#### Keio University Graduate School of Media and Governance Human Security and Communication-SD

Morigrant Report

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2018/02/26

#### <u>Title: Social and economic factors in public health treatment issues in rural Mozambique- Barriers to</u> <u>HIV treatment adherence in Chókwè district, Gaza province</u>

<u>Research objective:</u> to find out the socioeconomic behind non-adherence of HIV treatment in Chókwè District, located in Gaza Province, in Southern part of Mozambique. Specifically, the second fieldwork aimed at finding out the factors depriving people living with HIV of access to food as this factor was found, during first fieldwork, as the main barrier to adherence to HIV treatment in public health facilities of Chókwè District.

## Research methodologies:

- Grounded Theory: ethnographic interviews with people living with HIV
- Sampling technique: Purposeful sample (selection of people living with HIV who abandoned treatment in public health facilities or facing HIV treatment adherence problem)
- Analysis: mixed method (quantitative and qualitative analysis);

## <u>Findings</u>

## 1. Difficult access to food and HIV treatment adherence problem

Mozambique is one of the sub-Saharan African countries with food insecurity issue. According to United States' President's Emergency Plan for AIDS Relief (PEPFAR), "food insecurity in Mozambique was anticipated to peak between October 2016 and March 2017, with 2.3 million people expected to need emergency humanitarian assistance in the first quarter of 2017 nationwide" (Mozambique Country Operational Plan 2016, PEPFAR, p.7).

Despite implementation of several programs to alleviate poverty and improve the ability of poor people to produce and access food, "significant challenges to food security and nutrition remain in Mozambique, as the vast majority- 80 percent of the population cannot afford the minimum costs for an adequate diet" (WFP Mozambique, 2017)<sup>1</sup>. It is estimated that 68.7% of Mozambique population were living below the poverty line in 2008 (The World Bank, 2017, *Poverty & Equity*)

<sup>&</sup>lt;sup>1</sup> http://www1.wfp.org/countries/mozambique

*Data Portal*)<sup>2</sup>, with rural areas accounting for 56.9% of the population below the poverty line (WFP, 2010, *Comprehensive Food Security and Vulnerability Analysis*, p.3)<sup>3</sup>, which contributes to the reduction of their ability to access food.

Thus, as Chókwè is one of the districts affected by food insecurity and has one of the highest HIV/AIDS prevalence in Gaza Province, I conducted this research to find out the possible connection between lack of adherence to HIV treatment and food insecurity within households, as most of respondents in this research depend on hired agricultural labor for livelihoods.

Food insecurity in Mozambique has been associated with cyclical floods and drought that mainly affects the central and the southern regions of the country, civil war, post-independence development policies, as well as inflation. According to World Food Program, in October 2016, inflation in Mozambique "*has recorded a five-year high*" (WFP Mozambique, 2017)<sup>4</sup>, which has been contributing, in some way, to rise of food prices. The present research has also found, in Chókwè District, that food insecurity is worsened by lesser capacity of people living with HIV to purchase food in the local market and lack of access to productive land in irrigated areas due to changes in land occupation and use, and climate conditions. According to people living with HIV in this research, this situation has negative impact on adherence to HIV treatment as the amount of food that they can access is not enough to take medicine.

Recent data about food insecurity in Chókwè District are scarce. However, the Strategic Plan of Development of Chókwè District-2010 emphasizes food insecurity as one of the major problems challenging the district, and leading to high rates of chronic child malnutrition (SPDCD, 2010, p.11). During fieldwork, seventy-four percent of the total respondents reported household food insecurity as the main factor leading to HIV treatment adherence problem, specifically abandonment and taking medicine irregularly. The reasons behind it will be explained below.

In the context of adherence to HIV treatment in this research, food insecurity among people living with HIV was considered as the state of not having sufficient amount and number of meals per day that would enable them to take antiretrovirals. For example, having only one "small" and "inadequate" meal per day or even "nothing"<sup>5</sup> to eat as a meal was considered by most respondents (74%) as difficult to take HIV medicine, as they usually feel dizzy and weak after taking it on empty stomach. It was difficult to quantify or specify the amount of food that they could consume per day when the food was available but, in many cases, sufficient or adequate meal was considered as a meal, at least with staple food (maize or rice) and basic curry made from vegetables, or fish and tomato, together with cooking oil. In most households involved in this study, the average number of meals per day was one, usually composed by "chima" (made from maize powdered starch) or rice as staple food, while tomato sauce or mashed onion and salt

