

# Youth Living with HIV in Mozambique: Reaching and Sustaining the “Last 95”

A Qualitative Study in Sofala, Manica, and Niassa Provinces





# Introduction

# Background

- **Global “95-95-95” targets.** By 2030:
  - 95% of all people living with HIV will know their HIV status
  - 95% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy (ART)
  - 95% of all people receiving ART will be virally suppressed
- Despite progress having been made in Mozambique, low rates of treatment initiation and retention—especially among children, adolescents, and young adults—threaten success
- To meet 95-95-95 targets, Mozambique needs to accelerate strategies to support adolescents (ages 15–19 years) and young adults (ages 20–24 years) living with HIV
- The Ministry of Health (MISAU) is rolling out strategies to address needs in these target groups, but more information is required to inform strategies

# Research Objectives

- Catalogue the **barriers** and **facilitating factors** affecting retention in care and ART adherence
- Describe any **services** or innovations that may improve outcomes across the clinical cascade among youth ages 15–24 years
- Document the current status of **viral load monitoring** among youth ages 15–24 years
- Gather perspectives to inform the **adolescent/youth HIV care model** currently being developed by MISAU

# HP+ Partners

- MISAU
- USAID
- Government of Mozambique's pediatric HIV technical working group
- COWI Moçambique, Lda
- FHI 360

A similar qualitative study was carried out in Tanzania. The results and methodology may inform the international dialogue on pediatric HIV care.

# A Few Facts at the Time of the Study (Mid-2018)

- “Test and Start” was rolled out in 2016
- Legal age:
  - 13 years—for HIV testing and disclosure of results independent of a caregiver
  - 18 years—consent for medical treatment
- Viral load testing was still being scaled up and lab logistics were being refined
- A limited number of adolescent clinics—SAAJs (*Serviços de Amigos dos Adolescentes e Jovens*)—existed, where youth ages 10–24 years are eligible to receive HIV treatment and support services, unless they are pregnant with their second child (or are mothers of two children)
- Few clinics offered support groups for adolescents and youth living with HIV
- Differentiated care models were being rolled out, but there were few customized care options available for adolescents



# Methods

# Design and Participants

- Qualitative study involving key informant interviews and focus group discussions (FGDs)
- Participants:
  - Youth ages 15-24 years living with HIV
  - Caregivers of adolescents living with HIV
  - Healthcare providers (e.g., doctors, nurses, psychologist, health technicians)
  - Social care providers (e.g., case managers, activists, counselors)
  - National- and provincial-level program managers and policymakers
- Ethics approval obtained (Mozambique and U.S.)

# Setting

- Three provinces selected: Sofala, Manica, Niassa

Province	Diagnosed	On ART	Virally Suppressed
Sofala	49%	76%	97%
Manica	50%	82%	88%
Niassa	40%	98%	75%

- Selection criteria:
  - USAID-supported facilities with adolescent-specific clinics (SAAJs)
  - High adolescent client volume
  - Rolling out “Test and Start” and viral load testing
- Three CHASS project facilities selected, one per province:
  - Ponta Gêa (Sofala)
  - Nhamaonha (Manica)
  - Cidade de Lichinga (Niassa)

# Site Characteristics

Characteristic	Sub-characteristic	Sofala (Ponta Gêa)	Manica (Nhamoanha)	Niassa (Lichinga)
Test and start (all ages)	--	Yes	Yes	Yes
SAAJ	--	Standalone	Integrated	Standalone
Number of clients (all ages) currently on ART (TX_CURR)	Ages 15–19 years (adolescents)	Female: 165 Male: 63	Female: 130 Male: 131	Female: 55 Male: 15
	Ages 20–24 years (young adults)	Female: 746 Male: 162	Female: 494 Male: 61	Female: 244 Male: 30
	All ages	9,751	5,370	2,956
12-month retention rate (ages 15–24 years)	--	66%	57%	66%
Clients on three-month drug distribution (all ages)	--	61%	14%	57%
Rate of viral suppression (TX_PVLS <sup>1</sup> )	Ages 15–19 years (adolescents)	Female: 32% Male: 49%	Female: 20% Male: 26%	Female: 55% Male: 53%
	Ages 20–24 years (young adults)	Female: 36% Male: 27%	Female: 24% Male: 15%	Female: 57% Male: 37% <sup>2</sup>
	All ages	45%	26%	64%

