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YOUTH LIVING WITH HIV IN MOZAMBIQUE—REACHING THE LAST 95

A Qualitative Study in Sofala, Manica, and Niassa Provinces

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Abbreviations

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
CCR	*consulta da criança em risco* (clinical services for at-risk children)
CCS	*consulta da criança sadia* (well child clinic)
CHASS	Clinical and Community HIV/AIDS Services Strengthening
CPN	*consulta pré-natal* (prenatal services)
FGD	focus group discussion
HIV	human immunodeficiency virus
HP+	Health Policy Plus
MISAU	*Ministério da Saúde* (Ministry of Health)
ml	milliliter
PEPFAR	The U.S. President's Emergency Fund for AIDS Relief
SAAJ	*Serviços de Amigos dos Adolescentes e Jovens* (Services of Friends of Adolescents and Young People)
TLD	tenofovir disoproxil fumarate/lamivudine/dolutegravir
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	U.S. Agency for International Development

Executive Summary

Introduction

Mozambique is working to achieve sustained epidemic control through the "95-95-95" goals outlined by the Joint United Nations Programme on HIV/AIDS (UNAIDS)—that by 2030, 95 percent of people living with HIV know their diagnosis (1st 95), 95 percent of those diagnosed receive sustained antiretroviral therapy (ART) (2nd 95), and 95 percent of those on ART are virally suppressed (3rd 95). With more than 1 million people on treatment, Mozambique is making progress toward reaching these goals. However, low rates of treatment retention, especially among children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years), threaten to undermine epidemic control. For example, in 2017, the 12-month rate of retention in care was only 70 percent—and only 62 percent among adolescents (PEPFAR, 2018).

To meet their global commitments, Mozambique must continue to use data to rapidly design, refine and scale up programming to address the specific barriers faced by adolescents and young adults, building on successes so far achieved. The Government of Mozambique is rolling out various epidemic control strategies to strengthen the HIV response and better meet the needs of young people living with HIV. However, the response is hindered by a lack of input from young people living with HIV and their caregivers.

This study was conducted by the Health Policy Plus (HP+) project, funded by the U.S. Agency for International Development (USAID) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), in collaboration with the *Ministério da Saúde* (Ministry of Health, Mozambique) (MISAU). It is intended to provide novel and timely data to guide policymakers and program managers in designing and refining adolescent HIV treatment strategies. HP+ also aimed to take stock of progress in rolling out new initiatives (such as viral load testing and *Serviços de Amigos dos Adolescentes e Jovens* (Services of Friends of Adolescents and Young People) (SAAJs), to guide government partners in their efforts to strengthen Mozambique's HIV response. This study, conducted in mid-2018, had the following research objectives:

- To catalogue the barriers and facilitating factors affecting retention in care and ART adherence
- To describe any services or innovations that may improve outcomes across the clinical cascade among youth ages 15–24 years
- To document the current status of viral load monitoring among youth ages 15–24 years
- To gather perspectives on a new adolescent/youth HIV care model currently being developed by MISAU

Data from this study will inform the development of clinical policies and strategies to improve retention and adherence among adolescents and young adults living with HIV, with the goal of achieving sustained viral load suppression.

Methods

This qualitative study used focus group discussions (FGDs) and key informant interviews to elicit information on enablers and barriers affecting clinical retention, viral load testing, and viral suppression among adolescents and young adults ages 15–24 years. HP+ conducted 24 FGDs: three with healthcare providers, three with social care providers, six with caregivers of adolescents living with HIV, six with adolescents living with HIV (ages 15–19 years), and six with young adults living with HIV (ages 20–24 years). HP+ also conducted 10 interviews with high-level program managers and policymakers at the provincial and central levels. Data were collected in mid-2018. Data were collected in three urban healthcare facilities—one in each of three provinces (Sofala, Manica, and Niassa). These sites were selected based on their relatively high adolescent client loads, the fact that they had adolescent-specific clinical services, and their performance indicators. Two researchers analyzed the data using Nvivo 12, guided by a standardized codebook.

Results

Across the three study facilities, 68 youth (29 adolescents ages 15–19 years and 39 young adults ages 20–24 years), 42 caregivers, 37 social care providers, and 28 healthcare providers participated in FGDs. In addition, HP+ held interviews with 10 key informants from the provincial and national levels.

Barriers to retention and adherence

Commonly cited barriers to retention and adherence include slow acceptance of HIV serostatus; teenage independence and testing of boundaries; lack of family support; communication and disclosure challenges; shame and discrimination; fatalism; side effects of ART medication; changes in ART regimen; lack of food; cultural and religious reasons (e.g., fasting); having inaccurate information (i.e., that people living with HIV only need to take medication when they are feeling sick); and health systems barriers (e.g., requiring a caregiver to be present during consultations and ART pick-up).

Facilitators of retention and adherence

Family support was the principal enabler of retention and adherence mentioned in all FGDs. Other facilitators of retention and adherence include peer and community support; disclosure; acceptance of HIV status; fear of becoming ill; being treated well by providers; adequate household-level financial resources; and being in treatment since childhood.

Services to support retention, adherence, and viral suppression

Services received. Youth were asked about the services they receive that support them to stay on treatment. The most commonly cited services were counseling, patient tracing (*busca activa*), appointment reminders, and reminders by phone or text message to pick up medication (*lembretes*). Youth specifically noted the importance of being counseled by healthcare providers and social care providers on the advantages of ART, the importance of treatment adherence, and other issues.

Additional services needed. FGD participants identified a variety of missing or inadequate services, namely, nutritional support (food and training on how to prepare nutritious meals for people living with HIV), youth groups, educational initiatives and sensitization campaigns, family counseling, and novel ART distribution modalities, such as community dispensing.

Viral load monitoring

Provider experiences. Healthcare providers noted that they routinely order viral load tests, although mainly for new clients. They described facing challenges related to viral load testing, including a lack of viral load testing commodities at the health facility and difficulty coordinating client appointments across services. Healthcare providers described frustrations with laboratory delays in processing blood samples and issuing test results. The introduction of the DISAlink system was mentioned as a crucial improvement that has decreased delays in viral load results return.

Client experiences. Few adolescents and young adults could describe what a viral load test was, and fewer still knew whether they had received a viral load test. Moreover, many adolescents who had received a viral load test perceived the test to be in response to a poor clinical indicator (e.g., weight loss), rather than part of the routine standard of care. Adolescents under 18 years of age received their viral load test results through or together with their caregiver, while young adults received their results directly. Rather than providing clients with their viral load count, providers shared an overall assessment that their viral load was “good” and the ART is working well. When asked whether they understood the meaning of their viral load test results, some adolescents and young adults claimed to understand the results and others said they did not to know or understand their test results. These differences appeared to be linked to how results were delivered by providers. Those who received their test results from the healthcare provider in person were more likely to say that they understood the results and their treatment implications. Those who received the test results from someone other than the healthcare provider (i.e., their caregiver), appeared more likely to say that they were not informed of their test result.

Adolescent care and transition

Standard of care. Healthcare providers across the health facilities reported different policies regarding age of direct disclosure of HIV test results. However, in practice, youth under 18 years who independently seek HIV testing are often asked to return with a caregiver to receive their test result. Often, providers noted, this requirement leads to delays in treatment initiation. Once a positive test result has been shared with the client, they are referred to psychosocial support for counseling and begin ART. ART consultations take place at the general care and treatment clinic or, if the facility has a functioning youth clinic (SAAJ) and the client meets eligibility criteria, at the SAAJ.

SAAJs. A common view among participants in all FGDs was that transitioning adolescents and young adults on ART to the SAAJ would strengthen retention in care and adherence to treatment. Advantages of the SAAJ cited by adolescents and young adults in all three health facilities included shorter waiting times, the availability of other (non-HIV) services in one place (i.e., a “one-stop shop”), a friendly environment, the opportunity to share problems and to learn from peers and providers. Key informants also suggested that SAAJs may improve relationships between clients and healthcare providers, especially if SAAJ staff are trained/ better skilled in working with adolescents. A few concerns were cited—mainly in terms of staff capacity (numbers of people and skills). Healthcare providers and key informants stressed that, for SAAJs to be effective, they need to be adequately staffed and equipped to meet an increased demand for services by adolescents and young adults.

Transition. Different opinions were expressed about eligibility and, specifically, the age of transition into the SAAJ. Participants were in favor of an age of entry of 13 to 15 years. There is a lack of consensus on where pregnant youth and young mothers should be seen. Key informants expressed that SAAJs should provide services to all girls within the age range, regardless of whether they are pregnant or mothers already.

Participants from all FGDs agreed on a number of markers for "transition readiness," other than age, namely that the child is fully disclosed to; capable of remembering appointment dates, attending the health facility, and picking up prescriptions on their own (i.e., without the caregiver); and assents to moving from their current clinic to the SAAJ. Young adults, caregivers, healthcare providers and key informants agreed that counseling and preparation are key for successful transition. Transition support should include accompanied visits to the new clinical service. Key informants also recommended that transition be voluntary rather than compulsory. Caregivers in all locations noted that they would want to stay involved in their adolescents' care, even after transition to the SAAJ, which social and healthcare providers and key informants agreed is critical to ensure retention and adherence.

Package of services. Key informants and healthcare providers explained that SAAJs should be a "one-stop shop" for medical appointments, pharmacy pick-ups, and laboratory tests, including peer support groups, psychosocial support services, family planning services, and other sexual and reproductive health services. Key informants were unanimous in noting the importance of counseling/psychosocial support services. Overall, informants noted that the SAAJ model should allow for differentiated care, adapted to different stages of adolescence.

Recommendations

Based on these findings, HP+ offers the following recommendations:

Improve treatment literacy and address knowledge gaps around viral suppression and failure and viral load monitoring through information, education, and communication strategies. There is a need to increase knowledge about the benefits of viral suppression—the individual health benefits of having an undetectable viral load (that a person living with HIV who has an undetectable viral load cannot transmit the virus), as well as its public health importance, including that of community viral load suppression. Strategies should use all available communication modalities, such as radio and social media, and make use of existing information, education, and communication materials on viral suppression and viral load testing. Initiatives to reduce misinformation are also required, including targeted initiatives to engage influential stakeholders, role models, and gatekeepers. Engaging faith-based organizations and traditional leaders as change agents is particularly important.

