportunity due to COVID-19 were not the problem in this research. This discrepancy occurred due to the fact that study participants in this research were not absolutely restricted in their income generating activities and study participants in this research were already had engaged in their business activities and were not waiting job opportunities. The government was giving free health and health related service to those people living with HIV in the study area but this was contradict with the other research done that showed insured people are getting easily access of care than that of non-insured people (34). In the research area people living with HIV are getting free health and health related service and this indicate that during COVID-19 pandemic people on ART are not face hardship of getting health access if they seek the service.

Some participants mentioned as they restrict themselves from visiting ART clinic and stopped taking ART. The reason was their fear of contracting the virus in the health institution. They may assumed the health institutions

were shifting their routine service to COVID-19 and the information disseminated about the severity of disease made them to be stressed and stopped visiting ART outpatient department. The result of this study is similar with the study done in Uganda (28) and a qualitative study that was done in Ethiopia on adolescent living with HIV and study done in China (14, 23) supplement the finding of this research. But the reasons for this similarity were different. In china study participants want to conceal their status to their families because the government faced challenging condition to ART medication face to face and used mailing of ART services. Whereas in this study the causes for interruption were participants' fear of contacting someone who was infected with COVID-19 and their assumptions as there were no routine services including ART in the health facility which were similar with the study done on adolescent about their lived experience.

## **Limitation Of The Study**

This study was conducted after the lockdown period; it would be better if it was conducted at time of lockdown for better understanding their experiences. This led participants to recall bias. Rural residents were not accessed at the time of study and this led difficulty of exploring their experience in rural contexts. Shy people could not completely share their experience as the interview conducted face to face. Some people on ART did not agree to be interviewed. They might have high level of experiences if they were explored.

## **Conclusion**

In this descriptive phenomenological study, the lived experiences of people on ART in context of COVID-19 pandemic were explored. Main themes and sub-themes were emerged from the interview. The main themes were psychological experience, change in social interaction, economic hardship and interruption of ART drugs intake. Hostile personal, household and community contexts leading the above distressing experiences were also explored. HIV only by itself creates psychosocial problems and people on ART were not gaining support of it in COVID-19 pandemic period. They also faced economic problem as a result few of them were living in challenging condition to fulfill the household food security. The social interaction of people on ART was compromised as they isolate themselves from different social activities and people suspect them as they are already infected with COVID-19. In the lock down period few participants explained as they interrupted ART drug intake. The contexts for their drug interruption were that they feared the risk of contracting the virus at the health facility and they considered health institution had shifted from their routine activity to caring of COVID-19 patients. As they narrated any type of support was not given to them. All participants stated as they need different type of support because they were disadvantaged group of the population.

## **Declarations**

### **Ethical approval and consent to participat**

Ethical approval was obtained from Institutional Review Board (IRB) of Bahir Dar University, College of Medicine and Health Science, School of Public Health. After that written permission was obtained from Tach Gayint district health office to collect data. written informed consent was obtained from all participant prior to the commencement of data collection. Personal information kept confidential and the privacy of participating was protected. Participation was vountary and any participant could withdraw at any time if he/she did not want

to participate. There was no risk to participate in the study and participants were benefited indirectly from the study. All methods were carried out in accordance with the Helsinki declaration principles.

### **Consent for publication**

Not applicable

### **Availability of data and materials**

Data may be available upon your request. You can ask the corresponding author if you want any further data

### **Competing interest**

The authors have no competing interests to declare that are relevant for the content of this article.

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### **Authors contribution**

T.D and F.A collect data and write the manuscript and Y.W analyze data write the whole document

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## **References**

1. Meintjes G, Maartens G. Guidelines for antiretroviral therapy in adults. *Southern African Journal of HIV Medicine*. 2012;13(3):114–33.
2. UNAIDS GS. Fact sheet—Latest statistics on the status of the AIDS epidemic.[Internet]. Geneva, Switzerland Retrieved March. 2016;16.
3. Tanser F, Barnighausen T, Grapsa E, Zaidi J, Newell M-L. High coverage of ART associated with decline in risk of HIV acquisition in rural KwaZulu-Natal, South Africa. *Science*. 2013;339(6122):966–71.
4. Akullian A, Morrison M, Garnett GP, Mnisi Z, Lukhele N, Bridenbecker D, et al. The effect of 90-90-90 on HIV-1 incidence and mortality in eSwatini: a mathematical modelling study. *The Lancet HIV*. 2020;7(5):e348-e58.
5. health eMo. National comprehensive HIV prevention, care and treatment training for pharmacy professionals participant manual. 2018.
6. CDC. 2019 Novel Coronavirus, Wuhan, China. CDC. Available at <https://www.cdc.gov/coronavirus/2019-ncov/about/index.html>. January 26, 2020; Accessed: January 27, 2020.