Source: CHASS project data (July–September 2018)

<sup>1</sup> Percentage of clients on ART who have a viral load test result documented in the medical record and/or laboratory information systems within the past 12 months which shows a suppressed viral load (<1,000 copies/ml)

<sup>2</sup> Low counts; interpret with caution

# Recruitment

- 10 key informant interviews and 24 FGDs
- Key informants were identified by COWI in partnership with MISAU, USAID, and FHI 360
- FGD participants were identified with support from health facility HIV focal points
- Consent/assent was documented for participants; guardian consent was documented for minors

Focus Groups	Participants	Sofala (Ponta Gêa)	Manica (Nhamaonha)	Niassa (Lichinga)	Total
Health facility staff	Healthcare providers (e.g., doctors)*	1	1	1	3
	Social care providers (e.g., activists)*	1	1	1	3
Caregivers of children and adolescents living with HIV	--	2	2	2	6
Adolescents living with HIV Ages 15–24	Females, ages 15–19	1	1	1	3
	Females, ages 20–24	1	1	1	3
	Males, ages 15–19	1	1	1	3
	Males, ages 20–24	1	1	1	3
Total number of FGDs	--	8	8	8	24

# Data Collection and Analysis

- FGDs were conducted by a trained facilitator and a trained notetaker; key informant interviews were conducted by one trained interviewer
- Interviews and FGDs were tape-recorded
- Compensation:
  - All FGD participants were given a snack and a drink before or after the FGD
  - Youth and caregivers were given 100 *meticals* (US\$1.50) to compensate them for transportation costs to the clinic and their time
- Two analysts applied the Framework Analysis method to code transcripts in NVivo

# Limitations

- Generalizability: three urban settings only
- Population limitations:
  - By design, we did not include adolescents and youth not on ART, lost-to-follow-up, or their caregivers
  - We experienced challenges in recruiting adolescents in Manica and Niassa, which resulted in smaller FGDs of 3-4 people
- Selection bias
- Response bias



# Results

Retention in Care and Adherence to ART

# Participants

Participant Group	Number
Healthcare providers (e.g., doctors, nurses, medical technicians, psychologists)	28
Social care providers (e.g., activists, case managers)	37
Caregivers of adolescents living with HIV	42
Adolescents living with HIV, ages 15–19 (female/male)	29 (15/14)
Young adults living with HIV, ages 20–24 (female/male)	39 (22/17)
Key informants (provincial and national levels)	10
Total	185

# Facilitators of Retention and Adherence

- **Knowledge of HIV status**
- **Family support for adolescent/youth to continue and adhere to treatment**
- **Peer support, such as access to peer groups of youth living with HIV**
- Youth's acceptance of HIV status and fear of becoming ill should treatment stop
- A perception by youth that they are treated well by health providers at the clinic
- Financial resources to travel to the clinic

# Knowledge of HIV Status

- Participants in all FGDs said that disclosure of their HIV status was necessary for adolescents to manage their health/healthcare
- Adolescent girls, caregivers, and healthcare providers noted that early disclosure of their HIV status may prevent rebellion (non-adherence) in late adolescence

*“My daughter is in grade four. Last week she came and told me, ‘Mommy, do you know what I learned at school about HIV? The teacher said that HIV is transmitted through the knife and needle, is that right?’ I told her yes, and she said that it kills and there are children who are born with that disease. She asked me if that was true and I said yes. She has learned about it... So most of the kids today have information... They are prepared psychologically. You know, all we want is to tell children the truth, have them hear from their mother’s mouth that this pill you’re taking is because mommy did this and was not able to spare you.”*

*– Caregiver and social care provider,  
Lichinga*

*“When a son or daughter or relative has this disease, the main thing, the first medicine, is the family’s support. When they live with support they are motivated to continue treatment without fear, concerns, shame, nothing. They continue to take [medicine] as if nothing has happened. Yes ... family support is very good.”*

*—Male adolescent, Nhamaonha*

# Family Support

- Helps youth cope with/move past shame
- Acts as an incentive to continue ART

*“I returned [to treatment] not because I got sick, but because my relatives knew about my [sero]status and were always on top of me, almost every day, begging me to go back to my medication. They made me realize I was risking my life and talked me through until I understood they were right, and I decided to take my medication again.”*

*—Male young adult, Ponta Gêa*

# Family Support

- Helps youth get back on treatment

# Peer and Community Support

- Adolescents said that seeing other youth attending services helped them do the same