Expand peer support interventions for adolescents. Youth emphasized the importance of peer support in enabling them to stay on treatment. Peer support groups/interventions should be scaled up to build treatment literacy and self-efficacy skills among youth and empower youth to become able in managing their care. Groups may be based in health facilities, the community, or schools and should provide peer support on living with HIV and supporting family members with HIV.

Enhance disclosure and peer support for caregivers. Peer support services (one-on-one or group-based) for caregivers should be created to offer caregivers opportunities to discuss their concerns and develop and share solutions.

Enhance training for health and social care providers in working with adolescents and youth. HP+ recommends building providers' skills in an assets-based approach to engaging adolescents and youth—enabling providers to communicate with adolescents and youth about their health and healthcare in ways that put them at ease and can be easily understood. Further, providers should receive training on how to support caregivers through disclosure processes and new strategies should be used to incentivize providers for their important work in engaging and empowering adolescents.

Improve healthcare provider training in viral load monitoring. Specifically, providers should be trained in using viral load test results in patient care decision making (including when to order first tests and follow-up tests) and explaining the significance of viral load test results to patients (especially that having an undetectable viral load means that they cannot transmit the virus).

Address facility-level factors that delay viral load testing and results return. Health facilities should streamline procedures for carrying out and returning the results of viral load tests, including scaling up DISALink, improving commodity tracking, and aligning appointments across hospital services.

Reconsider SAAJ eligibility criteria. The age of entry for SAAJs should be increased to at least 12 years. Further, adolescent mothers should be made eligible to receive services in the SAAJ, regardless of their number of children.

Implement SAAJ transition guidelines and pre-transition counseling guidance. In addition to full-scale implementation of these guidelines, these policies should specify a mechanism for continued caregiver involvement in adolescent care and accompanied visits after transition; transition to a SAAJ should be optional; and efforts should be made to minimize the number of transitions between clinics.

Standardize policies for HIV testing, disclosure, and involving adolescents in their care. Clinical policies, including the age of consent for results disclosure and treatment, should reflect national legislation and be posted publicly in all health facilities. Health and social care providers should be reminded of the age of consent and trained to rapidly assess subjective consent criteria (individual readiness) and to involve adolescents in their care.

Identify and scale up models for customized care for youth. HP+ recommends offering flexible, differentiated care models for adolescents, such as evening clinics and differentiated drug distribution modalities.

Study "positive deviants." To unlock successful strategies and explore the importance of linked interventions delivered at the community level or in school settings, there is a need for focused research on individuals who have successfully navigated social, community, and clinical issues that many have struggled with, especially male youth who have stayed on treatment and caregivers who have successfully disclosed to their children in early adolescence.

Build and review a policy scorecard. To hold stakeholders accountable, a policy scorecard should be designed and used, beginning with scanning pediatric and adolescent policy and guidelines to unpack the status of priority guidelines from conception to implementation.

Introduction

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) outlined fast-track targets, known as the “95-95-95” goals, to end the HIV epidemic by 2030 by ensuring that 95 percent of people living with HIV know their diagnosis (1st 95), 95 percent of those diagnosed receive sustained antiretroviral therapy (ART) (2nd 95), and 95 percent of those on ART achieve viral suppression (3rd 95) (UNAIDS, 2014). The targets were set for 30 countries, including Mozambique, that account for most the world’s new HIV infections.

Progress in Meeting the 95-95-95 Goals in Mozambique

HIV prevalence in Mozambique is 13 percent among men and women ages 15–49 years, up from 11.5 percent in 2009 (MISAU et al., 2015). For this age group, prevalence is higher among women (15.4 percent) than men (10.1 percent). Among adolescents and young adults ages 15–24 years, HIV prevalence is 10 percent among females and three percent among males (MISAU et al., 2015).

Overall, with more than 1 million people on treatment, Mozambique is making progress in reaching 95-95-95 targets. However, low rates of treatment retention, especially among children (ages 0–14 years), adolescents (ages 15–19 years), and young adults (ages 20–24 years), threaten to undermine epidemic control. Using available data, HP+ calculates that Mozambique has diagnosed only 38 percent of adolescents and young adults living with HIV (139,827/370,798), of whom 85 percent are on ART (119,275/139,827), and 89 percent of those on ART are virally suppressed (106,027/119,275). Mozambique has diagnosed 46 percent of children living with HIV (88,936/193,339), of whom 89 percent are on ART (79,269/88,936), and 73 percent of those on ART are virally suppressed (58,002/79,269) (see Table 1).

Table 1. Estimated Performance against 95-95-95 Targets (Calculated Using 2015 Data)

Target Areas	Ages 15–24 Years		Ages 0–14 Years	
	Number	Percent	Number	Percent
Diagnosed	139,827	38%	88,936	46%
On ART	119,275	32%	79,269	41%
Virally suppressed	106,027	29%	58,002	30%
Estimated number of people living with HIV/Percent of total population	370,798	6.5%	193,339	2%

Sources: HP+ calculations, based on data from MISAU et al., 2015; INE, 2017; PEPFAR, 2017; and MISAU, 2017 (see Footnote 2 for additional information).

Why Focus on Adolescents and Youth?

With nearly half of the country’s population under 15 years of age, Mozambique is facing a “youth bulge” (PEPFAR, 2018; UNAIDS, 2018a). This youth bulge, together with the fact that, globally, more children living with HIV are surviving into adolescence and adulthood, is the impetus for Mozambique to seek focused measures to improve prevention and treatment outcomes among young people. Improved treatment outcomes (i.e., viral suppression) among people living with HIV lead to reductions in HIV incidence, thereby helping to curb the epidemic.

Mozambique has made significant progress in ART scale-up. Nevertheless, equity challenges remain, as progress toward achieving HIV goals continues to reflect disparities among different groups based on a variety of social, economic, and demographic characteristics, including age. Analysis conducted by the Health Policy Plus (HP+) project, funded by the U.S. Agency for International Development (USAID) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) found that adolescents are the only age group in which the number of HIV-related deaths has increased over the last decade (Barker et al., 2016). HIV is the leading cause of adolescent deaths in Africa and the second leading cause of death among adolescents globally (UNICEF, 2015a; 2015b). Retaining adolescents in ART is important, not only for their own health, but also to prevent HIV transmission. Without consistent viral suppression, adolescents have a high potential for drug resistance, as well as for transmitting HIV to others, as HIV risk behavior tends to be highest in adolescence (Dahourou et al., 2017).

Adolescents living with HIV consist of two distinct and growing populations: those who acquired HIV vertically (from their mothers), and those who acquired HIV horizontally (i.e., by any other route of transmission). An increasing proportion of children who acquired HIV vertically are surviving into adolescence, due in part to improvements in the timeliness of pediatric diagnosis and ART initiation through prevention of mother-to-child transmission programs (Lowenthal et al., 2014). Adolescence brings increased risks for horizontal transmission as adolescents begin their sexual lives. Pediatric clients who acquired HIV horizontally face different challenges than those who were diagnosed as infants or in early childhood. For example, a pediatric client who acquired HIV vertically may have many years of experience with ART and may have a well-established clinical routine. There is also some evidence from other settings that adolescents who acquired HIV perinatally may be more prone to virologic failure, as time to diagnosis and treatment initiation may be longer among this group than among clients who acquired HIV in adolescence (Judd et al., 2017; Salou et al., 2016). Adolescents who acquired HIV perinatally may have already dealt with the death of family members and may struggle with issues related to intimacy and sexual identity. Pediatric clients diagnosed with HIV early in life also face clinical transitions—changes in their ART dosage and in the type of clinical care they receive. A growing number of pediatric clients living with HIV are "aging out" of pediatric care and transitioning to adult care (Dahourou et al., 2017). Pediatric clients with horizontally acquired HIV may experience different challenges, including those related to beginning treatment and establishing a treatment routine during a time of substantial biological and psychosocial change.

All adolescents living with HIV face an abundance of transitions; adolescence is characterized by an acceleration of physical growth and psychological and behavioral changes. These changes necessitate the provision of enhanced, customized, and supportive clinical care. Navigating adolescence with any chronic disease may be difficult, but to do so with a disease potentially transmissible to sexual partners and children is especially complicated—a challenge that is often compounded by the stigma associated with HIV (Pantelic et al., 2018; Sohn et al., 2017). Further, adolescents require tailored health education messages that address the frequently conflicting and influential cultural messages they receive from the outside world. Without proper education and support, adolescents may lack the knowledge and confidence they need to make informed decisions about their health and safety, decisions that may have lifelong consequences (Sharer and Fullem, 2012).

The Government Response

The Government of Mozambique is committed to epidemic control and is leading the way in strengthening the HIV response. The government has rolled out various epidemic control strategies to better reach those in need. Some of these strategies are specific to adolescents and youth, while others are more general. Strategies focused on retaining HIV-positive individuals in treatment and improving treatment adherence are outlined below.

General strategies to improve progress toward 95-95-95 targets

Test and Start. In 2016, Mozambique began a phased rollout of the World Health Organization's (WHO's) "Test and Start" policy, making all people living with HIV eligible for treatment upon diagnosis.

TLD: A New ART Regimen. In anticipation of new WHO guidance, Mozambique is also preparing for phased rollout of a new first-line ART regimen: tenofovir disoproxil fumarate/lamivudine/dolutegravir (TLD) fixed-dose combination. This regimen has been shown to have high efficacy, durability, and tolerability, with a high resistance barrier and also comes with possible cost savings (PEPFAR, 2017). The change in first-line ART regimen is intended to improve rates of viral suppression and reduce treatment failure among people living with HIV weighing more than 30 kilograms, due to fewer side effects and a lower pill burden. In Mozambique, the use of TLD among pediatric clients weighing more than 30 kilograms is still under discussion.

Viral Load Testing. The Government of Mozambique is expanding HIV viral load testing capabilities to enable providers to better manage clients' care. Viral load monitoring (the use of routine viral load tests to manage clients' care) has been found to be a cost-effective measure to improve life expectancy among people living with HIV (Hyle et al., 2017).