7. Baud D, Qi X, Nielsen-Saines K, Musso D, Pomar L, Favre G. Real estimates of mortality following COVID-19 infection. *The Lancet infectious diseases*. 2020.
8. <https://covid19.who.int/>.
9. WHOAFRO[23/12/2020;08:00]
10. CDC. Coronavirus Disease 2019 (COVID-19) in People with HIV [Internet]. Centers for Disease Control and Prevention. 2020 [cited 2020 Mar 23]. Available from:
11. Sachdev D, Mara E, Hsu L, Scheer S, Rutherford G, Enanoria W, et al. COVID-19 susceptibility and outcomes among people living with HIV in San Francisco. *Journal of acquired immune deficiency syndromes (1999)*. 2021;86(1):19.
12. CDC. Coronavirus Disease 2019 (COVID-19) in People with HIV[Internet]. Centers for Disease Control and Prevention. 2020 [cited 2020 Mar 23]. Available from: <https://www.cdc.gov/coronavirus/2019-ncov/specifc-groups/hiv.html>.
13. Karmen-Tuohy S, Carlucci PM, Zervou FN, Zacharioudakis IM, Rebick G, Klein E, et al. Outcomes among HIV-positive patients hospitalized with COVID-19. *Journal of acquired immune deficiency syndromes (1999)*. 2020.
14. Sun S, Hou J, Chen Y, Lu Y, Brown L, Operario D. Challenges to HIV care and psychological health during the COVID-19 Pandemic among people living with HIV in China. *AIDS and Behavior*. 2020:1.
15. Kowalska JD, Skrzat-Klapaczyńska A, Bursa D, Balayan T, Begovac J, Chkhartishvili N, et al. HIV care in times of the COVID-19 crisis—Where are we now in Central and Eastern Europe? *International journal of infectious diseases*. 2020;96:311–4.
16. Hochstatter KR, Akhtar WZ, Dietz S, Pe-Romashko K, Gustafson DH, Shah DV, et al. Potential influences of the COVID-19 pandemic on drug use and HIV care among people living with HIV and substance use disorders: experience from a pilot mHealth intervention. *AIDS and Behavior*. 2020:1–6.
17. Shiau S, Krause KD, Valera P, Swaminathan S, Halkitis PN. The burden of COVID-19 in people living with HIV: a syndemic perspective. *AIDS and Behavior*. 2020:1–6.
18. De Francesco D, Underwood J, Bagkeris E, Anderson J, Williams I, Vera JH, et al. Risk factors and impact of patterns of co-occurring comorbidities in people living with HIV. *Aids*. 2019;33(12):1871–80.
19. Jena PP. Exploring the lived experiences of adolescents living with vertically acquired HIV 2014.
20. Marbaniang I, Sangle S, Nimkar S, Zarekar K, Salvi S, Chavan A, et al. The burden of anxiety among people living with HIV during the COVID-19 pandemic in Pune, India. *BMC public health*. 2020;20(1):1–9.
21. Siewe Fodjo JN, Villela EFdM, Van Hees S, dos Santos TT, Vanholder P, Reyntiens P, et al. Impact of the COVID-19 Pandemic on the Medical Follow-up and Psychosocial Well-Being of People Living With HIV: A Cross-Sectional Survey. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2020;85(3):257–62.
22. Dyer J, Wilson K, Badia J, Agot K, Neary J, Njuguna I, et al. The Psychosocial Effects of the COVID-19 Pandemic on Youth Living with HIV in Western Kenya. *AIDS and Behavior*. 2020:1–5.
23. Emirie G, Iyasu A, Gezahegne K, Jones N, Presler-Marshall E, Tilahun K, et al. Experiences of vulnerable urban youth under covid-19: the case of youth living with HIV. Policy brief: COVID-19 Series, Ethiopia, London: Gender and Adolescence: Global Evidence (GAGE). 2020.

24. Martawinarti RN, Nursalam N, Wahyudi AS. Lived Experience of People Living with HIV/AIDS Undergoing Antiretroviral Therapy: A Qualitative Study. *Jurnal Ners*. 2020;15(2):157–63.
25. Omer T, Lovering S, Al Shomrani M. The lived experience of living with HIV/AIDS in the western region of Saudi Arabia. *Diversity & Equality in Health & Care*. 2014;11.
26. Ballester-Arnal R, Gil-Llario MD. The virus that changed Spain: Impact of COVID-19 on people with HIV. *AIDS and Behavior*. 2020;24(8):2253–7.
27. Asante KO. Social support and the psychological wellbeing of people living with HIV/AIDS in Ghana. *African journal of psychiatry*. 2012;15(5):340–5.
28. Linnemayr S, Mayo-Wilson LJ, Saya U, Wagner Z, MacCarthy S, Walukaga S, et al. HIV care experiences during the COVID-19 pandemic: Mixed-methods telephone interviews with clinic-enrolled HIV-infected adults in Uganda. *AIDS and Behavior*. 2021;25(1):28–39.
29. Hiv TL. The syndemic threat of food insecurity and HIV. 2020.
30. Elvstam O, Medstrand P, Yilmaz A, Isberg P-E, Gisslén M, Björkman P. Virological failure and all-cause mortality in HIV-positive adults with low-level viremia during antiretroviral treatment. *PloS one*. 2017;12(7):e0180761.
31. Gray ES, Madiga MC, Hermanus T, Moore PL, Wibmer CK, Tumba NL, et al. The neutralization breadth of HIV-1 develops incrementally over four years and is associated with CD4 + T cell decline and high viral load during acute infection. *Journal of virology*. 2011;85(10):4828–40.
32. Ballivian J, Alcaide ML, Cecchini D, Jones DL, Abbamonte JM, Cassetti I. Impact of COVID–19-Related Stress and Lockdown on Mental Health Among People Living With HIV in Argentina. *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2020;85(4):475–82.
33. McLinden T, Stover S, Hogg RS. HIV and Food Insecurity: A Syndemic Amid the COVID-19 Pandemic. *AIDS and Behavior*. 2020:1.
34. Santos G-M, Ackerman B, Rao A, Wallach S, Ayala G, Lamontage E, et al. Economic, mental health, HIV prevention and HIV treatment impacts of COVID-19 and the COVID-19 response on a global sample of cisgender gay men and other men who have sex with men. *AIDS and Behavior*. 2020:1–11.