<sup>&</sup>lt;sup>2</sup> http://povertydata.worldbank.org/poverty/country/MOZ

<sup>&</sup>lt;sup>3</sup> http://documents.wfp.org/stellent/groups/public/documents/ena/wfp226896.pdf?iframe

<sup>&</sup>lt;sup>4</sup> http://www1.wfp.org/countries/mozambique

<sup>&</sup>lt;sup>5</sup> "Nothing" was considered as lack of normal meal composed at least of staple food (maize or rice)

was used as soup, and sometimes vegetables to eat with staple food. In this case (using only tomato sauce or mashed onion with salt), even if the amount of staple food (chima or rice) was relatively considered enough for one meal, it was hard for some respondents to eat the same food "every day" while others consider it difficult to absorb or swallow, especially when the staple food was *chima*.

In Lionde Administrative Post, a woman supporting her three children said that "...*it is difficult to take medicine (antiretrovirals) just eating arroz-cebola (cooked rice mixed with onion and oil) or chima without curry. Sometimes I feel pain in my throat when I am swallowing it.* 

Another experience was also collected in Lionde where one respondent said: "I have dizziness problem, especially after taking medicine. I think it is because of hunger since it is normal for us to stay one or two days without food. Sometimes it forces me to skip these drugs."

Similar stories about negative impacts of lack of food on respondents' ability to take antiretrovirals were collected in many households with food insecurity problems.

The chart below shows the impact of daily number of meals on HIV treatment adherence or respondents' ability to take HIV medicine in Chókwè District. However, as a limitation, most respondents were not able to specify or to say exactly, for example, how frequently they usually stay without "normal" meals within one month, as they access regular or enough food occasionally. Provided information was only based on an estimation of how often they have irregular number of meals within one week. Thus, to quantify or estimate the frequency of certain number of meals that people living with HIV can have per week, I used two words: "sometimes "and "usually", which explanation is given below.

- Sometimes I have two meals per day: it occurs at least twice a week (two days)
- Sometimes I have one meal per day: it occurs at least once a week (one day)
- Sometimes nothing: it occurs at least once or twice a week (one or two days)



#### Figure 1: Impact of Number of Meals on ART Adherence

One another limitation in this section was to quantify or specify the amount of calories and ingredients of food that respondents could consume every day and the impact on HIV treatment. The first reason behind this limitation was that the access to food itself (even if not enough food) was irregular. Second, consumed or absorbed amount of calories and its immediate impact may depend on several biological and physical factors that were not part of this research. Thus, specific research on bio-medical impact of calories and composition of food on HIV treatment based on people living with HIV diet in Chókwè District is needed.

## 2. Wages in informal agricultural sector are lower than prices of food

Mozambique is one of African countries with the highest rate of labor force in the informal sector "with nine out of 10 workers" (International Labor Organization, 2017)<sup>6</sup>. Among sectors, "subsistence agriculture continues to employ the vast majority of the workforce" (Danish Trade Union Council for International Development Union, 2017, p.iii)<sup>7</sup>, with approximately 80 percent of the population involved in agricultural activities (Consultative Group to Assist the Poor-CGAP, 2016, p.1)<sup>8</sup>. In most of rural areas, agricultural activity continues to be the main source of households' livelihood either for smallholders and sharecroppers, or even for tenant farmers. In Chókwè District, smallholders and small livestock (poultry) farmers represent 75% of the total population of Chókwè District and they are considered the most vulnerable groups within the district (SPDCD, 2010, p.10). In this research, almost all main respondents belong to this socio-economic group.

Sixty-seven percent of people living with HIV involved in this research exclusively depend on agricultural labor in informal sector for their livelihoods as they lack access to formal jobs and fertile land to produce food for themselves, especially in irrigated area. Reported wages were lower than prices for households' basic needs, especially food as the price for one regular or normal meal was higher than daily wages. The average, and common, salary or payment from hired agricultural labor in informal sector was *"Setenta e Cinco Meticais"* (75.00MT) per day, in Mozambican currency, which was approximately equivalent to 137.61 Japanese yen. This amount of money was considered too low to meet household daily expenses that also include food-the main determinant of HIV treatment adherence in this research. Wages were also too low to buy food in bulk amounts in informal markets.