The process for viral load testing in Mozambique is as follows: The first viral load test is ordered six months after initiating ART (three months after for pregnant women). A client's first test serves as the baseline for decision making about their treatment. If the test result shows a viral load below 1,000 copies/milliliter (ml), treatment is deemed to be working well and a follow-up viral load test is scheduled for 12 months later (three months later for pregnant women). A test result of 1,000 copies/ml or above indicates that treatment is not working and/or the client is not adhering well to treatment and a follow-up viral load test is scheduled for three months later. During these three months, the client undergoes additional intensive psychosocial and counseling sessions to improve treatment adherence and assess whether the test results are due to poor adherence. If the second viral load test result is 1,000 copies/ml or above, this may be indicative of therapeutic failure. The healthcare provider submits the case to the district- or provincial-level ART committee for discussion and decision making about whether to move the client to the second-line treatment regimen.

Regional laboratories are responsible for processing viral load tests. Dried blood spot samples for viral load testing are extracted at health facilities and sent (either overland or by air) to the provincial hospital, then onward to the regional laboratory for analysis. Regional laboratories send test results back to health facilities, via the provincial hospital, either through the DISALink system (an electronic lab requisition system available in a small number of health facilities) or through paper files sent overland or by air.

Differentiated Care Models. Mozambique is in the process of rolling out various viral load-informed differentiated care models, including three-month drug distributions (*dispensa trimestral* or *dispensa semestral*) for stable clients (those with viral loads ≥1000 copies/ml) and community adherence and ART groups (in which group members share responsibility for collecting drugs monthly).

Strategies to improve progress toward 95-95-95 targets among youth

Youth "One-Stop Shop" Health Clinics. Mozambique has established a limited number of adolescent-specific HIV services, provided within *Serviços de Amigos dos Adolescentes e Jovens* (Services of Friends of Adolescents and Young People) (SAAJs). SAAJs are one-stop shops where adolescents and youth can obtain general sexual and reproductive health services, including psychosocial support services. Currently, SAAJs are few and generally only in urban centers; however, the government is committed to extending adolescent-friendly services to adolescents and young people ages 10–24 years across the country. Studies have shown adolescent-friendly services to be successful in improving care outcomes. One study found uptake of first viral load testing to be lower among adolescents living with HIV attending conventional primary care, compared to those attending SAAJs (Swannet et al., 2017). Similarly, a cohort study using client medical records in Mozambique and elsewhere found adolescent-friendly services to be associated with reduced attrition among youth, particularly after ART initiation (Lamb et al., 2014).

Study Rationale

To meet 95-95-95 targets, Mozambique must continue to use data to rapidly design, refine, and scale up programming to address the specific barriers faced by adolescents and young adults, building on successes so far achieved. HP+, in collaboration with the *Ministério da Saúde* (Ministry of Health, Mozambique) (MISAU), conducted this study to provide novel and timely data to guide policymakers and program managers in designing and refining adolescent HIV treatment strategies. HP+ also aimed to take stock of progress in rolling out new initiatives (such as viral load testing and SAAJs, discussed above) to guide government partners in their efforts to strengthen Mozambique's HIV response. This study had the following research objectives:

- To catalogue the barriers and facilitating factors affecting retention in care and ART adherence
- To describe any services or innovations that may improve outcomes across the clinical cascade among youth ages 15–24 years
- To document the current status of viral load monitoring among youth ages 15–24 years
- To gather perspectives on a new adolescent/youth HIV care model currently being developed by MISAU

Methodology

This qualitative study used focus group discussions (FGDs) and key informant interviews to elicit information on enablers and barriers affecting clinical retention, viral load testing, and viral suppression among adolescents and young adults ages 15–24 years. Specifically, HP+ conducted 24 FGDs: three with healthcare providers, three with social care providers, six with caregivers, six with male and female adolescents living with HIV (ages 15–19 years), and six with male and female young adults living with HIV (ages 20–24 years). Data were collected in mid-2018.

Location

The study was conducted in three provinces: Sofala, Manica, and Niassa. These provinces were selected in consultation with USAID/Mozambique and MISAU. Selection criteria included the presence of a PEPFAR-funded Clinical and Community HIV/AIDS Services Strengthening (CHASS) project health facility, pediatric and youth client load, and provinces' cultural characteristics.

HP+ calculated each province's progress in reaching 95-95-95 targets:[1]

- Sofala has diagnosed 49 percent of adolescents and young adults (ages 15–24 years) living with HIV (13,880/28,327 estimated to be living with HIV), of whom 76 percent are on ART (10,552/13,880), and 97 percent of those on ART are virally suppressed (10,270/10,552).
- Manica has diagnosed 50 percent of adolescents and young adults living with HIV (12,737/25,679 estimated to be living with HIV), of whom 82 percent are on ART (10,400/12,737), and 88 percent of those on ART are virally suppressed (9,116/10,400).
- Niassa has diagnosed 40 percent of adolescents and young adults living with HIV (4,146/10,261 estimated to be living with HIV), of whom 98 percent are on ART (4,043/4,146), and 75 percent of those on ART are virally suppressed (3,017/4,043).

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[1] Calculations were based on data from the 2015 Demographic and Health Survey (MISAU et al., 2015), the 2017 Census (INE, 2017), PEPFAR program data cited in the 2017 Country Operational Plan (PEPFAR, 2017), and MISAU's 2016 Annual Report (MISAU, 2017). HP+ used Spectrum projections to disaggregate 2017 census data by age at the national and provincial levels. Importantly, these estimates do not reflect changes in Mozambique's HIV epidemic or programmatic efforts since 2015.

Table 2. Estimated Performance against 95-95-95 Targets for Youth Ages 15–24 Years (Calculated Using 2015 Data)

Targets Areas	Sofala		Manica		Niassa	
	Number	Percent	Number	Percent	Number	Percent
Diagnosed	13,880	49%	12,737	50%	4,146	40%
On ART	10,552	76%	10,400	82%	4,043	98%
Virally Suppressed	10,270	97%	9,116	88%	3,017	75%
Estimated number of people living with HIV/HIV prevalence	28,138	6.4%	25,679	6.8%	10,261	3%

Populations

This study included five population groups:

- Healthcare providers, including physicians and nurses, who provide care to children and adolescents living with HIV
- Social care providers, including health facility-based social workers, para-social workers, *activistas* (community-based client case workers), and staff involved in adolescent support groups and other social care activities for children and adolescents living with HIV
- Caregivers of children and adolescents living with HIV and currently on treatment[2]
- Youth ages 15–24 years living with HIV who are aware of their HIV status and currently on ART
- High-level program managers and policy stakeholders at national and provincial levels

Data Collection

Data collection tools

HP+ developed unique topic guides for each population group. Table 3 summarizes areas of inquiry by study population.

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[2] Unless otherwise noted, "caregivers" will be used in this report to refer to caregivers of children and adolescents living with HIV

Table 3. Areas of Inquiry, by Study Population

Area		Adolescents/ Young Adults (Ages 15–24 Years)	Caregivers	Healthcare Providers	Social Care Providers	Policy-makers
Clinical Standards	Protocols for viral load testing, dosing, and regimen changes					X
	Clinic operating procedures			X		
	Process for viral load testing and results return			X		
Retention and Adherence	Barriers to retention	X	X	X	X	X
	Factors that support retention and adherence	X	X			
	Services to support retention and adherence	X	X	X	X	X
Viral Suppression	Knowledge about viral suppression/treatment literacy	X	X	X	X	X
	Viral suppression discussions with clients			X	X	
	Services in support of viral suppression			X		
Viral Load Monitoring	Experience ordering viral load tests			X		
	Viral load test results discussions with clients			X		
	Experience in using viral load test data to make clinical decisions			X		X
	Viral load monitoring: client experiences	X	X			
Dose and Regimen Changes	Experience with dose and regimen changes		X	X		
	Barriers to following ART clinical protocols			X		X
SAAJ Transition	Experience with SAAJ	X	X			
	General views	X	X	X	X	X
	Readiness for transition	X	X	X	X	X
	Avoiding loss to follow-up	X	X	X	X	X
	Package of care					X

Topic guides were developed in English and then translated into Portuguese. HP+ translated key concepts and terms, rather than the entire guides, into local languages (Sena and Ndau for Beira city, Chitewe for Chimoio City, and Yao for Lichinga). All topic guides were pilot tested with study populations in Bagamoyo health facility in Maputo.

Sampling

Sampling occurred in two stages: First, HP+ purposively sampled sites; second, HP+ sampled and recruited individual study participants from study sites using convenience sampling. The goal was to sample one site in each of the study provinces (Sofala, Manica, and Niassa). When sampling facilities, HP+ applied the following selection criteria:

- Facilities must be operating as a "Test and Start" site and must have rolled out viral load testing before October 1, 2017.
- Facilities must be operating a sexual and reproductive health service for adolescents (i.e., an SAAJ clinic).
- At least one facility must be relatively high performing—i.e., having a higher proportion of adolescents on ART, with viral load tests, and retained in care than other eligible facilities.
- At least one facility must be relatively low performing—i.e., having a lower proportion of adolescents on ART, with viral load tests, and retained in care than other eligible facilities.
- Facilities with higher volumes of pediatric and adolescent HIV clients were prioritized.
- Facilities that are extremely hard to access were excluded.
- At least one facility should be offering three-month drug distribution.

Applying these criteria, HP+ selected the following CHASS facilities: Ponta Gêa health facility in the city of Beira (Sofala Province); Nhamaonha health facility in the city of Chimoio (Manica Province); and Lichinga health facility in the city of Lichinga (Niassa Province). Information about these sites (facilities) is presented in Table 4.

