

Factors that facilitate or hinder access to HIV testing and treatment for children and adolescents

Lessons from Mozambique

2023



Project supported by



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Table of Contents

- 01 HIV in Mozambique at a glance
- 02 Research Question and Methodology
- 03 Findings: Is HIV still a problem in our communities?
- 04 Findings: Who is most impacted by HIV in our community?
- 05 Findings: Is there still stigma in the community?
- 06 Findings: What are the risk factors in terms of HIV in our community?
- 07 Findings: What are the barriers to access to HIV testing and treatment in our community?
- 08 Findings: How can the barriers to access to HIV testing and treatment be reduced?
- 09 Findings: Who can do what to reduce barriers?
- 10 Key takeaways and Recommendations



HIV IN MOZAMBIQUE AT A GLANCE

2 400 000

ADULTS AND CHILDREN
LIVING WITH HIV

86%

PERCENT OF PEOPLE
LIVING WITH HIV WHO
KNOW THEIR STATUS

1 300 000

ORPHANS DUE TO AIDS
AGED 0 TO 17

"HIV is a problem...because there are people who even today ignore their HIV results, they think that HIV is a witchcraft disease that they do not know how to explain because until today people hide their results, that is why we have seen cases of abandonment because they do not understand the reasons for that result, they start and later give up the treatment because they feel they are healthy, but those who appear sick do the treatment because they know they were sick in my community."

Health Care Worker

86

Percent of people
living with HIV who
know their status

81

Percent of people
living with HIV who
are on ART

72

Percent of children
aged 0 to 14
receiving ART

Research Question and Methodology

Research question

What are the factors that facilitate or hinder access to HIV services

A mixed-method approach was utilised, whereby both qualitative and quantitative data was collected from respondents in Maputo and Sofala. Informed consent was obtained from all participants or their parents (if under 18).

At the start of the project **quantitative data** was collected from adolescents, adolescent mothers, and community members in Beira and Maputo who were going to participate in the project. The quantitative survey included questions regarding stigma (using an adapted version of the Brief Stigma Scale) and barriers to HIV testing and/or treatment (a 24-item scale was created based on literature, existing scales, and the focus of the research and its context). Quantitative data analysis included descriptive and bivariate statistics to examine the distribution of all variables, assess relationships between variables, and differences between groups.

Qualitative data was collected from a smaller sample of key respondents in Beira and Maputo and explored HIV broadly, who it impacts on most, the barriers and facilitators to services, and what different role-players (such as health care providers, government, CBOs, Activist, and communities) can do to improve access.

Thematic content analysis was undertaken with the qualitative data. Here, each response was coded into themes. During this process, important quotes illustrating themes were noted. This provides a broad picture of the main emerging themes, as well as an indication of how many respondents spoke about the same theme and how many times, which provides an indication of the level of importance of each theme.

RESPONDENTS



FINDINGS

Is HIV still a problem in our communities?

In 62% of the qualitative interviews, respondents indicated that HIV is still a problem in the community. Much of this was related to non-adherence to treatment, lack of knowledge, and stigma and discrimination.

On the other hand, in 38% of the qualitative interviews, respondents felt that HIV was no longer a problem as communities have a lot of knowledge about it and access to health services and ART.

"HIV has been a big problem in our community because of discrimination and prejudice, HIV is often not accepted in many communities, they still see HIV as a big problem that has no solution while HIV today has treatment."
Peer Educator

"In our community I think it is still a problem because there are still those taboos that HIV kills, there is not much information about HIV. It is still a problem because there is still a lot of discrimination. It is still a problem because we still take and withdraw the medicines secretly. If it was not a problem we would not hide but we hide for fear of being discriminated."
Peer educator