During fieldwork, I visited some of the local informal markets providing basic products for normal meal (mentioned bay people living with HIV in this research) in Chókwè such as rice, maize powder, vegetables, tomato, fish, beans, onion, oil, salt and other kind of products usually

<sup>&</sup>lt;sup>6</sup> http://www.ilo.org/addisababa/countries-covered/zambia/WCMS\_462681/lang--en/index.htm

http://www.ulandssekretariatet.dk/sites/default/files/uploads/public/PDF/LMP/Imp\_mozambique\_2017\_final.pdf <sup>8</sup> https://www.cgap.org/sites/default/files/Working-Paper-National-Survey-and-Segmentation-Mozambique-March-2016.pdf

needed for basic meal. The purpose of this visit was to observe and compare food prices in the informal market with daily wages of people living with HIV in informal agricultural sector. As result, although food price in informal market was relatively reasonable or cheaper than in formal market, food in informal market is still expensive for respondents working in agricultural informal sector as the price of some products was even higher than the daily wage of people living with HIV and much higher when the number of household members increases. For example, for one day's meals for a household, respondents needed at least half kilogram of rice or one kilogram of maize powder for "*chima*", half a kilogram of fish, a "small" plastic of packet cooking oil, vegetables, one onion and four tomatoes (depending on size). Putting all these products together, the result shows high gap between food price for one meal and labor wages. The picture below shows one of the informal markets in Chókwè District providing basic food. Below it are the prices of some basic products usually consumed by respondents, in this research, when money is available. Each price represents the cost of the smallest unit of food that people living with HIV can buy for one household meal (usually for five household members).



Photo: Informal market with basic products in Chókwè

Prices of some basic products for regular or normal meal (in August 2017):

- <sup>1</sup>/<sub>2</sub> kg of rice: 25 MT=45.871 yen
- 4 or 8 tomatoes: 10MT=18.35 yen
- 1 onion: 5MT=9.1742 yen
- <sup>1</sup>/<sub>2</sub> of fish: 35MT=64.2197 yen
- Cooking oil (small plastic bag): 20MT=36.697 yen
- Vegetables: 10-20MT (18.3485-36.697 yen, depending on season)
- 1 kg of maize powder: 70 MT=128.43 yen
- <sup>1</sup>/<sub>2</sub> of beans: 40 MT=73.39 yen

The total is over 100 MT (183.49 yen), while the average daily wage is only 75 MT (137.61 yen).

In addition to food, incomes of people living with HIV were also used to cover other household expenses such as medical expenses, water bill, transportation, school fee (for children), clothes, and other expenses.

Similarly to what happens in some other informal jobs, number of working days per week was also irregular, as it depends on job availability and connections to access it. The average (maximum) number of working days reported by people living with HIV in this research was four within a week. However, this number may vary from activity to activity or tasks as well as from landlord to landlord. In most cases, low total monthly earnings are the result.

Irregular number of days was also related to lack of written contract and unclear tasks and time to finish work each day, which has been resulting in overworking without additional payment and lack of time to visit health facilities for consultations and collect drugs. In addition to lack of time to visit health center, lack of written contract and unclear tasks and working schedule also was also affecting wages in informal agricultural sector.

For example, a divorced woman working in agricultural informal sector and supporting her mother and two children said that she has been working without fixed number of hours and days. Depending on job availability, she may engage in part-time work in someone's land where she receives *100 "meticais"* (MT) (approximately equivalent to 183.49 yen) for each demarked area. However, she was not able to estimate how big the area is, but she usually spends between one and three days to finish her work in each piece of land or demarked area. According to her, the oral contract between her and the land owner (boss) determines *100 "meticais"* for one day; however she has never got paid for any overtime, when she is not able to finish her work on time and stays later. In this case, wage (100 meticais or MT) is not based on number days or working hours, but based on demarked area of land. Such way of working has been negatively affecting her health condition as she usually gets back home very tired and has to take care of her family, especially her mother who is sick.

In addition, according to her, since the money from agricultural part-time is not enough to meet her basic needs and other household expenses, such as water bill and school fees of her children, she has to find other ways of getting money or food. These include washing clothes in other people's houses and ask for food in neighborhoods. Similarly to agricultural work, there is also no specific amount of clothes that she has to wash per day, which also affects her health condition. According to her, she usually gets paid between *100 "meticais"* and *200 "meticais"* (approximately between 183.49 yen to 366.97 yen). Again, this activity is also not regular, which also affects her ability to buy food (irregularly). As result of this situation, associated with insufficient meals, she has been taking antiretrovirals irregularly since she feels dizzy after taking it without any meal or eating enough. "It is hard for me to work many hours without eating anything and receive only 100 meticais, but I have no choice since I have to feed my children, my mother and myself. And as you can see, my mother is sick and this morning (during interview) she ate only food from last night, which wasn't enough, but that is the life. You can't stop just because you didn't find something to eat, especially if you are the one supporting the family. I have to work."

In similar reported cases, securing jobs for livelihood, when there is a lack of alternatives, was mentioned as one of the main factors forcing people living with AIDS to stay in informal sector with unregulated working conditions.