*“This thing of awareness raising (“palestras”) really helps. My daughter felt really well and strong enough not to stop treatment because of the group of friends who have AIDS and are on treatment. They met, gave strength to each other, counseled each other. It helped a lot. She thought she was alone but there she saw other people and got stronger. Up to today she is motivated. You don’t even have to talk to her, she goes [to the hospital] alone.”*

*—Caregiver, Ponta Gêa*

# Barriers to Retention and Adherence

- Slow acceptance of HIV status
- Teenage independence
- Lack of family support
- **Youth's lack of knowledge of their HIV status and inadequate communication with family members**
- **Youth's and caregivers' feelings of shame and stigma based on HIV status**
- A perception that life is over (after an HIV-positive diagnosis)
- Side effects of ART
- A lack of food to take with ART
- Changes in regimen that bring changes in routines and/or increased pill burden
- Inaccurate beliefs about how HIV is transmitted and cured
- Religious practices, such as fasting
- **Health systems barriers, such as the requirement to access ART from one pharmacy only**

# Shame and Discrimination

- Shame in sharing HIV status with family
- Youth may skip ART doses or stop ART completely out of fear that their HIV status will become public

*“I think that another issue is discrimination: we have people aged about 16, 17, 18 years who have sex without condoms, perhaps their parents don’t even know their partners. Then one day they do the test and it turns out to be positive. They are afraid to tell this to their family because of discrimination. So they abandon [treatment], they can’t hide [the treatment] and they leave the house.”*

*–Social care provider,  
Nhamaonha*

# Shame and Discrimination

- Male youth reported struggling more with shame than their female counterparts
- Young adults may struggle more with shame, compared to adolescents
- Caregivers may stop attending clinics with youth due to fears of discrimination

*“Boys are more careless... girls are more disciplined, even if hiding. I think most of the people do not take [the medication] in front of others; it is always set aside. But I find that boys feel this issue of shame more frequently.”*

*—Male young adult, Nhamaonha*

*"I heard my 18-years-old son say, 'Mom, did you know that I don't need to take medicine every day?' I asked, 'Where did you hear that?' He said, 'I read on the Internet.' I was dumbfounded and said, 'Keep with that Internet of yours and you will die.' He said, 'No mom, this disease is only for women and poor people.'*

*—Caregiver, Lichinga*

# Inaccurate Information

- Youth and their caregivers have access to multiple sources of information, some of which are inaccurate
- Feeling physically well is conflated with no longer needing ART
- Viral suppression is conflated with being cured

# Health System Barriers

- Caregiver presence is required in cases of minors, especially for disclosure of HIV status
- Providers talk to caregivers, not adolescents
- Difficulty picking up ART prescriptions at pharmacies (where the client is not registered) or without a caregiver—for clients under 18 years
- Youth often see different providers at every clinic visit, limiting the establishment of a trusting relationship

*“Basically, we talk with the caregiver, because the [adolescent] is not well prepared to receive that information. We wait until the person is about 18 years of age or so, then we can talk directly with the patient.”*

*—Healthcare provider,*

*Ponta Gêa*

# Other Barriers: Illustrative Quotes

- A fear that life is over after a positive HIV diagnosis
- Cultural practices

*"Others say, 'I have HIV and I want to die because I have HIV. I am dead. My life is over.'"*

*—Female adolescent, Lichinga*

*"I remember being taken by my father and mother to Zimbabwe, to cure this disease. They told us to buy goats and use the blood as medication. They mixed many things. We stayed almost one month wasting money and taking filth, but nothing changed."*

*—Male adolescent, Ponta Gêa*

*“A great deal of [why we adhere to treatment] is because of the initiative of healthcare providers. Because when they know you and have your contacts, they won’t stop calling you to know if you are taking your medication and urge you to come get your medication when the next scheduled date is about to come. This is [very nice] because it helps you to take your medication and your treatment seriously.”*

*—Male young adult, Ponta Gêa*

## Services in Support of Retention and Adherence: Available

- Appointment reminders (*lembretes*)
- Counseling from healthcare workers and social care providers related to HIV status disclosure, living with HIV, and ART
- Patient tracing (*busca activa*)