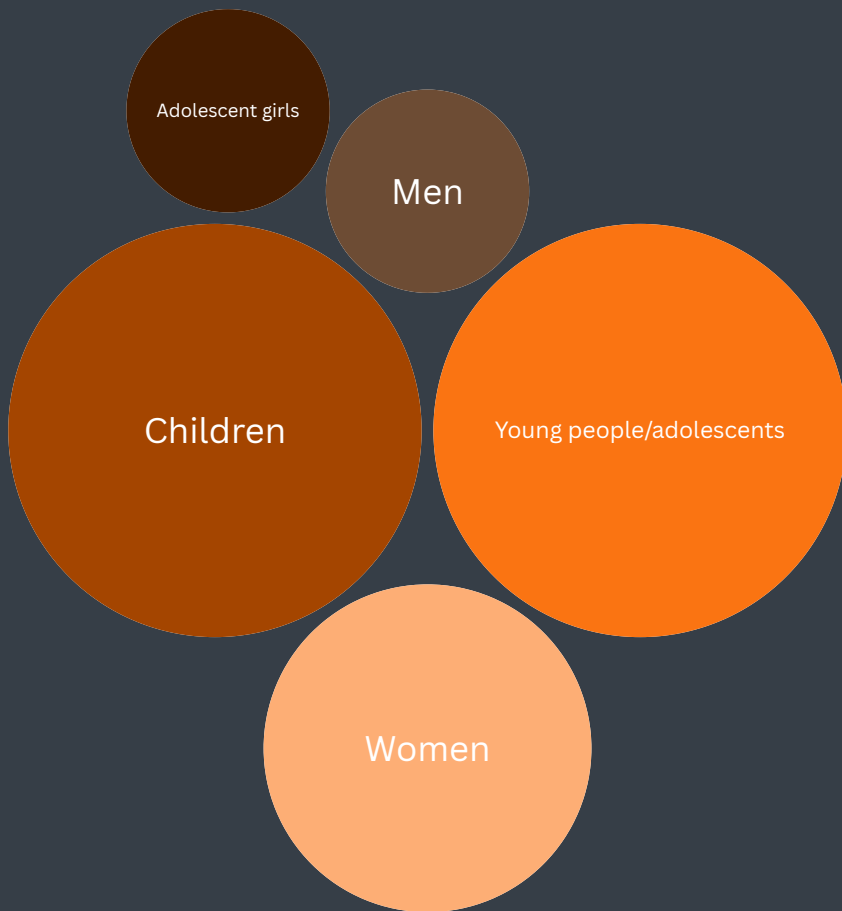
"HIV is really a big problem in our community where we live, much more because of the effects that HIV has in the life of our society...one of the things that has happened in our community are the deaths, we have lost many people, we have to look at the issue of work, if we lose a young person who produced for a family, cascading through the whole family can be damaged, orphaned children, companies that are not productive because of the debilitated state of people with HIV, so there are many situations out there that can really affect directly or indirectly our community."
Provincial Directorate of Health

Who is most impacted by HIV in our community?

Respondents indicated that children and young people/adolescents (62%) were the most at risk in terms of HIV, followed by women (39%) and men (15%). In 15% of the interviews, respondents specifically mentioned young adolescent girls as being at risk.

"The children are more affected much more by the negligence of the mothers who don't medicate well, they will get the medicines but they don't take them even knowing that they are pregnant, the children depend a lot on the caregivers children of 2 years won't be able to medicate themselves so the children are more affected because of the dependence"

Activistas



Respondents indicated that **children were most at risk because:**

- their mothers do not adhere to treatment
- children cannot access medication themselves
- their mothers have not disclosed that they are HIV positive
- some HIV+ children are orphans and living with family that may not be aware of the mother's status or do not ensure adherence
- HIV+ mothers are giving birth outside of hospitals

For young people or adolescents, the risk factors mentioned included:

- Lack of information
- Not being aware of status
- Risk-taking sexual behaviour
- Fear of going to clinics
- Fear of discrimination if they are HIV+

"Speaking of adolescents and the way in which the current society is living, they have maintained sexual relations without prevention, this in a way puts them in a position of risk"
Health Care Worker

"...many young people do not seek the health unit because they are afraid to come to the health unit with their friends and discrimination will start from that very moment that the result is positive."
Peer Educators

Is there still stigma in the community? Qualitative findings

92

Percent of qualitative interviews where respondents indicated that stigma is still an issue in the community

Respondents felt that discrimination still exists in the community although many felt that this was decreasing. They acknowledge that much work has been done to reduce stigmatization through sensitisation and awareness raising, but that it still exists and may be playing a role in limiting access to HIV testing and treatment.