# **3.** Lack of food producing land along Chókwè Irrigation Scheme (irrigated land) and difficult access to food

In this research, lack of productive land was found as one of the main factors depriving people living with HIV of access to food in Chókwè District, as they cannot produce food for themselves. Fifty-three percent of respondents reported lack of food producing land and 42 percent of them have mentioned it as one of the most important barriers to access food. The other respondents who reported lack of access to productive land but without impact on household food security (11%) had other sources of income such as receiving remittances from relatives working in South Africa, fishing activity, working in supermarkets, and husbands' support.

However, having land for agriculture did not always mean access to food as it was depending on other associated factors such as distance between land and home, access to water for irrigation, and health condition or physical ability to work. For example, 36 percent of respondents claimed to have productive land but they were experiencing food problem. The main reason behind difficult access to food, even with access to land, was that land for agriculture was (for most of respondents) outside irrigated area (rainfed), not within Chókwè Irrigation Scheme, while others' land was in Chibuto District, located approximately 68 kilometers away from Chókwè District.

The chart below shows the relation between land tenure and access to food among people living with HIV.



Figure 2: Productive Land and Access to Food

## 3.1. Land laws: Behind lack of access to food producing land

Mozambique is one of the countries where land belongs to the state. According to Mozambique Land Law, "*land rights may not be sold, mortgaged or otherwise alienated*" (IS academie, *GOMbLand Law 1997*, p.3). Individual or collective access to land-use rights has to be under the government approval through acquisition of land certificate, or through customary law, under approval of local authorities such as community leaders and official head of each neighborhood. However, as I mentioned in previous paragraphs, lack of access to productive land was reported by people living with HIV in Chókwè District as one of the main barriers to access food. Expensiveness of land certificate (land-use rights), rent or even to buy it, and being an outsider or in-migrant were mentioned as major factors behind difficult access to productive land.

Access to a certificate granting land-use rights in Chókwè District was estimated at 6,000 MT (*meticais*) in Mozambican currency, which is approximately equivalent to 11,000 yen (half hectare). This amount covers all the documentation needed for *DUAT* (land certificate). However, in practice, this amount can differ from person to person (much higher or even less), as well as the time of receiving *DUAT*.

On the other hand, for people who want to, informally, buy food producing land (even though the Mozambique Land Law does not allow it), respondents did not specify the cost to buy land around Chókwè Irrigation Scheme as it was too expensive for them and also the price differs from one landowner to another. However, according to respondents, for those who want to rent land for agricultural purpose, the average monthly cost of using approximately 0.5ha in irrigated area was "Três mil e Quinhentos Meticais" (3,500 MT) during fieldwork in 2017, which is approximately equivalent to 6,421 yen. Although respondents know the average price to rent productive land in irrigated area, they cannot rent it as this amount is considered higher than their wages from agricultural informal sector and also due to the money that they have to spend for household daily expenses. The price of renting productive land is also high even for those living only based on Mozambican minimum wage in Agriculture formal sector, estimated at 3,642.00 MT = 6,682.5 yen (in 2017).

The chart below presents the main factors reported by people living with as barriers to access food producing land in Chókwè District. Lack of money to request land-use rights, to rent or buy land from individuals (even it is illegal, according to Mozambique Land Law) appears as the most significant obstacles to access land in irrigated area of Chókwè District, including along Chókwè Irrigation Scheme. The second most reported factor behind lack of food producing land (reported by 38% of respondents) was being an in-migrant or originally coming from another district or province, most of them during civil war (between 1976 and 1992). According to respondents, being an "outsider" has reduced their chance to negotiate with local authorities to access land-use rights through customary law. However, a deeper analysis showed that being an outsider was not only the main reason depriving this group of respondents of access to productive land, but also lack of money, as there are foreign private investors exploring large area of land within Chókwè District. Some respondents had land but sold it because the land was in a rainfed area and far away from their home.



Figure 3: Factors behind lack of productive land

In Chókwè District, official land-use rights can be requested and acquired from two public institutions; from the Department of Economic Activities (under the Ministry of Agriculture) or from the Public Hydraulic Company of Chókwè (HICEP- responsible for land administration and concession in Chókwè Irrigation Scheme area). In both institutions, official procedures for individuals to access land-use rights are similar, which consist of submitting a request paper with specific purpose of asking the land and a copy of national ID. However, many respondents

consider this process difficult as it requires money to prepare all the documents, including ID, and also their education level is not enough to write a request proposal to explain the reasons why they are asking for land (in case of land under HICEP administration). Both HICEP and the Department of Economic Activities did not mention the amount of money required for land certificate that people living HIV have mentioned during interview. However, it is commonly known that there is some amount of money to be paid in order to access land certificate.