Table 4. Study Site Characteristics

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	Female: 165 Male: 63	Female: 130 Male: 131	Female: 55 Male: 15
Ages 20–24 Years	Female: 746 Male: 162	Female: 494 Male: 61	Female: 244 Male: 30
All Ages	9,751	5,370	2,956

Characteristic	Sofala (Ponta Gêa)	Manica (Nhamoanha)	Niassa (Lichinga)
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[1])			
Ages 15–19 Years	Female: 32% Male: 49%	Female: 20% Male: 26%	Female: 55% Male: 53%
Ages 20–24 Years	Female: 36% Male: 27%	Female: 24% Male: 15%	Female: 57% Male: 37%[2]
All Ages	45%	26%	64%

Source: CHASS project data (July–September 2018)

[1] 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 (<1000 copies/ml)

[2] Low counts; interpret with caution

In each site, HP+ aimed to conduct eight FGDs: one with healthcare providers, one with social care providers, two with caregivers, and four with adolescents (see Table 5 for details).

Table 5. Number of Focus Groups, by Population and Location

Group	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., *activistas*)*	1	1	1	3
Caregivers of Children and Adolescents Living with HIV	Caregivers	2	2	2	6
Adolescents and Young Adults Ages 15–24 Years	Females, ages 15–19 years	1	1	1	3
	Females, ages 20–24 years	1	1	1	3
	Males, ages 15–19 years	1	1	1	3
	Males, ages 20–24 years	1	1	1	3
Total Number of Focus Groups	–	**8**	**8**	**8**	**24**

* See Annex A for a full list of provider types

In partnership with USAID/Mozambique, CHASS, and the National HIV/AIDS Program at MISAU, HP+ identified key high-level program managers and policy stakeholders at the national and subnational levels (in study provinces) to participate in key informant interviews.

Recruitment

High-level program managers and policy stakeholders were recruited via email or telephone. A list of key informants at national level was produced in partnership with MISAU. Other key informants were identified by individuals from this first list of participants.

HP+ recruited a convenience sample of youth and caregiver respondents, with the support of the CHASS project, led by FHI 360—specifically, CHASS provincial HIV supervisors. CHASS helped the study team gain access to the selected health facilities, introducing the local research team to key facility personnel. The local research team, in turn, shared details of the study and target populations with facility personnel and requested the support of facility management, who nominated the facilities' HIV focal points as counterparts to the research team for the duration of the study. The HIV focal points coordinated with the research team to identify potential participants based on the inclusion/exclusion criteria described above. Health facility staff—healthcare providers, managers, and social care providers—identified as eligible by HIV focal points were invited to participate in the study by the facility's Clinical Director.

Adolescents and young adults (ages 15–24 years) living with HIV and currently on ART, as well as their caregivers, were recruited into FGDs using the following process: One month before data collection, HIV focal points identified eligible participants based on criteria provided by the research team. Two weeks prior to data collection, HIV focal points contacted these eligible caregivers, adolescents, and young adults to inform them about the study and determine whether they were interested in participating. For underage adolescents, their guardians were also contacted to consent to their participation. Guardians were given study information sheets and consent forms during clinic appointments. One week before data collection, adolescents, young adults, and caregivers who had given their "pre-consent" were contacted again to confirm their participation and to inform them about the date, time, and venue for the FGD. Throughout this mobilization process, the research team did not directly contact eligible participants, but communicated regularly with the HIV focal points of the selected health facilities.

The day and time of each FGD was established in coordination with HIV focal points to ensure that research activities did not disrupt work (in the case of caregivers and healthcare providers) or school (in the case of youth).

Data collection procedures

Once participants arrived at the FGD/interview site, two members of the data collection team (one acting as a witness) jointly sought and documented informed consent/assent from each participant privately, and then collected participants' demographic data. For underage participants (i.e., below the age of 18 years), signed guardian consent forms were collected before initiating the assent process.

All FGDs and interviews were conducted by one of three trained facilitators (two females, one male). FGD facilitators were supported by a trained notetaker. For adolescent FGDs, facilitators and notetakers were of the same sex as FGD participants. FGDs were conducted primarily in Portuguese; however, translation to national languages was done as needed, particularly in FGDs with caregivers. With participants' consent, all FGDs were audio recorded using digital recorders. Following each FGD, the data collection team jointly reviewed notes and summarized findings. Each FGD lasted less than two hours.

All FGDs took place in a private space within a health facility. To enhance FGD participants' comfort, HP+ offered snacks and drinks and reimbursed travel expenses to and from the facility. To compensate participants for their time, HP+ offered each FGD participant 100 *meticals* (US$1.25) of mobile credit. Interviews with high-level program managers and policy stakeholders were conducted at their place of work and no incentives were provided.

Data Handling and Analysis

All FGD recordings and notes were labeled, uploaded onto a password-protected study computer at the end of each day, and sent to the local lead researcher for review. Transcripts of each audio recording were made, revised, and analyzed. Data from FGDs and interviews were analyzed with qualitative analysis software (Nvivo 12), using a standardized codebook with themes that addressed the research questions and subthemes and emergent themes identified during analysis. Two researchers analyzed the data, following five interrelated steps: reading, coding, displaying, reducing, and interpreting (Miles and Huberman, 1994; Tolley et al., 2016).

The initial "structural" codebook was drafted by two researchers, based on the research questions and topic guides. To expedite analysis, one researcher began the analysis process by using the draft codebook to separately code the detailed and structured notes taken during FGDs and interviews. Next, she coded a selection of the full transcripts. Based on this round of coding, she made additional adjustments to the codebook. She then used the finalized codebook to code all the transcripts and notes and drafted code summaries based on the coded text reports.

Next, the code summaries were reviewed by the second researcher and key findings were agreed upon for each research question. Essential concepts and relationships between the different themes and subthemes were identified by the researchers through coding queries using the qualitative analysis software. Lastly, the analysts, together with the wider research team, identified and explained the core meaning of the data and synthesized the findings.

All analysis was conducted in Portuguese. Key quotes were later translated into English.

Research Ethics

This study adheres strictly to U.S. and international ethical guidelines for research, including U.S. Department of Health and Human Services Title 45 CFR, part 46 and the Council for International Organizations of Medical Sciences. HP+ received institutional research board review and approval in Mozambique from the *Comitê Nacional de Bioética para a Sáude* and in the U.S. through Health Media Labs, Inc.

Limitations

Generalizability. Findings may not be generalizable across Mozambique because FGDs were only conducted in three purposively selected urban health facilities in three provinces.

Population limitations. The study did not include youth living with HIV who have dropped out of care, or their caregivers, due to resource constraints and ethical challenges with identifying this population. The sample also included few caregivers of adolescents who acquired HIV horizontally. HP+ was not able to select caregivers based on this criterion, as this would have required an assessment of clients' clinical files. Finally, in the two health facilities that did not have adolescent support groups or a strong SAAJ (Nhamaonha and Lichinga), HP+ had difficulty mobilizing male adolescents ages 15–19 years to participate. This led to smaller FGDs of three or four participants, rather than the expected six to eight participants.

Selection bias. Participants were selected with support from health facilities. Health facility staff may have identified individuals for participation who were known to them and whom they expected to be interested in participating in this study.

Response bias. The purpose of focus groups is to extract common perspectives as well as dissenting ones. However, at times, participants do not offer their views if these are different from the "majority view" of the group. It is possible that this type of response bias occurred in this study.

Translations. Topic guides were in Portuguese and discussions were held in both Portuguese and local languages. Analysis was then conducted in Portuguese and the report was written in English. It is possible that some terms or concepts may have been misinterpreted through this translation process.

Results

In this section the main study findings are presented in relation to five key issues: 1) barriers to retention in care and ART adherence, 2) facilitators of retention in care and ART adherence, 3) support services, 4) viral load monitoring, and 5) adolescent care and transitioning to adult care. Findings are synthesized and presented by topic, rather than by participant group or geographic area. Similarities and differences across study populations are also noted.

Participants

Across the three study facilities, 68 youth (29 adolescents ages 15–19 years and 39 young adults ages 20–24 years), 42 caregivers, 37 social care providers, and 28 healthcare providers participated in a focus group. In addition, HP+ held interviews with 10 key informants from the provincial and national levels. Participant demographics, by location, are provided in Annex A.

Retention in Care and ART Adherence

Although all youth participants were on treatment at the time of study, participants in all youth and caregiver FGDs acknowledged that they (or their children) had, at some point in their lives, temporarily stopped taking their medication. In demographic intake questionnaires, 10 adolescents (33 percent) and four young adults (10 percent) reported sometimes missing doses of their ART medications (see Annex A).

Adolescent girls were least likely to report interrupted treatment (stopping treatment for a period, not just missing doses). Nearly all young adults reported at least one episode of interrupted treatment. The most common reason given for temporarily stopping treatment was no longer feeling ill/feeling healthy enough not to need the medication. Some youth participants noted that treatment interruptions occurred gradually—they missed doses and did not immediately feel ill and, ultimately, stopped taking their medication.

This section discusses barriers to retention and adherence, factors that support retention and adherence, and services to support retention and adherence.

Barriers to retention and adherence

The following barriers to retention and adherence were noted:

- Slow acceptance of HIV status
- Teenage independence and testing of boundaries
- Lack of family support
- Communication and disclosure challenges
- Shame and discrimination
- Fatalism
- Side effects of ART medication

- Changes in ART regimen
- Lack of food
- Culture and religion
- Inaccurate information
- Health service challenges
- Crosscutting issues: Gender and age

Difficulty accepting HIV status. Participants across all FGDs mentioned that some youth living with HIV, especially adolescents, find it hard to accept their HIV-positive status. Difficulty accepting HIV status was associated with challenges with retention in care and, to a small degree, with treatment adherence. Reasons given for difficulty accepting HIV status included not feeling sick and not believing a positive test result.

> *"The way I see it is like this: as they grow up, it is hard for them to accept the reality—that this disease we carry actually exists and that these are things that are happening in our society. That's what makes these young people give up—they think that this thing does not exist, so they also need support from their caregiver, to tell them what is really happening, what is this disease, what they must do, what is the advice from the health facilities."* (Caregiver, Ponta Gêa)

Adolescent girls in two of the three health facilities mentioned that it is difficult to believe that someone their age can be infected with HIV. Young adult females in Beira (Ponta Gêa health facility) noted that some youth take an HIV test without preparing for the possibility of a positive HIV diagnosis. They noted that acceptance takes time and a certain level of maturity. Healthcare workers in all facilities agreed with these perceptions.