"People still judge, they do not accept people with HIV, as my colleagues were saying, HIV brings fear in people and this ends up bringing discrimination and when the person is discriminated, he/she cannot go to the health unit to make an appointment or do anything."

Peer educator

Percent of qualitative interviews where respondents indicated that stigma is reducing in the community

46

"The stigma and discrimination has not been totally eliminated, but with our interventions, sensitization, various actions that we have carried out in community discussion groups, the community has reduced the stigma, because the community used to see people in different ways, or else they thought they had no knowledge about HIV, but in recent times with the availability of information people already know how to live with people with HIV, without judging them, not to see people living with HIV as a different person from them they are the same as any of us and they do the same things as any of us no longer exist sufficient factors to be able to judge the community the judgment of children and adolescents."

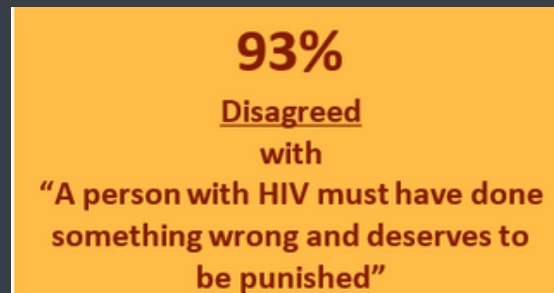
Project officer

"In the community there are still cases of judgment, including us, we suffer with AIDS and how are we going to help a sick person, they do speak, although there are lectures, but people continue to speak badly of those with HIV and even give names, some still have discrimination and some do not, with the publicity that has been given, some are already sensitized and recognize our work."

Activist

Is there still stigma in the community? Quantitative findings

Overall, participants in the survey reported low levels of stigma and largely positive attitudes in relation to HIV.



Over 90% did not agree with the following statements:

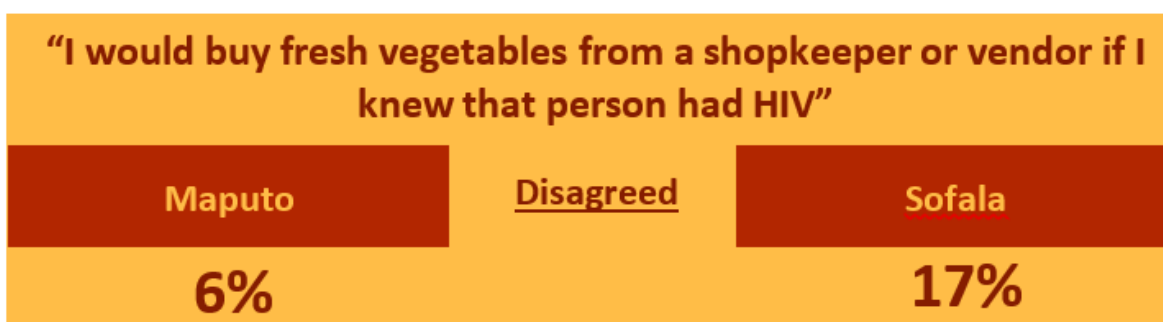
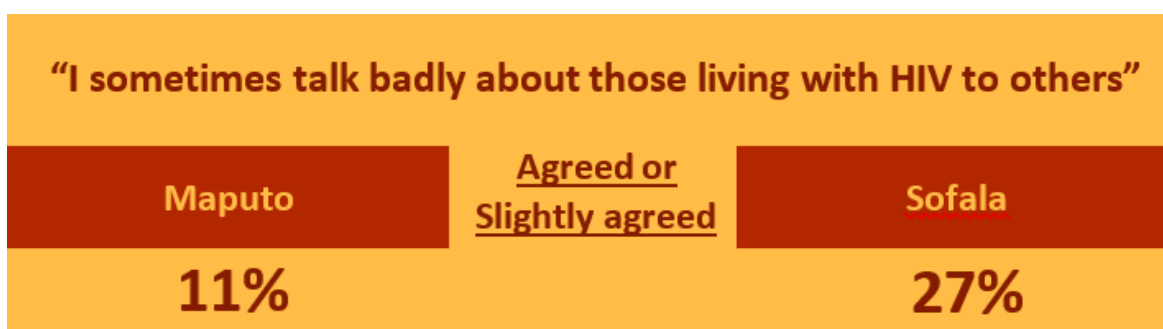
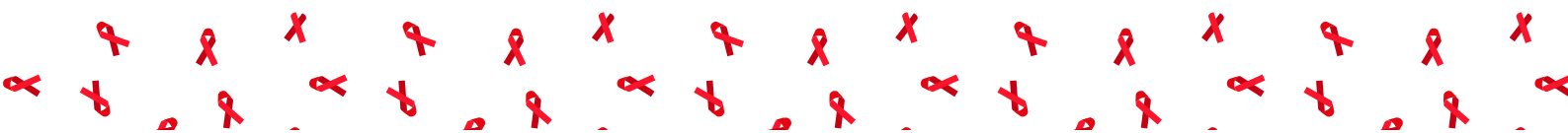
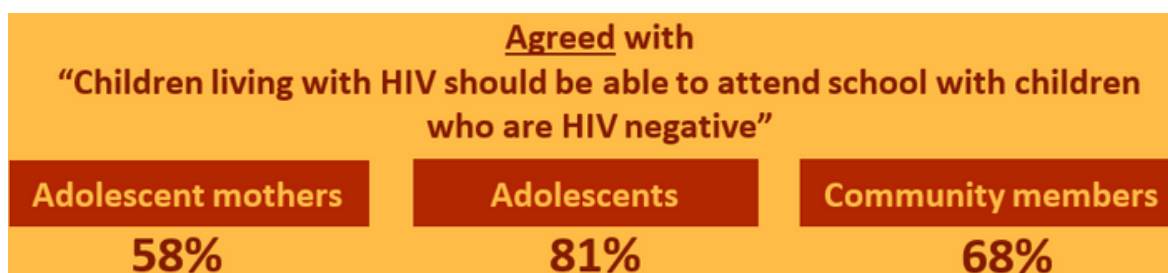
- "People who have HIV are dirty" (96%)
- "A person with HIV must have done something wrong and deserves to be punished" (93%)
- "People who have HIV should be ashamed" (92%)
- "People who have HIV should be isolated" (92%)
- "People living with HIV should lose respect or standing" (92%)
- "People who have HIV are cursed" (91%)

On the other hand, 18% of respondents disagreed that it is safe for people who have HIV to work with children and 12% agreed that they did not want to be friends with someone who has HIV.



Is there still stigma in the community? Quantitative findings - differences between groups

When exploring the differences in stigma between participant groups, adolescent mothers held more negative views of HIV+ people followed by community members, then adolescents. Finally, participants from Sofala held more negative views than those from Maputo.



What are the risk factors in terms of HIV in our community?



"Adolescents are affected by sharp instruments, it can also be via sexual intercourse when they don't use condoms, because some think that when they use contraceptive methods other than condoms, they have already prevented the disease, and they forget that it is the condom that prevents pregnancy and diseases."

Health Care Worker

Lack of disclosure

Non adherence

Hunger/Poverty

Lack of knowledge

Risk-taking and experimenting

Lack of testing

Lack of access to services

Not using condoms

Respondents identified various existing risk factors for HIV in their community, namely:

- Lack of knowledge (92%)
- Risk-taking and experimenting (85%)
- Lack of access to services (77%)
- Non-adherence to treatment (69%)
- Lack of disclosure (62%)
- Lack of testing (46%)
- Hunger/Poverty (31%)

"They discriminate because they don't understand that HIV is a disease like any other, even when someone has diabetes, but when it comes to HIV they think that it is transmitted only through sexual intercourse, they discriminate saying that the one who has HIV is because he/she had sexual intercourse, while HIV is transmitted by several ways, sharp objects, blood transfusion, if the community understood that they would not discriminate against people with HIV."