## 4. High transportation cost from home to health center

Transportation cost was found as another important factor contributing to abandonment of HIV treatment in public health facilities of Chókwè District. Thirty-one percent of people living with HIV reported transportation problem affecting their treatment, as they have to visit health center at least twice a month for consultation and other purposes related to their health condition. Transportation problems, associated with long distance from home to health centers and low income of people living with HIV, was reported in both administrative posts where this study was conducted, Macarretane and Lionde.



Figure 4: Transportation Cost and Impact on HIV Treatment Adherence

Respondents living in Macarretane Administrative Post usually receive HIV treatment at Manjangue Health Center five kilometers away from their home, while most respondents from Lionde Administrative were receiving treatment in Chókwè City, located ten kilometers away. Despite different distances between home and treatment facilities, the cost of transportation was same for those living in Macarretane and also those from Lionde, which was 30,00 MT for a round trip, approximately equivalent to 55.05 yen (in 2017). This price is high, given that the average informal wage mentioned above is 75 MT (137.61 yen) and they have to cover other household expenses.

In Macarretane Administrative Post, transportation problem was not related only to cost, but also availability. According to some respondents, even when the money is available, they have to spend at least one or two hours waiting for transportation, which most of times forces them to walk to Manjangue Health Center in order to save time. However, walking from home to health Manjangue Health Center makes them tired and weak, especially without enough meal.

To minimize this problem, the government has introduced some programs in public health centers providing antiretroviral therapy. The most popular and used program is called Community Antiretroviral Therapy Groups (CAG).

According to the Ministry of Health of Mozambique, in its document titled "Community ART Groups Strategy" published in 2015, CAG aims to reduce the demand of patients at health facilities, promote strong participation of patients in drugs collection and delivery, reduce the number of patients visiting health facilities, reduce the cost of transportation, improve the link and interaction among local communities and health facilities, and some other objectives (Ministry of Health of Mozambique, 2015, p.17). The program was firstly implemented in Tete Province, central region of Mozambique, and later replicated to all provinces as a way of improving the retention of patients in HIV treatment.

In Chokwe district, Community ART Groups consist of group of six people living with HIV (adults over fifteen) or less ( $x \ge 3$ ,  $x \le 6$ ), usually living within same community and know each other, or are close to each other. In addition, they must receive HIV treatment at the same health center. The main purpose of this each group is to discuss how to pick up antiretrovirals every month, taking into consideration transportation problem and financial capacity of each member.

All group members meet every month to discuss ART problems or challenges, decide who is going to collect medicine for others, money for transportation, and also report the health condition of every group member to the doctor. Usually, each person visits health facility twice a year for consultation and collects drugs for others, instead of going every month to hospital. However, they can visit health centers in case of emergency or any serious health problem.

In Macarretane Administrative Post, all respondents (except two) belong to Community ART Groups and they have described the benefits of being members of these groups. Most of the answers were associated with low cost of transportation and time saving. However, two other respondents from this group reported transportation problem to visit health facility. According to some respondents from Macarretane (two), despite the fact that they belong to CAG, they must visit Manjangue Health Center usually more than two times per month for other health issues, and thus have to spend more money for transportation, or even walk.

In Lionde Administrative Post, not all respondents belong to CAG as they are receiving HIV treatment from different health centers of Chókwè City, and most of them live relatively far from each other (approximately 2km or more) compared to respondents in Macarretane (approximately 200 meters or less apart). The other explanation about it is that Carmelo Hospital, where most respondents from Lionde receive HIV treatment, does not have a CAG system. According to one physician from Carmelo Hospital, "*Community ART Groups system has advantage only in terms of low transportation cost and time saving, but it has huge* 

disadvantages in terms of patients follow-up, since they visit health center or doctor only twice a year". To him "good adherence to HIV treatment should not be measured only based on collecting medicine at health facility. It should include, also, frequent contact and interaction between patient and doctor, at least in every within fifteen days in order to monitor the progress, clinical condition, immune system, and if he or she has any infection that requires an emergency intervention,...these are the reasons why our hospital do not adopt CAG model...".

Thus the patients would need to spend their own money for frequent transportation to visit health facilities for consultation (Carmelo Hospital), and as shown above, their informal wages are lower to cover the costs.

## 5. Dehumanization at health centers and stigma and discrimination within households

In this research, stigma and discrimination of people living with HIV was also found as one of the barriers to HIV treatment adherence in Chókwè District. The most reported cases about stigma and discrimination was within households (among married women) and at health centers.