Teenage independence and testing of boundaries. Participants in all focus groups, including youth, expressed that teenagers can be rebellious, sloppy, and forgetful with their medication. Caregivers, health and social care providers referenced youth who refused to take their medication. Male and female youth mentioned challenges with dating and being out late. Some participants in each focus group blamed friends for adherence challenges—friends who prevent them from taking their medication on time by keeping them away from home, even when they know their status. Male youth also mentioned alcohol and drug consumption as challenges to adherence, affecting their ability to make sound decisions or to take their medicine on time. Female young adults said that sometimes people are just too lazy to take their pills. Male youth reported that knowing they will have to take ART medication for the rest of their lives makes them feel tired and creates adherence challenges.

Lack of family support. Across all groups, participants mentioned that sometimes youth do not receive the support they need to cope with HIV and adhere to treatment (i.e., to accept that they have HIV and need lifelong treatment, and to consciously make the decision to continue treatment). Youth participants who found out about their positive status after independently seeking a test indicated that young people are afraid to reveal their status to their caregiver and other relatives for fear of being expelled from their home or being judged for having initiated their sexual lives. This fear affected youth who acquired HIV both vertically and horizontally.

Social care providers mentioned that some youth fear their family's reaction to their positive HIV status to the point that they may run away from home.

> *"I think that another issue is discrimination. We have people aged about 16, 17, 18 years who have sex without condom, 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)

Both caregivers and healthcare workers acknowledged that some families do not provide adequate support to adolescents living with HIV, such as accompanying them to pick up their medicine. Caregivers expressed that they are responsible for ensuring that their children stay on treatment, but this responsibility is easier to carry out with children than with adolescents, who are more autonomous.

Communication and disclosure challenges. Caregivers noted that there is a lack of honest communication between parents and children about HIV—that parents do not know how to explain to their children that they will need to take medicine for the rest of their lives. Caregivers find it easier to medicate their children without having to tell them that they are infected with HIV, which becomes more difficult to keep a secret as children age. At times, parents may resort to outright deceit about their children's HIV status. Some caregivers expressed belief that their children are unable to comprehend their HIV status; others described feeling ashamed and resorting to secrecy because they want to protect their children from discrimination.

> *"There are mothers whose child has this disease but do not want to take them to the hospital. Only, when the child gets worse, they run to the hospital and there they are criticized—'Why did you let the child at home for so long and did not bring him to the hospital?' So that too—the feeling of shame, I guess."* (Caregiver, Lichinga)
>
> *"When a relative finds out my son or daughter has this disease, they forbid their children from playing with mine. So, I prefer to hide this disease, not going to the hospital nor picking up the medication."* (Caregiver, Lichinga)

Adolescents and young adults across the FGDs also referred to these communication challenges. In one case, a female young adult (from Ponta Gêa) who had contracted HIV vertically, but whose HIV-positive status had not yet been disclosed to her, decided on her own, at the age of 15, to get tested for HIV. She tested positive but kept her diagnosis a secret, expressing her fear of disclosing the result to her mother. A few years later, she found out that she had contracted HIV vertically and that her mother had not disclosed her status to her, fearing that her daughter would blame her for giving her HIV:

> *"For me ... it was vertical transmission. All that time my mother did not want to tell me, for fear that I would blame her [for the transmission], so I was not disclosed. Activistas used to come to school and do awareness raising about testing. Back then, I was in the second year of escola industrial [vocational training]. I wanted to test out of curiosity, to know how I am. I was chubby back then. I tested out of curiosity, really. That was back in 2012. I was age 15 and thought I had nothing. I was chubby. [The test] accused [was positive] and I did not accept [the test result]. I waited, waited. I got fever that would not stop. So, I wondered, 'Should I tell my mom?'—thinking that she did not know. I wondered how I could tell her that I had done the test and it came out positive.*

> *I feared her reaction. So, in 2016, when I saw I was getting really skinny and had to go back to the hospital, I told her. I started treatment on that very same day."* (Female young adult, Ponta Gêa)

According to caregivers, adolescents, and key informants, youth find it difficult to take their medication because they are not told why they need to take it every day.

> *"... The process of disclosing the serostatus to a child should start at the age of nine, 10 years. We talk about 'bichinho' [tiny worm] pills. Disclosure should be done by the age of 12, 13 years ... The kids are smart, they can get angry, someone will disclose it to them and they can get frustrated. They understand why they are taking pills. Or worse, they can retain wrong ideas that they heard in the street, at school, or a hallway in the health facility."* (Key informant)

These issues affect adolescents who acquired HIV either horizontally or vertically, as most healthcare providers will not disclose a positive HIV test result to anyone below 18 years of age—although anyone age 13 years or above can legally seek and receive the results of an HIV test in Mozambique (Government of Mozambique, 2014). Healthcare providers, in particular, mentioned that they did not feel comfortable disclosing test results to anyone younger than 18 without caregivers being present (see also section on adolescent standard of care).

Both female and male youth explained that they prefer not to discuss their HIV status with their sexual partners and avoid taking medication in front of them, which can lead to missing doses. Girls and women, in particular, feared that their partners would leave them if they revealed their positive HIV status. Participants in different groups mentioned that the lack of communication is so engrained that often both partners may be taking medicine, without the other knowing.

Shame and discrimination. Both female and male youth, regardless of how they acquired HIV, said they felt ashamed to share their positive status with friends and families. Female youth feared that their friends would not keep the information confidential but would share it with the rest of the community, who would then shun them because of their HIV status. Male youth said that, to avoid other people learning their HIV-positive status, youth may avoid treatment altogether, pretending they are healthy. One male young adult gave an example of a breach of confidentiality:

> *"With me, it was a worker from the center—but not a nurse, an attendant. At the moment I was tested she was in the center ... And she was my neighbor ... The information started spreading everywhere. I was finger pointed everywhere I passed. Even at school I was teased. People have fun with the status of other people, as if they were armored and could never get the disease."* (Male young adult, Ponta Gêa)

Caregivers said that they fear that relatives will stop talking to the family or prevent their children from playing with their HIV-positive child, should they find out their status. They worried that neighbors would stop coming to their homes due to fear of becoming infected and that other children would tease and bully their child or talk badly about them to others. Due to these concerns, some caregivers reported stopping taking their child to the hospital.

Informants from all FGDs were unanimous that male youth were more ashamed of taking their medicine outside the home, noting that it is easier for females—a sentiment echoed by caregivers. Participants across FGDs said that males struggle more with feelings of shame and adolescent boys noted that they felt more shame about their status as they got older—a sentiment also expressed by their caregivers.

> *"Male partners—it is difficult for them to accept. But for a woman, it is normal. When she does the test, she reacts, she goes home and talks with her husband about it. But when a man comes here to get tested, he won't talk with his wife about it, he just … takes his pills."* (Social care provider, Nhamaonha)
>
> *"Girls easily accept it, they don't get bothered with shame—most of that [shame] is with the boys."* (Caregiver, Ponta Gêa)
>
> *"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)

However, caregivers noted their belief that adolescent girls fear revealing their status, as it may hamper them in finding a suitor or lead to relationship break-ups. Fear of abandonment by partners was mentioned by both adolescent girls and female young adults.

> *"I talked with my boyfriend and he said he wanted to do the test with me. I ran to do the test on my own [at] Nhacongo Hospital. It turned out positive. I repeated the test in Munhava [health facility]—positive too, so I took it seriously. Then we went together [to the health facility], did the test to him only. He did not have a good look at the result but he saw it was positive … I told him, for example, if I get tested one day and it turns out to be positive, will you continue to be with me? He said, 'Of course not.' That was when he stopped talking to me. He disappeared. I would call him and he would not pick up."* (Female young adult, Ponta Gêa).

Healthcare workers consider that young adults are more prone to feelings of shame than adolescents and are afraid of being seen at the health facility refilling their medication, regardless of how they acquired HIV. Youth echoed this sentiment, saying that feelings of shame get stronger as they get older and become more conscious of community perceptions of HIV.

Fatalism: The sense that life is over or has no meaning after testing positive for HIV. Some adolescents reported that youth may be overtaken by fear and determine that there is little value in taking their medication, especially if it is not making them feel better.

Some male youth referenced others' suicidal thoughts.

> *"Suicidal thoughts contribute to carelessness, because there are many youth who, knowing their status, try to commit suicide. Others think about taking their own life."* (Male adolescent, Ponta Gêa)
>
> *"Others say, 'I have HIV and I want to die because I have HIV. I am dead. My life is over.'"* (Female adolescent, Lichinga)

Some adolescents reported that their families and friends share these fatalistic views, believing that there is no point in taking ART, and thus fail to provide the support adolescents need to stay adherent. All adolescents and young adults, as well as caregivers, mentioned that health facilities and social care providers do provide counseling and psychological support to counteract these feelings.

Side effects of ART medication. The second most commonly mentioned reason for stopping treatment was side effects perceived to be due to ART medication. Effects described by girls included nausea, vomiting, and tiredness. Boys mentioned extreme tiredness, increased hunger, and nausea. Male young adults reported that ART medication affects their ability to carry out heavy duty work. Some adolescents and young adults noted that youth do not have the patience to let their bodies "get used to" the medication. Some mothers explained that they may interrupt their child's treatment if the child is experiencing side effects and is complaining of feeling unwell.

Changes in regimen. Healthcare workers explained that some youth stop taking their medication when they change to second-line treatment, due to the increased number of pills.

Lack of food. All groups mentioned lack of food as a reason for nonadherence, saying that the pills are too strong, that they make people hungry, and that people often do not have enough food to eat.

Culture and religion. Both female and male youth mentioned traditional healers as a reason for some youth not adhering to treatment. According to FGD participants, some youth believe, not that they are ill, but that they have been bewitched, leading them to seek traditional treatment instead of ART. Male youth talked about churches that claim to cure HIV, saying, "as long as you have faith, there will be a cure for it." One adolescent male described his own experience of being taken to a traditional healer:

> *"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)

Health and social care providers also mentioned religion and cultural factors as potential impediments to retention and adherence. They reported that some churches encourage congregants to stop their treatment and have faith in the power of prayer. Healthcare providers also mentioned challenges faced by Muslim clients during periods of fasting, noting that some Muslim clients ask to interrupt their medication during these times.