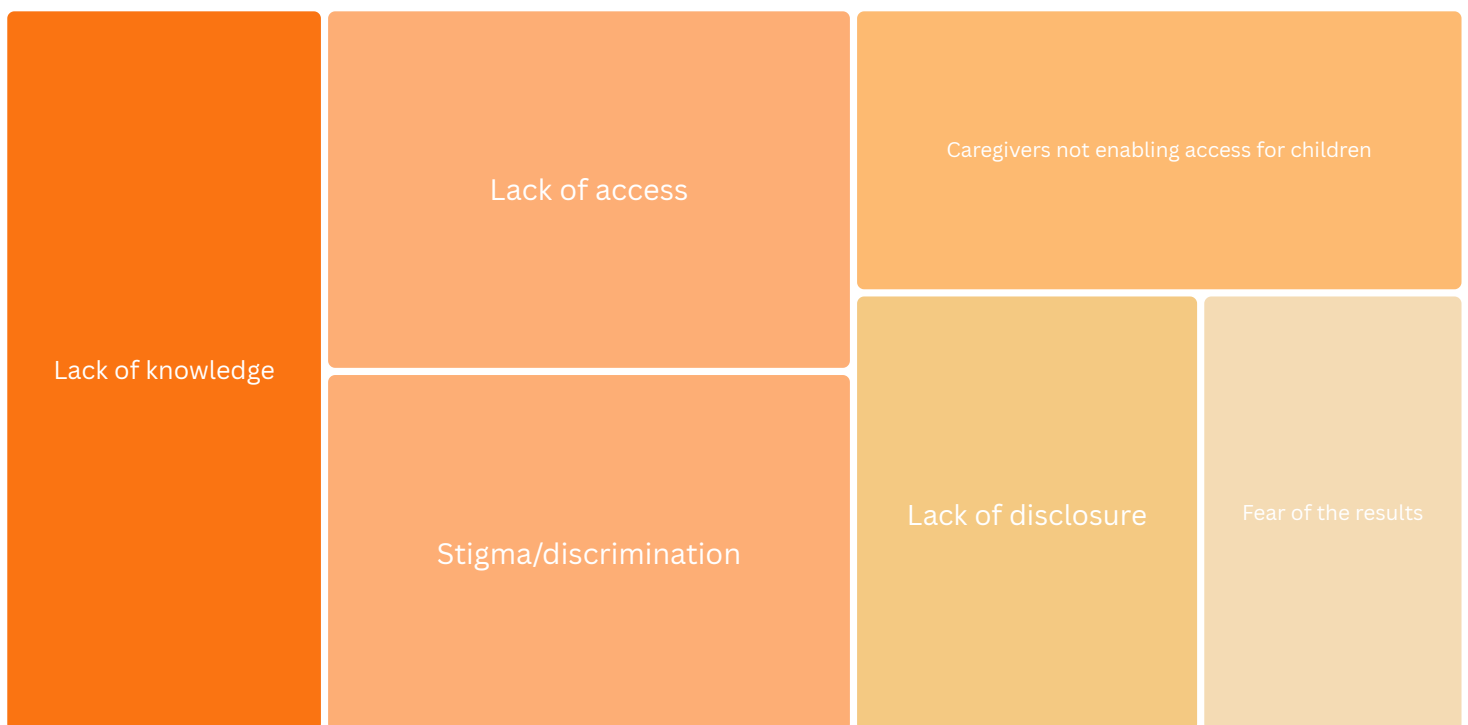
Health Care Worker

What are the barriers to access to HIV testing and treatment in our community? Qualitative findings



Barriers to HIV testing and treatment identified by respondents included:

- Lack of knowledge (92%)
- Lack of access to services (77%)
- Stigma/discrimination (77%)
- Caregivers not enabling access for children (69%)
- Lack of disclosure by caregivers (62%)
- Fear of the results (46%)



Percent of qualitative interviews where respondents identified **lack of knowledge** as a barrier

92

Respondents spoke about lack of knowledge as a barrier in different ways including not knowing how to transmission happens, how transmission can be prevented, that HIV can be managed, what will happen if you are positive, that being HIV positive is not a death sentence, and where they can get tested.

"I think it is the lack of the right information, because there are people who, although there is already information, still don't have the right information, after that they don't even eat with someone who has the HIV virus because they think they will contract the virus, so these people really need information, we need to cultivate that the HIV virus is a disease like any other now."