Although Mozambique has made significant progress about protection of rights of people living with HIV and their household members, challenges remain to improve humanization of services in some health centers in terms of stigma and discrimination related to HIV positive status.

This study found that, despite implementation of several HIV/AIDS response programs in local communities, and gradual improvement of communication and interaction between health workers and patients, people living with HIV are still facing challenges to adhere to HIV treatment in public health facilities and take antiretrovirals regularly as result of stigma and discrimination within households and at health centers.

According to respondents who reported this issue, (fifteen percent) the main challenge to HIV treatment adherence in public health center is dehumanization of services, marked by misconduct behavior and attitudes of some health workers. In most reported cases, such behavior consists of harshly judging patients, especially when they ask for an explanation or additional information about their treatment, or when they intend to collect pills at health facilities again after prolonged absence. This leads some patients to stop visiting health facilities for HIV treatment related issues.

In one of the neighborhoods of Chókwè District, a thirty-one-year old woman said that she had abandoned the treatment for two years because she went to South Africa to visit her family without reporting her absence at health center. Due to lack of money, she could not return to Chókwè on time. When she went back to the health center, eight months later, she was "insulted" by health workers because of prolonged absence. As result, she decided to stop visiting the health center and taking antiretrovirals since she was afraid of being judged by health workers. However, despite this episode, she could get back to the treatment in 2017 through the support of

one community health worker (community volunteer) from Anglican Association, a communitybased organization working on HIV/AIDS response and assisting people living with HIV in Chókwè.

Similar episodes about dehumanization at public health center affecting HIV treatment adherence in Chókwè District were reported by a twenty-two year old woman who started receiving ART in 2014. According to her, she went to Inhambane Province (Southern Mozambique) in 2016 to visit her family and she spent more than one month without reporting her absence to the health center.

"When I came back from Inhambane, a nurse from the health center told me that the card I used for consultation and to pick up drugs had already expired, and she took my card in order to get new one. However, she never gave me it back. I tried several times to get my card back, but she (the nurse) always told me to wait, wait and wait until the day I decided to give up."

According to this respondent, despite this story, she would like to continue taking medicine again but at different health center, so that she can avoid meeting the same nurse.

"It was not my intention to stop taking medicine because I know how important it is, but I do not want to meet that woman again. I went to another health center this year (2017), here in Chókwè, and they took my blood and told me to go back after three months. Hopefully everything will go well."

Thus, dehumanization or uncaring attitudes from some health workers discourage people living with HIV to visit health facilities again after prolonged absence which, according to respondents, results in lack of adherence to HIV treatment.

## 5.1. Long waiting time for consultations and to collect medicine

In addition to being harshly judged by health workers, people living with HIV in Chókwè District have also mentioned long waiting time at public health centers as another issue negatively affecting adherence to HIV treatment. The most common cases were related to the inconvenient time or number of hours that patients have to spend at health facilities for consultations and to collect drugs, while they have to work.

"Most of us, taking this treatment (HIV treatment), are living based on 'biscato da machamba' (agricultural part-time job) where we have to be there by 6:00 AM or 5:00 AM. But when you go to hospital, you have to spend almost half of day there just for consultation or to take blood test, and usually without eating anything. Sometimes they say come tomorrow, but it is hard for me to ask my boss' permission always." – said a woman from Administrative Post of Lionde, who sometimes skips going to health center for fear of losing her job.

## 5.1.1. Long waiting time at health center: discrepancy in explanations

The Public Department of Health in Chókwè District acknowledges the problem of long waiting time at health centers reported by people living with HIV. However, the same department assumes it is an issue already improved since December 2016. According to the coordinator of HIV/AIDS Response at Public Department of Health in Chókwè District, the government has introduced new programs and strategies in public health system in order to improve the access and adherence to HIV treatment. According to him, the fact is that long waiting time at health centers was mainly associated with limited number of public health facilities proving HIV treatment, which was fourteen in total, before December 2016. According to the coordinator, this number was considered very low to meet patients' demand, and was one of the main causes of abandonment to ART. Since December 2016, the number of health facilities providing HIV treatment has increased from fourteen to twenty-three. Because of this, although without specific numbers, "the flow of patients visiting public health facilities for ART has significantly reduced since many of them can now access treatment at the closest clinic in their villages or communities". Moreover, according to him (the coordinator), another strategy implemented by health sector in order to reduce the flow of patients visiting health centers just to collect antiretrovirals is "Dispensa Trimestral" (Quarterly Waiver).