Inaccurate information. Some caregivers complained that children and adolescents are influenced by inaccurate information from multiple sources, including friends and the Internet. They may read or hear that there is a cure or that they do not need to take their medication as directed. For example, one caregiver shared the following story:

> *"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)

Female young adults explained that some people believe that AIDS is caused by the medication. Caregivers and female young adults mentioned that some people believe they have been cured because their viral load is undetectable. Both caregivers and female young adults (some of whom are mothers themselves) believed (inaccurately) that if a child is without symptoms, they do require treatment any longer, or at least not until their symptoms return. Some caregivers even mentioned interrupting their children's treatment when they saw their symptoms dissipate.

Health service challenges. FGD participants noted that the lack of flexibility within health services hampers retention and adherence. In two groups of adolescent males, participants who had traveled for a long period or changed their place of residence complained of having trouble filling prescriptions in health facilities where they were not registered, because they had not applied for a transfer. Health and social care providers reported that a parent needs to be present for testing clients under 18 years of age—although, as described above, the law allows anyone age 13 years or above to independently seek, and receive the results of, HIV testing. Further, health facility staff remarked that youth who test alone are unlikely to come back with a parent to get prescriptions and treatment recommendations.

Key informants also reported that HIV clients commonly seek care from multiple healthcare providers, rather than sticking with one provider throughout their treatment. This practice hinders the establishment of relationships of trust and confidence between providers and clients, which takes time. Clients' tendency to seek care from multiple providers was cited as a barrier to both retention and adherence. Youth mentioned that lack of trust is a barrier to retention. Healthcare providers reported that knowing their clients and having their confidence enables them to provide better care and quickly identify treatment challenges.

Youth also mentioned difficulties related to trusting the health system. Some participants said that some people believe that the health system is profiting by telling people that they are ill and giving them medicine.

> *"Test and Start is causing many people to abandon treatment because people's [status is] not [properly] disclosed to [them] … they even tell their [case worker/social care provider], 'You have a business here of opening files and saying the person is on ART. You are after money. We get no benefit from [ART], You are lying to us.' … The [client] refuses to be visited by the [case worker/social care provider]. If [the case worker/provider] brings them medicine and offers help, they may even hold a machete or stick and say, 'Leave, leave.'"* (Social care provider, Nhamaonha)

Crosscutting issues: Gender and age. Overall, FGD participants reported that male youth find it harder to get tested and disclose their status and give up on treatment more easily than female youth do. Caregivers noted that girls are more burdened with chores than boys are. As a result, when it is time for girls to take their medication, they may feel tired and skip a dose.

Most FGD participants felt that adherence challenges lessen with age—older youth can pick up their mediation alone, without disclosing their status, and are better able to understand the importance of treatment. However, a few adolescent girls felt that adherence becomes harder as one ages and takes on increased care responsibilities, such as funding their own transport to the health facility.

Facilitators of retention and adherence

Participants mentioned several factors as conducive to retention and adherence:

- Family support

- Peer and community support
- Disclosure
- Fear of becoming ill
- Being treated well by providers
- Adequate household-level financial resources
- Being in treatment since childhood

Family support. Family support was the principal enabler mentioned in all FGDs. Youth respondents and caregivers considered that family acceptance of their HIV status encourages youth to take their medication as prescribed and helps them move past the embarrassment and shame of going to the hospital to pick up their medication. Participants in all focus groups noted that encouragement from family members to continue with treatment was a major incentive to attend appointments and pick up medication on schedule.

> *"… First of all, the family. 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 also helped adolescents and youth reengage in treatment after interruptions. One male young adult noted:

> *"I returned, 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 Gea)

Peer and community support. Adolescents were vocal about their need for peer and community support. They mentioned that seeing people their age going to appointments encouraged them to continue going as well.

> *"This thing of awareness raising (palestras[3]) 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, counselled 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)

Disclosure. Disclosure of HIV-positive status was mentioned by adolescents, young adults, caregivers, and health and social care providers in all FGDs as a key facilitating factor for retention and adherence. Two types of disclosure were discussed: first, caregivers disclosing children's HIV-positive status to them; second, adolescents and young adults disclosing their

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[3] *Palestras* are debate sessions in which a topic is presented by a social or healthcare provider and discussed with a group, in this case adolescents and young adults.

HIV-positive status to family and friends (if diagnosed independently). Adolescent girls, caregivers, and healthcare providers all mentioned that earlier disclosure of children's positive HIV status (at age 11 or 12 years) is preferred and avoids inadvertent disclosure or miscommunication in the late teenage years.

> *"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)

However, some caregivers and young adults expressed a preference for disclosure in late adolescence, when adolescents can fully understand the consequences of nonadherence.

With respect to the second type of disclosure, both adolescents and young adults reported that they resist disclosing their status to family and friends. Yet, they agreed that disclosure does improve adherence.

Fear of becoming ill. Adolescents, young adults, and healthcare workers alike mentioned that seeing other people become sick in their families motivated them to seek help and demonstrated the importance of their treatment.

> *"The truth is, what really made me return to treatment was that I had a brother who was also on treatment. All of a sudden, he decided to quit [treatment] and a while after that he started not feeling well. When he returned to treatment, it was already too late; he ended up dying. This has served as an example for me ever since. I realized that tomorrow it could be me and I decided to return to treatment."* (Male young adult, Ponta Gêa)

Pregnant adolescents and young women, or those who had recently miscarried, were most likely to fear becoming ill. This fear led them to take ART medication as prescribed and avoid engaging in risky behavior to increase their chances of carrying healthy children to full term. Further, a sense of feeling better while ART adherent encouraged both male and female youth to attend their clinical consultations and continue treatment—particularly if they had abandoned treatment and relapsed in the past.

Being treated well by providers. Adolescents, young adults, and caregivers unanimously expressed the view that being treated well at the health facility encourages youth to continue returning to the facility for care. Caregivers and national-level key informants opined that establishing a close relationship with healthcare providers and facilities improves retention and adherence among adolescents. Caregivers and young adults noted that they are more likely to trust healthcare providers if they feel assured of the confidentiality of their HIV status and treatment. Healthcare providers in Namaonha and Lichinga noted that children in school uniforms do not need to wait in line at the health facility—a practice used to improve retention among children and adolescents.

Crosscutting issues: Gender and age. Length of time on treatment, older age, greater educational attainment, and female sex were cited, not as facilitating factors, but as factors positively associated with retention and adherence. According to healthcare providers, adolescents who have been in treatment since childhood are easier to retain. Healthcare providers also noted that older adolescents and young adults, and those with more education (typically urban dwellers), are easier to retain due to heightened knowledge and increased personal motivation to stay healthy. However, caregivers described finding it easier to "control" the treatment of their younger children, as adolescents are more likely to experiment with their treatment and/or forget to take their ART medication. Social care providers reported that female clients are "easier" because they pay better attention to instructions and are concerned about having healthy (HIV-negative) babies.

Services to support retention, adherence, and viral suppression

Services received. Youth were asked about services they receive that support them to stay on treatment. The most commonly cited services were counseling, client tracing (*busca activa*), appointment reminders, and reminders to pick up medication (*lembretes*). Youth specifically noted the importance of being counseled by health and social care providers on the advantages of ART; the importance of taking medicine as prescribed, despite a lack of food; the possibility of having HIV-negative children; and how to lead a healthy life as an HIV-positive individual. Some youth who reported treatment interruptions noted that counseling provided by health and social care providers was the impetus for their return to treatment.

> *"A great deal of [the reason 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)

Less commonly mentioned services, which varied from one health facility to another, were nutritional support (food support, culinary demonstrations, and awareness raising about how to eat well on ART), adolescent support groups (Ponta Gêa only), and community adherence support groups (*grupos de apoio e adesão comunitária*). Only Ponta Gêa currently provides food for adolescent clients, in the form of soy. However, adolescent clients and caregivers from Nhamaonha and Cidade de Lichinga health facilities recalled having received food support previously and emphasized that food support had helped them adhere to ART. Adolescents from Ponta Gêa praised the adolescent support group at their SAAJ, saying that it helps them stay on treatment. Participants in Lichinga and Nhamaonha also mentioned the availability of three-month drug distributions for adolescents with good adherence and low viral load.

Additional services needed. FGD participants identified a variety of missing or inadequate services: nutritional support (food and training on how to prepare it), youth groups, educational initiatives and sensitization campaigns, family counseling, and novel ART distribution modalities such as community dispensing. All participant groups noted the importance of peer support groups in improving retention and adherence. Caregivers and male young adults suggested that these groups could be school-based and open to all youth (not only HIV-positive youth). Social care providers suggested that these groups could teach adolescents a trade or skill, while caregivers proposed the creation of savings groups to help youth generate income/savings and, at the same time, provide a supportive community of youth living with HIV.

Caregivers and social care providers mentioned that adolescents need more information about HIV. Youth noted that they learn from others and suggested that people who had suffered health consequences from treatment interruptions should explain these consequences to people who refuse or discontinue treatment. Social care providers and male youth suggested that community-based sensitization campaigns need to be intensified to counter widespread ignorance; they specifically mentioned the power of radio. Social care providers and male youth said that families should be counseled to enable them to provide better support to their youth. Adolescents in Ponta Gêa noted that counseling by peers living with HIV, who have gone through the same experience, was also a trusted and effective medium.

Youth, their caregivers, and social care providers favored the possibility of receiving medication in their communities, rather than at health facilities, saying that youth and their caregivers do not have time to go to the clinic during working hours. Healthcare providers noted the possibility of offering "night clinics" to support people who cannot, or do not want to, attend the clinic during the day due to conflicts with work or school, or fear of being seen collecting medication. Male adolescents and young adults also mentioned a need for a more integrated healthcare/pharmacy system that allows them to pick up their medication from any health unit.