# Services in Support of Retention and Adherence: Needed

- Peer support groups (HIV-specific and general)
- Educational initiatives and sensitization campaigns for youth and their caregivers
  - Improve understanding of viral suppression and viral failure
  - Underscore the need to take ART even when feeling physically well
  - Counter misinformation
- Family counseling to better support youth
- Customized ART distribution modalities, such as community dispensing



# Results

Viral Load Monitoring

# Providers' Perspectives on Viral Load Monitoring

- Providers routinely order viral load tests for new patients
  - Challenges: Stockouts of viral load test commodities, patient scheduling (medical vs. lab appointments), delays in processing, provider inconsistency in ordering follow-up tests
- Policies for return of viral load test results are similar across facilities but practice does not always follow policy
- Providers discuss viral load test results with caregivers rather than with adolescents themselves
- Providers are reluctant to change youth to a second-line regimen due to adherence concerns; providers work with ART committees

# Client Experiences with Viral Load Monitoring

- Youth lack knowledge about viral load testing
  - Few youth knew what it is, and even fewer knew whether they had received a viral load test
- Youth who had received a viral load test said the test was ordered in response to a clinical concern (e.g., weight loss)
- Youth receive basic information (i.e., the result is “good/bad”) either via caregivers (adolescents) or directly (young adults)

*“The nurse said ‘I am pleased with your viral load.’ I asked the nurse why. She said it was very good and I got very happy.”*

*—Female young adult,  
Ponta Gêa*

*“[Nobody] explained anything about the test result... I was only told I was getting better.”*

*—Female adolescent, Lichinga*



# Results

## HIV Care for Youth

*“Here young people feel more open, because the others around here are of the same age. Whereas [with general care and treatment services] it is difficult for them to open up. Here we manage to open up. Here is our home. We feel at ease, more friendly, less fear, hiding, less shame.”*

*—Young adult and social care provider, Ponta Gêa*

# Perspectives on Youth Clinics

- Limited exposure among group; Ponta Gêa had the most functional SAAJ at the time of the study
- SAAJ clients were extremely positive about their experiences
- **Benefits** cited by clients and others included friendly environment, one-stop shop service (*paragem única*), peer support services (youth groups), and shorter wait times
- **Challenges** cited included staffing, infrastructure

# Transition of Care

- General view: Adolescents up to *at least* age 13 years should be accompanied to clinic by an adult
  - Caregivers wanted to stay involved in their adolescents' care even after transition to an adolescent-specific service
- Need strong transition guidance, including:
  - Counseling to avoid attrition during transition both into and out of youth services
  - Accompanied appointments
  - Concept that transition should be optional and the number of transitions between different clinics should be minimized
  - Protocols for pregnant youth and young mothers

# Package of Care for Adolescents and Youth Living with HIV: Key Informant Perspectives

- One-stop shop
  - Medical appointments, pharmacy pick-ups, and laboratory tests
  - Peer support groups
  - Psychosocial support services
  - Family planning and other sexual and reproductive health services
- Institute customized/differentiated care to meet client status and needs
  - Explore community adherence support groups (*grupos de apoio e adesão comunitária*) using existing peer support groups
  - Adjust clinic hours to extend beyond school hours



# Recommendations

# Recommendations

- Improve treatment literacy and address knowledge gaps around viral suppression and failure and viral load monitoring through information, education and communication campaigns
- Expand peer support interventions for adolescents
- Enhance disclosure and peer support for caregivers
- Enhance training for health and social care providers in working with adolescents and youth, including
  - Communicating effectively with adolescents and youth
  - How to support caregivers and youth through disclosure processes
  - Empowering adolescents to become involved in their care
  - Age of consent and rapid assessment of subjective consent criteria (individual readiness)
- Improve healthcare provider training in viral load monitoring, including
  - Using viral load test results in patient care decision making
  - Explaining viral load test results to clients (youth as well as caregivers)

# Recommendations

- Address facility-level factors that delay viral load testing and results return
- Reconsider SAAJ eligibility criteria
  - Increase the age of entry to at least 12 years
  - Make adolescents mothers eligible, regardless of their number of children
- Implement SAAJ transition guidelines and pre-transition counseling guidance
  - Ensure that these policies specify a mechanism for continued caregiver involvement and accompanied visits after transition
  - Transition should be optional
  - Minimize the number of transitions between clinics
- Standardize policies for testing, disclosure, and involving adolescents in their care
- Identify and scale up differentiated care models for youth
- Study “positive deviants”
- Build and review a policy scorecard

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# HP+

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