"The Quarterly Waiver strategy allows patients to visit health facilities within a period of three months either for consultation or to collect antiretrovirals, based on the doctor's recommendation. Unlike Community ART Groups (CAG) which consist of group of six people taking HIV treatment at same health center and living in the same community or neighborhood, the "Quarterly Waiver" strategy is only applied to one person or individual who has good ART adherence, low level of viral load, stable level of CD4, good immune system, and some other criteria." - an explanation from the coordinator of HIV/AIDS Response at Public Department of Health in Chókwè District during fieldwork in 2017.

During fieldwork, only one respondent claimed to belong to "Quarterly Waiver" system. However, despite reduced number of times visiting health centers, she faces food problem, that in fact has been forcing her to take antiretrovirals irregularly.

## 5.2. <u>Receiving irregular number of antiretrovirals at public pharmacies and unclear explanation</u> to patients

Although only three respondents reported this issue, lower doses of medications (antiretrovirals) at public health facilities was mentioned by people living with HIV as another barrier to HIV treatment. According to these respondents, there are months that the public pharmacies do not provide the same number of pills as in the medical prescription and they are not explained the reasons behind this issue.

"I have to walk to the city to pick up medicine, when I do not have money for transportation, but once I get there those people working at pharmacy tell me to go back another day, and they

never explain why. I cannot tell how often it happens per year, or even if it happens to everyone or not, but sometimes you just go to hospital for nothing, while we were told that we should never stop taking this medicine."- said a woman who is receiving HIV treatment at one of the public health facilities in Chókwè City.

Another woman who is also receiving HIV treatment at the same health facility has been taking antiretrovirals irregularly because she usually collects insufficient pills from the public pharmacy. According to her, the amount of pills that she receives from the pharmacy is not always the same prescribed by doctor, but fewer.

"There are some cases that the doctor tells me to go back to hospital after thirty days, whether for consultation or to collect pills, which is also equivalent to the amount of pills that I have to take per month. However, when I go to pharmacy they give me pills only for twenty days or even less, but they never explain me why. Depending on the month, I have to stay home without medicine for two weeks or more, while I am waiting until thirty days to meet doctor. I never complained about it because I am afraid of their reaction." She did not give details about which reaction she was afraid of reporting this issue to the doctor or other health staff.

Although this issue is not directly related to lack of adherence to HIV treatment from the perspective of patients' will or attitude to take antiretrovirals, receiving lower doses of medication itself is another form of adherence problem as people living with HIV have to spend some days without medicine, which may lead to worse health condition.

Respondents were not able to explain if the issue of lower doses of medication was associated with lack of antiretrovirals at public health centers or not, but one of the persons working on HIV/AIDS response in Chókwè District, involved in this study, said that the problem mentioned by some people living with HIV was related to stock rupture. However, due to political issues and rules, doctors or health workers are not allowed to share such kind of information with patients or with other people beyond the health system.

On the other hand, the coordinator of HIV/AIDS Response at Public Department of Health in Chókwè District, and also working at "Centro de Saúde da Cidade de Chókwè" (One of the public health centers providing HIV treatment in Chókwè city), said that he does not have any information about such irregular access to antiretrovirals in public pharmacies, and it was his first time (during interview) hearing about it. According to him, "the main purpose of antiretrovirals is to suppress the viral load in people living with HIV and, thus, reducing the number of tablets to be taken or giving patient irregular amount of drugs can lead to virus resistance and replication". He disagrees with the assumption of "stock rupture" or lack of antiretrovirals in public pharmacies because "antiretrovirals are allocated or provided based on the amount of consumption or needs of each district. The Ministry of Health or the Provincial Directorate of Health in Gaza provides medicine based on the number of patients we have or

## receiving antiretroviral therapy and we always try to make sure that everyone will have equal access to it".

Similar to the explanation from the Public Department of Health in Chókwè District about long waiting time for consultation or to collect pills at health centers, there is also a discrepancy about the availability of antiretrovirals at public health centers. In any case, this discourages patients to visit health centers or even abandon the treatment.

#### 5.3. Stigma and discrimination within household: negative influence of husbands to wives

Within households, husbands' negative influence to wives and decision was found as another factor contributing to lack of access and adherence to HIV treatment in Chókwè District, with high impact on antiretrovirals.