Viral Load Monitoring

Provider experiences

Ordering viral load tests. Healthcare providers said that they routinely order viral load tests—mainly for new clients—but described facing several challenges related to viral load testing. They explained that they often lack the necessary materials to order the tests (test requisition forms and laboratory materials such as tubes and syringes). They also described difficulty coordinating clinical appointment dates and laboratory schedules for the blood draw.

> *"For a patient who comes on a monthly basis, I try to line up the scheduled medical appointments with the pharmacy dates. When I request laboratory analysis, they are often scheduled one day for CD4, hemogram, another day for viral load … The other day, I requested a viral load for a patient; the laboratory scheduled his turn for next week … I think we can coordinate patient flow better, so he does not have to miss school or work four, five times a month. It is very difficult."* (Healthcare provider and key informant)

The laboratory must schedule a date for the blood draw that allows enough time for the test results to be processed before the client's next appointment. However, this does not always occur and sometimes clients are required to make an additional visit to the health facility to collect their results. No client-level barriers to viral load testing were cited by providers, clients, or caregivers.

Viral load results return. All three heath facilities had similar protocols for viral load test results return. Each has a small laboratory where blood and other samples, including dried blood spot, are collected. Facility laboratories send dried blood spot samples to a reference laboratory (the provincial reference unit, often located in the provincial hospital) for processing, receiving viral load test results in return. A laboratory technician writes the results in the laboratory protocol book and hands the book to reception staff, who enter results into the facility's electronic database before relaying them to the appropriate clinical service (e.g., *consulta pré-natal* (CPN) [prenatal services]; *consulta de criança em risco* (CCR) [clinical services for at-risk children]; *consulta da criança sadia* (CCS) [well-child clinic]; *consulta de TARV geral* [general ART clinic]), after which the respective clinical case manager inserts the results into each client's clinical file. Technically, clients cannot obtain their test results directly from the laboratory. However, in practice, healthcare providers agreed that, in places (such as the *consulta de TARV geral)* where there is no one-stop shop, clients can obtain viral load test results directly from the health facility and bring the results to their next medical appointment to show to the clinician. Although FGD participants who mentioned having obtained their own test results did not specify where at the health facility they went to do so, they would have received these results at the facility's laboratory or at reception. Adolescents confirmed this description. Adolescent girls in Ponta Gêa and Nhamaonha health facilities said that they (or their caregivers) picked up their viral load test results from the facility's laboratory and gave them to their healthcare provider at their next scheduled appointment.

Healthcare providers described frustrations with laboratory delays in processing blood samples and issuing test results. At the time of study, according to FGD participants, it was taking longer than 30 days to receive viral load test results in Nhamaonha and Lichinga health facilities. Although, delays in Nhamaonha will be reduced shortly due to the inauguration of an onsite regional laboratory. In Ponta Gêa, delays were reduced in 2018 by doing the viral load testing in house (the health facility is co-located with a regional laboratory). Providers and key informants both noted that delays were caused by laboratory machine breakdowns. Key informants also perceived that delays were caused by poor communication between laboratories and health facilities regarding problems with blood samples or requisitions, as well as by poor quality blood samples. The introduction of the DISAlink system was mentioned by providers in Nhamaonha and Lichinga as a key improvement that has decreased delays in viral load results return (Healthcare providers at Ponta Gêa obtain their results directly from the onsite laboratory).

All healthcare providers stated that they talk about viral load testing with their clients, explaining that a test is done after six months of treatment to show whether the medication is working, and describing what a high or low result means. The age at which viral load test results are discussed directly with the client varies. Healthcare providers in Ponta Gêa noted that, for clients under 18 years of age, test results are discussed with a caregiver rather than with the client:

> *"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)

In Lichinga, social care providers said they prefer to engage the caregiver for clients up to 19 or 20 years of age, depending on their perception of the client's maturity.

Providers reported that pediatric and adolescent clients are engaged in discussions about the importance of adhering to treatment and coming to consultations to achieve and maintain a low viral load. Social care providers across health facilities reported using non-technical language when communicating with clients to improve their understanding.

> *"We use a language that is easily understood by the patient—accessible, informing that when the person has a high viral load the possibility of getting ill is higher, but if you take your medicine well the virus tends to decrease, and the person continues to live normally … the possibility of passing the disease to a child, or even sexually, is reduced."* (Social care provider, Nhamaonha)

Using viral load test data to make clinical decisions. All healthcare providers expressed familiarity with the viral load test interpretation protocol and noted no difficulties in interpreting test results. All healthcare providers and most social care providers (from two of the three health facilities) were able to state that a result below 1,000 copies/ml indicates a low viral load, while a result equal to or above 1,000 copies/ml indicates a high viral load.

All healthcare providers were able to name ART clinical protocols. However, all provincial-level key informants noted that the use of viral load test results to monitor ART remains a challenge, as clinicians are still getting used to requesting the follow-up tests (three months after the first test for clients with a high viral load; 12 months after for clients with a low viral load) necessary for clinical decision making.[4] Healthcare providers reported that they avoid changing clients to the second-line regimen except in clear cases of therapeutic failure, due to adherence concerns (the second-line regimen requires that clients take more pills more often). Healthcare providers stated that provincial ART committees are helpful in discussing suspected cases of treatment failure.

Stock challenges were not identified as a challenge by any participant group, especially for the first-line ART regimen. As stated by one male young adult:

> *"Another thing that helps is the availability of medication at the health facility. Nowadays, you may not have food, money, but there is always medication at the hospital. At times there may be shortage of medication for other diseases like malaria, but antiretroviral is full. It is difficult, if not rare, to come to the hospital and be told that there is no medication."* (Male young adult, Ponta Gêa)

Client experiences

Adolescents and young adult FGD participants demonstrated different levels of understanding about viral load testing. When asked if they knew what a viral load test was, some adolescents and young adult participants responded affirmatively. However, when asked to explain viral load testing, some described CD4 testing:

> *Researcher: "Can anyone explain to me what a viral load test is?"*
>
> *Participant: "It is a CD4 control, to see if it is low, stable or high."* (Male adolescent, Ponta Gêa)

Some adolescent and young adult participants realized that they knew about viral load testing only after the FGD facilitator explained it to them, while others did not know about the test—

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[4] It is not advisable for providers to make decisions regarding a client's treatment (whether to move to the second-line regimen) based on a single high viral load test result, as it is difficult, in the absence of genotyping, to accurately assess whether the result is due to poor adherence or to therapeutic failure. Making this determination is particularly difficult for patients who have been on ART for several years.

even after listening to the explanation. All these different levels of understanding were prominent, even among participants of the same FGD, highlighting variations in viral load testing experiences, even among clients attending the same health facility. Looking across the different focus groups, adolescents and young adults in Ponta Gêa were most familiar with viral load testing. In contrast, in Lichinga, few youth were aware of viral load testing or knew whether they had received a viral load test. Young adults—both male and female—were more familiar with the meaning of viral load testing than adolescents. Across the 12 FGDs conducted with youth, male participants were better able to explain a viral load test than female participants.

Youth familiar with viral load testing (participants from nine of the 12 youth FGDs) were asked if they had ever had a viral load test. While all reported having blood work done as part of their treatment, not all knew whether they had received a viral load test. Adolescents who had received a viral load test linked providers' ordering of the test with a clinical concern (e.g., weight loss, persistent cough, poor adherence to ART, or pregnancy).

Adolescents received viral load test results either with or through their caregiver, while young adults received their results directly. Female adolescents appeared more likely to receive their results through their caregiver, while male adolescents appeared more likely to receive their results alongside their caregiver. Rather than sharing the actual viral load count, providers shared an overall assessment: either that their viral load was "good" and ART was working well—with congratulations—or, conversely, that their viral load was "bad" and ART was not having the expected effect, adding that this outcome was usually associated with poor adherence. Only one male young adult from Nhamaonha stated that his healthcare provider showed him the test result numbers:

> *"The doctor informed me of the result. He said it was good and that I had little virus in my blood. Yes!"* (Male young adult, Lichinga)
>
> *"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)

The adolescents and young adults who mentioned having had a viral load test (participants of eight FGDs) were asked if they understood what their viral load test results meant. Most claimed to understand the results (participants of seven FGDs); however, in one FGD (adolescent females, Lichinga) a few participants claimed not to know or understand their test results. These differences appeared to be linked to how results were delivered. Adolescents who received their test results in person from the healthcare provider were more likely to say that they understood their results and the implications for their treatment. In turn, those who received the test results from someone other than the healthcare provider (i.e., their caregiver) appeared more likely to say that they were not informed of their test result. One adolescent female from Lichinga, whose viral load test results were shared directly with her father, said she was "not explained anything about the test result … I was only told I was getting better."

Few of the adolescent and young adult FGD participants who had ever had a viral load test reported changes in their dose and/or regimen following a viral load test. Such changes were only mentioned by a few adolescent FGD participants from the Ponta Gêa and Nhamaonha health facilities. Other participants who claimed to have experienced a change in their dose and/or regimen said that this change was precipitated by side effects of the medication or poor treatment results, not confirmed by a viral load test.

Youth—even participants in the same FGD—experienced different wait times for receiving their viral load test results. Clients from Ponta Gêa reported having to wait two to four weeks for their test results, clients from Lichinga reported waiting between three weeks and two months, and clients from Nhamaonha reported wait times of one to two months. It is difficult to ascertain the accuracy of participants' recollections, given the confusion between viral load and CD4 testing observed in the focus groups and the fact that some participants' results were given to caregivers, rather than directly to the youth themselves.

Some adolescents and young adults stated that they had to have their blood drawn more than once to produce one valid viral load test result. For example, an adolescent female from Lichinga reported having to do the blood test three times, and two female young adults from Ponta Gêa reported having to do the blood test twice. Youth were unable to explain what caused this repetition. While these statements need to be interpreted with caution, given that adolescent and young adult FGD participants at times appeared to confuse CD4 with viral load, it is important to note that some healthcare providers also reported that they sometimes have to request that clients repeat the viral load test (i.e., draw a second blood sample) because of delays in receiving test results from the original blood sample.