Health Care Worker

Percent of qualitative interviews where respondents identified **lack of access to services** as a barrier

77

When speaking about lack of access to services respondents spoke about the limited number of clinics available in communities where testing and treatment can be accessed, lack of time to go to clinics, long distances from clinics, lack of staff leading to long queues, and the clinics only being open during the week.

"Okay, for our young people, at some point I look at the adolescents and youth, the access has been limited because looking at our health facilities not all of them are prepared to offer the adolescent and youth services, which is the space where the whole HIV prevention and treatment package is offered, so if the health facilities don't meet the conditions to be able to attend young people in a youth only environment it ends up being difficult, they might not have the services they need, the testing, treatment, safe space for young people."

Provincial Directorate of Health

"...some people don't get tested because of the fear of the result, stigma, discrimination still happens in the community, some people still think that HIV is synonymous of death, while no, now you can treat and live positively without any problem, so I think that stigma and discrimination is still a problem."

Provincial Directorate of Health

Stigma and discrimination continue to be described as a barrier to testing and treatment. Respondents spoke about name-calling, forced marriages if positive, health care providers discriminating, fear of being exposed and discriminated against, and prejudice from communities as some of the barriers.

Percent of qualitative interviews where respondents identified **stigma/discrimination** as a barrier

77

What are the barriers to access to HIV testing and treatment in our community?

Quantitative findings

Participants were asked to identify to what degree different barriers to accessing HIV testing and treatment were a problem in their community. For each barrier, participants indicated if it was a big problem, a small problem, or not a problem at all.

Of interest is that **the barriers that most participants identified as big problems in their community were all related to fear of the potential consequences, especially in terms of their relationships.** Over half identified the following barriers as being a **big problem in their community:**



On the other hand, 40% or more respondents said that the following **barriers were not a problem at all in their communities:**

- The test is too expensive (54%)
- They cannot afford treatment, so why get tested? (49%)
- They do not have transportation to get to a testing site (40%)
- They do not know where to go for testing (40%)

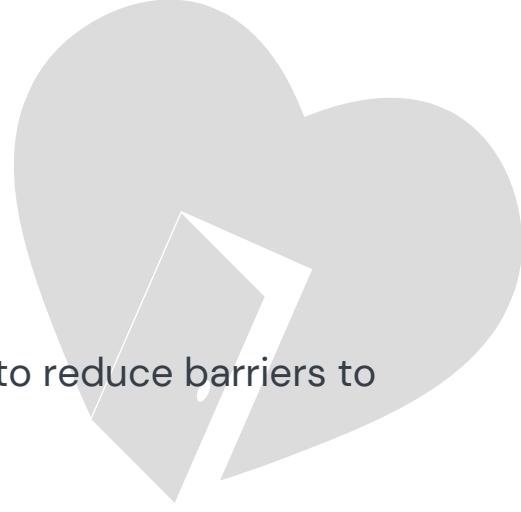
What are the barriers to access to HIV testing and treatment in our community?

Quantitative findings - differences between groups

Sofala respondents identified significantly more barriers to HIV testing and/or treatment, on average, compared to Maputo respondents. The table below show the % of participants who identified each barrier as a big problem in their community.

Barrier	Maputo	Sofala
They are afraid of losing their partner	49%	80%
They are afraid of losing their family	45%	80%
Sites are not open at convenient times	28%	52%
They do not like the people who work at the testing site	29%	59%
They are shy or embarrassed	26%	57%
The people who work at the testing site might judge them or be rude to them	42%	61%
They are worried about confidentiality and/or privacy	34%	56%
People might recognize them at the testing site	25%	59%
They think 'there is no cure, so why get tested?'	38%	67%
They do not want to know the results	51%	70%
They are afraid of losing their job	42%	74%
They are afraid of losing their friends and other social contacts	40%	72%
They are afraid of becoming sick	44%	75%

How can the barriers to access to HIV testing and treatment be reduced? Qualitative findings



Respondents identified the following strategies to reduce barriers to HIV testing and treatment:

- Increase access to services (100%)
- Awareness raising (92%)
- Using young/peer activists (77%)
- Create safe spaces for youth (69%)
- Parental involvement (54%)