The study found that 62.5 percent of married women (39% of all respondents) or women living with their male partners, either under customary law or civil law, have experienced negative influence of their husbands regarding HIV treatment initiation and adherence. The most common explanation behind this issue was related to fear of disclosing HIV health status to husbands because they wanted a secure relationship and financial support. According to respondents, other reasons behind this issue were associated with husbands' resistance to accept HIV positive result and to visit health centers, as they are assumed to be very busy on their work. Although health workers usually recommend each HIV positive patient to convince her or his partner to visit a health facility for HIV test or counselling, the study found that married women were more likely to take antiretrovirals secretly without informing their husbands, or even stop visiting health centers for HIV treatment fearing of being divorced.

Chókwè District has the "Changana" as its main ethnic group. This group is characterized by a patrilineal society, with most of the households' decisions being made by men. In other words, women in Chókwè District are under "control" of men or/and husband's relatives. Such "control" usually affects women's well-being including limited access and adherence to HIV treatment as was mentioned above (husbands' negative influence).

#### Conclusion

This study found that although progress has been made in Chókwè District in terms of provision and expansion of free HIV treatment to some rural areas, people living with HIV in areas covered by this research are still facing treatment adherence problem, mainly characterized by abandonment of HIV treatment in public health facilities, taking antiretrovirals irregularly and difficulties to visit health centers regularly, both for consultations and to pick up medicine. Behind these issues, this study found four factors leading to non-adherence of HIV treatment in public health facilities of Chókwè District. This consists of difficult access to food among respondents, lack of access to food producing land in irrigated area of Chókwè District (in Chókwè Irrigation Scheme), lower wages in agricultural informal sector compared to prices of food in the local market and difficult access to transportation from home to health centers, which is associated with long distance and low wages in informal sector. Among these four barriers, lack of access to food, associated with lack of producing land and high prices of food in the local market compared to respondents' wages in informal sector appears as the most important factor directly leading to lack of adherence to HIV treatment. Specifically, because of difficult access to food, respondents are forced to reduce their food consumption or to have only one small meal per day. According to them, having only one small meal per day (both in amount and composition) is not enough to take HIV-related drugs as they cannot have medicine on an empty stomach. This situation leads forces people living with HIV to skip antiretrovirals or take it irregularly, only when food is available.

In addition, sixty-seven per cent of people living with HIV in this research depend only on agriculture for livelihoods and household income. However, most of them lack access to productive land in irrigated area, specifically in Chókwè Irrigation Scheme. Because of lack of access to productive land, mainly caused by high prices to rent or to buy it and difficult access to land use rights from the public institutions, people living with HIV have to work in informal sector (hired agricultural labor) instead of producing food for themselves that would enable them to take medicine regularly or to meet households basic needs. As result of this issue (working in informal sector), they receive irregular and unfixed wages, usually lower than food prices in the local market and also below the Mozambican monthly minimum salary, as the number of day that they can work and be paid is also irregular. Furthermore, respondents depending on hired agricultural labor in informal sector also face inflexible working conditions such as lack of time to visit health centers due to unspecified time and day to finish their tasks, and also they have to secure their jobs and income first. This situation (inflexible working conditions) forces them to visit health centers irregularly both for consultations and to collect antiretrovirals, which consequently results in lack of adherence to HIV treatment.

Lack of adherence to HIV treatment, in this research, was also found as result of dehumanization in public health centers (reported by fifteen per cent of the total respondents), mainly related to long waiting time at health facilities for consultations and behavior and attitudes of some health workers, especially in cases where patients intended to return to their treatment facilities after prolonged and unreported absence, fearing of being harshly judged by health practitioners. However, the process of finding accurate information and explanation about this issue from the public health department side was limited as this institution, represented by its coordinator of HIV/AIDS response in Chókwè, did not acknowledge or recognize misconduct behavior and attitudes from some health practitioners as an important barrier to HIV treatment adherence, previously reported by people living with HIV in public health centers of Chókwè District.

In addition, despite existence of Community Antiretroviral Groups (CAG) that aim to reduce the cost of transportation among people living with HIV, based on the number of times that they have to visit health centers for consultations and to pick up antiretrovirals, challenges to HIV treatment adherence remain in Chókwè District due to lack of money to cover transportation costs. For respondents who belong to Community Antiretroviral Groups, for example, some of them usually visit health centers at least twice a month (instead of twice a year as in CAG plan) for other health related issues. Since such visits are not included in respondents' Community Antiretroviral Groups plan, patients with other health concerns have to cover transportation expenses themselves or walk more than ten kilometres from home to their treatment facilities (round trip). In most critical situation, they are forced to skip going to health centers, which leads to abandonment of HIV treatment. Transportation problem in Chókwè District is also related to irregular availability of public transportation services, especially in Macarretane Administrative Post where lack of adherence because of transportation problem was also reported by people living with HIV during fieldwork.

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