Strategies for increasing access to testing and treatment

Respondents felt that access to services could be increased through:

- Having more clinics
- Increasing staff at existing clinics
- Extending opening hours of services to later in the evenings and over the weekends
- Enable at home testing through peer educators or self-testing
- Create safe spaces for adolescents to access accurate information and services
- Use mobile clinics
- Involve family to support HIV+ individuals to get medications and adhere to treatment
- Ensure the availability of medication

In order to increase access, we must look at the issue of testing, we have to massify testing, because only then can we reach people for testing and treatment, community mobilizations, lectures that we can give, we can also use radio to spread the information, and at this time, even though it is not eligible for children, there is another modality which is self-testing in the community for HIV screening, so all these interventions make us increase the coverage of access to treatment.

Provincial Directorate of Health

Strategies for awareness raising and information giving

"So the lectures are helping a lot when the person has HIV or not, and has assistance from the peer educator, then hears testimonies from other young people at school, after watching it on television, then he/she will gather this information and realizes that we really don't need to discriminate against that person who didn't have HIV by choice, so the dissemination of information is actually improving the way in which this decreases."

Health Care Worker

Respondents felt that awareness raising could reduce barriers including stigma and encourage access to testing and treatment. They spoke of:

- Doing talks in schools and communities
- Using television programmes aimed at children and adolescents to discuss HIV
- Increasing understanding of why it is important to know your status and to adhere to treatment
- Counteract negative beliefs regarding HIV through accurate information giving
- Utilise motivational young HIV+ individuals to tell their stories

How can the barriers to access to HIV testing and treatment be reduced?

Quantitative findings

Participants were asked what they think could be done to make it easier for people in their community to get tested and/or treatment. The vast majority of respondents (78%) said that more testing and/or treatment facilities should be available, 69% said that more information on where to get tested and/or treatment should be shared, and 59% said that parents, caregivers, and family members should be more supportive and encourage each other to get tested and remain on treatment.

What could be done...	Percent
More testing and/or treatment facilities should be available	78%
More information on where to get tested and/or treatment should be shared	69%
Parents, caregivers and family members should be more supportive and encourage each other to test and initiate and remain on the treatment	59%
People should be able to get time off work to get tested and/or treatment	54%
The people working at the testing and/or treatment facilities should be more approachable/less judgmental	53%
People should be less judgmental of those getting tested and/or treated	42%
Transport to testing and/or treatment facilities should be provided	27%
Testing and/or treatment should be less expensive	12%

Who can do what to reduce the barriers to access to HIV testing and treatment

Qualitative findings

Communities



Share correct information

Support community members

Get informed and access services

Not discriminate

Welcome and support activists

"The community should create a supportive environment for children, people in the community should try to be more informed to be able to support children, also there should be no discrimination and one of the things that would help is not to be separated just because so-and-so has the virus we should not approach him or if my child is negative he can't play with another child who has it."

Activists

"The community also has an important role because they should welcome people who have HIV, support them because support is more important, for a person to get treatment, they have to have the support of the family as well as a community and avoid stigmatizing people who are HIV positive and sensitize the community to generate awareness because it is also a form of prevention, testing should be for everyone to know if they have HIV or not, and take into account the prevention measures."

Provincial Directorate of Health

Who can do what to reduce the barriers to access to HIV testing and treatment

Qualitative findings

"Community based organizations should assume that we want everyone to be well and adherent to treatment, but we should also understand the needs of the service users, one of the big ways that community organisations can help is to understand these users and see how they can help, even if it is to take medication to them from the community dispensary, one of the ways to help the individual to remain active in treatment"

Health Care Worker

"The organisations, together with the activists, can strengthen the sensitisation in the community, disseminate information that is important for the community, because a well-informed community lives aware of its health and risks and provides the necessary means to reach the communities."

Project Officer

Facilitate access to services

Information giving

Understand needs

Support activists

Cover basic needs



Who can do what to reduce the barriers to access to HIV testing and treatment

Qualitative findings

"In addition to increasing the days as my colleague said on the weekends, increase the number of testing posts, more brigades, and that there are more posts in the communities, see the communities that need health posts, let's see the case of the Marracuene area, there is only one health unit, we have many areas in there, many areas that are appearing there, people think of the distance, they think of the money for transport and even for people to leave their homes, it is a distance, so if the government enters those areas, setting up testing posts would be a good thing"

Peer Educator

"First to guarantee access to testing, is to have the tests in the health units, to have health providers ready to receive these cases and give support, as well as expand the health units to the communities that don't have them."

Provincial Directorate of Health

Increase access to materials/services 

Raise awareness 



Government

Who can do what to reduce the barriers to access to HIV testing and treatment

Qualitative findings

Peer educators/Activists



Information giving

Build trusting relationships

Monitor and support adherence

Work with others in the community

Provide testing

"we need to have Activists, peer educators of that age group because they are open to the same age group, because when it is an adult person they hide, that same age group is easy to talk to have more openness, and have those groups of those who are undergoing treatment together here and each one will say how they are coping, how they have been doing the treatment and will also motivate others to adhere to treatment."

Health Care Worker

"We should sensitise the community on testing and treatment, and also for those who are undergoing treatment we need to make more home visits so that we can understand the difficulties of the beneficiary and give the necessary accompaniment to the psychologist if there is any problem, we can also help to create gardens to guarantee food, this will help a lot for the beneficiaries to have something to eat and they can sell what they produce in the gardens"

Activist

Who can do what to reduce the barriers to access to HIV testing and treatment

Qualitative findings

Health Care Providers



Information giving

Be welcoming to adolescents

Be more patient

Provide mobile services

Work with others in the community

"Health providers should be more patient with beneficiaries who go there to test, because this influences a lot, if the patient is treated well he will always want to return there, Once, I went to a health centre and they didn't know that I was an activist and in the lectures I didn't contribute, not because I didn't know, but because I wanted to leave people at ease and one lady asked how she could go for testing and they answered her badly saying that until now she didn't know the door where the testing is done. Of course, she might have to return home knowing that her health is at stake, so those who work, especially in testing, should be very patient, so if there was a team of us there, we would minimise it because we know and understand each other"

Activist

"It is necessary that health providers, when faced with this situation, from the moment the patient arrives at the health unit, are responsible for listening to the patient's situation, attend to him/her with courtesy, and allow him/her to feel comfortable to expose his/her concerns, because if in the attempt to seek good care fails in a certain way this will cause the patient not to be for HIV treatment."

Project Officer

Key takeaways and Recommendations

Although the report covered a great deal of areas, in this section we highlight the most pertinent along with some recommendations.

1

Barriers to accessing HIV testing and treatment continue to persist

Recommendation

Efforts to eliminate barriers and facilitate access to services, especially for children and adolescents, are still needed and could be scaled up.

2

Children and adolescents are a high-risk group in relation to HIV

Recommendation

Activities could be developed with a specific focus on reaching children and adolescents. These could include work with parents to disclose status and ensure that perinatally infected children access treatment early and regularly. For adolescents interventions could include creating testing and treatment options that are easy for them to access, creating adolescent-focussed safe spaces, and the use of peer educators and activists to facilitate access to information, testing, and treatment.

3

Stigma and discrimination and fear thereof continue to be a significant barrier

Recommendation

Additional efforts could be made towards reducing the negative views regarding HIV and curbing the negative reactions to an HIV+ result for individuals and their family and friends. Additional support could also be given to individuals who need to disclose so that this is done in a safe way.

4

Sofala is more affected by barriers to HIV testing and treatment when compared to Maputo

Recommendation

More interventions should be done in Sofala to eliminate the barriers to HIV testing and treatment. These include increasing access, addressing stigma, and supporting.

5

Various suggestions are made in terms of decreasing barriers

Recommendation

Key activities could focus on increase access to services, awareness raising, using young/peer activists, create safe spaces for youth, and involving parents.

6

Various stakeholders are required to reduce barriers

Recommendation

Communities, government, health care workers, community-based organisations, and peer educators/activists all have an important role to play and should work together to reduce the barriers to HIV testing and treatment.

Thank you

We appreciate the participants who gave of their time and knowledge so that we may have a better understanding of the barriers to HIV testing and treatment and how these may be reduced.



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