Adolescent Care and Transition

Adolescent standard of care

The standard of care for adolescents and young adults was similar in the three health facilities. If an adolescent or young adult request an HIV test, the test will be performed at the counseling and testing clinic (*unidade de aconselhamento e testagem em saúde*). If the healthcare provider requests the test, it is done at the provider-initiated testing and counseling clinic (*aconselhamento e testagem iniciado pelo provedor*). The HIV test result is usually available in half an hour. The testing process is followed by counseling, which takes an additional 30 minutes. If the result is negative, it is disclosed to the client. If the result is positive, it may or may not be disclosed to the client, depending on their age and sexual life. Pregnant adolescent girls receive their test result directly at the time of testing. Minors with a history of sexually transmitted infections, or who have had an abortion, may also be disclosed to at the time of testing. For other adolescents, healthcare providers across the three facilities reported different practices regarding direct disclosure of (positive) HIV test results. Providers at Lichinga said results may be shared directly with clients ages 15 years and above, those from Nhamaonha reported the age of direct disclosure to be between 15 and 17 years, and providers from Ponta Gêa said that they may disclose results directly to clients ages 15 to 16 years, particularly if the client is already sexually active. However, in practice, youth under 18 years of age are often asked to return with a caregiver to receive their (positive) test result. Only one social care provider (Lichinga) mentioned that a minor may be disclosed to in the absence of their caregiver by child and maternal health nurses.

> *Participant: "If a 15-year-old boy tests positive, at some point we advise him to come back with his caregiver. We don't disclose the (test) result at that moment, so there is no shock. We invite him to return with the caregiver, so we talk with the caregiver, prepare the caregiver to do the disclosure, so that there is no shock in the disclosure of the result. …"*
>
> *Researcher: "At the age of 18 years, do you still ask to return with the caregiver?"*

> *Participant: "At the age of 18, no, we do the disclosure [directly]."* (Healthcare provider, Nhamaonha)

Often, requiring a caregiver to be present when sharing test results with adolescents leads to delays in treatment initiation. A healthcare provider who works at a SAAJ expressed concern about this requirement:

> *"We are having trouble with testing this group, because sometimes we do not find the [maternal and child health] nurse to test those younger than 18 years. There is no one close by to do the disclosure of the serostatus, so this young person must be accompanied by a relative in order to be disclosed to. Now, in secondary schools, children take the initiative to find out about their serostatus. We do not know what behavior they've had. But, if [the adolescent] comes to the health facility, it is not possible to test him, he must come with his father. The child wants to do the test, but the father has no time [to come to the facility], or at times the father creates barriers at home. The child may not return [to the health facility] and will be worried, wanting to know their serostatus. It is complicated."* (Healthcare provider, Lichinga)

Once a positive test result has been shared with the client, they are referred to psychosocial support for counseling and to start ART. ART consultations take place at the general care and treatment clinic (*consulta de TARV geral*) or at the SAAJ, if the facility has a functioning SAAJ. In most cases, SAAJs are open to clients ages 10–24 years. At the *consulta de TARV geral,* clients are prescribed ART, which they retrieve at the health facility's pharmacy the same day, and doctors request laboratory tests to monitor treatment outcomes (tests that may occur on a different day). All three health facilities use CD4 and viral load tests, as well as other laboratory tests. After starting ART, clients have monthly medical appointments, at which they receive prescriptions for ART. They also continue with psychosocial support services, although service standards may differ across facilities.

Some health facilities, including the three selected for this study, may allow three-month drug distributions for adolescent and adult clients with good adherence and undetectable viral load. Adults who are virally suppressed can access three-month drug distribution at quarterly clinic visits. However, adolescents (until the age of 18 years) on three-month drug distribution visit the clinic monthly so providers can monitor their adherence.

Pregnant adolescents and young adults are referred to prenatal services (CPN) for their HIV care, rather than to the SAAJ, even if they meet the SAAJ's age eligibility criteria. They continue receiving their HIV care at the CPN until they have given birth. Ponta Gêa health facility is an exception; at Ponta Gêa, girls in their first pregnancy receive HIV care at the SAAJ and are moved to the CPN beginning with their second pregnancy—not returning to the SAAJ, regardless of their age eligibility.

One positive aspect of the CPN is that it is a one-stop shop (*paragem única*); HIV-positive expectant mothers can retrieve their medication and have their lab samples collected in the same place (as they would at the SAAJ). After giving birth, HIV-positive mothers are referred to the *consulta de TARV geral* to continue their HIV care—again, regardless of whether they are eligible for the SAAJ based on their age. Newborn children of HIV-positive mothers are referred to the CCR if they test positive for HIV, or the well-child clinic (CCS) if they test negative for HIV and do not show other clinical symptoms of HIV infection. HIV-positive fathers of newborn children may continue receiving treatment at the SAAJ if their age allows, regardless of their fatherhood status.

Experience with and Perspectives on SAAJs

The presence of a SAAJ was a selection criterion for health facilities in this study; however, HP+ found that SAAJs functioned quite differently across the three study sites. Of the three facilities, Ponta Gêa had the most active SAAJ, in comparison with Nhamaonha, which offers integrated SAAJ services (*SAAJ integrado),* and Lichinga, which inaugurated its SAAJ around the time of data collection. Therefore, it is not surprising that most experiences with SAAJs came from FGDs held in Ponta Gêa. Only 14 participants—three adolescents and 11 young adults—across the study facilities reported routinely receiving their HIV treatment at a SAAJ.

Participants in the adolescent, young adult, and caregiver FGDs in Ponta Gêa reported positive experiences with the SAAJ. Adolescents, young adults, and caregivers from Lichinga and Nhamaonha, on the other hand, had little knowledge of and very limited experience with SAAJs. However, following the explanation provided by the data collector, FGD participants at those facilities stated that the SAAJ would be a good service for adolescents and young adults on ART.

Participants in all FGDs commonly felt that transitioning adolescents and young adults on ART to the SAAJ would strengthen treatment retention and adherence. Advantages of SAAJs cited by adolescents and young adults in all three health facilities included shorter waiting times, the availability of other (non-HIV) services in one place, a friendly environment, and the opportunity to share problems and learn from peers and providers.

> *"Here, young people feel more open, because the others around here are of the same age. Whereas there [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)

Key informants also suggested that SAAJs may improve provider/client relationships, especially if SAAJ staff are trained/better skilled in working with adolescents than providers in other parts of the health facility. The result of such training and skill is well expressed by a caregiver from Nhamaonha:

> *"The doctor plays with him, 'What is it that you have?' Like these technicians here, 'Ah, my friend, what did you eat today? What did you do at home? Did you go to school? Why didn't you?' With all this playing, the child begins to open up … From then on, when the date is near the child says, 'Mommy, aren't we going? I want to see my friend,' because he knows that when he comes here it is playful."* (Caregiver, Nhamaonha)

A few concerns about SAAJs were cited, mainly related to staff capacity—both the number of facility staff and their skills. Healthcare providers and key informants stressed that, for SAAJs to be effective, they need to be adequately staffed and equipped.

> *"The policy of moving adolescent patients to the SAAJ is welcome, but one must also look at the current conditions of the SAAJ. Look at our room—it is not ready to be used as a SAAJ. There isn't even a door to separate the waiting room from the consultation room. Anyone can hear. There is no privacy—one must talk in a low voice. I don't work*

> *here only. I must also do medical appointments in other clinics."* (Healthcare provider, Lichinga)

One national-level key informant expressed concern that, given high HIV incidence among adolescents, transitioning all adolescents to SAAJs for ART will considerably increase demand for SAAJ services. If the spike in demand is not met with an adequate infusion of resources, SAAJs will likely end up with long queues and poor service quality.

Transition

Respondents expressed different opinions about SAAJ eligibility requirements, including the age of transition into the SAAJ. Key informants, health and social care providers, and adolescents (males more than females) expressed concerns about children receiving HIV treatment through the SAAJ at 10 years of age, when they are not likely to have been fully disclosed to, have limited knowledge about their treatment, and, according to adolescents, are often shy and may have difficulty talking to healthcare providers.

> *"These children—age 10—do not yet have the experience of going alone to these places [health facilities]. At that age, it is better to go with the caregiver—alone, no. Also, this child does not yet know anything; things can be said that the child does not understand, or the child can talk about the disease carelessly. A 10-year-old should be accompanied."* (Male adolescent, Lichinga)

Participants were in favor of an age of entry into the SAAJ of 13–15 years. National-level key informants said they did not necessarily think that children under 13 years of age were incapable of taking responsibility for their treatment, but that children are covered in pediatric care (*TARV pediátrico)* until 15 years of age. Only community liaison social care providers from Lichinga and some caregivers from Nhamaonha thought that children should transition to the SAAJ at 10 years of age.

Avoiding loss to follow-up during transition is a key concern. Other than age, participants from all FGDs agreed on several markers of "transition readiness," namely that the child:

- Has been fully disclosed to
- Is capable of remembering appointment dates, attending the health facility, and picking up prescriptions on their own (i.e., without a caregiver)
- Assents to moving from their current clinic to the SAAJ

Young adults, caregivers, healthcare providers, and key informants agreed that counseling and preparation are key for successful transition.

> *"It is important to start preparing them, open up, tell them that, 'When you reach the age of 24 years, you will move to another ART service.' They grow up with that in mind, saying, 'When I become 24, I will leave for another place.' They grow up like that. Now, if you don't have this conversation when they are 10, 11, 12, and only talk about this when they are 22, 23, it is a bit difficult."* (Social care provider, Nhamaonha)

National-level key informants stressed that preparing for transition to the SAAJ should be a gradual process and may continue until adolescents reach the age of 15 years (when pediatric care [*TARV pediátrico*] ends) and beyond—continuing for some time while a client is being seen at the SAAJ. FGD participants expressed that "exit counseling" should start three to four years before the designated age of transition. Social care providers opined that transition support should include accompanied visits to the new clinical service and, if needed, maintenance of the clinical relationship with the former healthcare provider until the client (and their caregiver) has embraced the new clinic. Also, key informants recommended that transition not be compulsory; instead, a child should only be transitioned when they have both been assessed as ready for transition *and* want to move to the SAAJ. If the child (and their caregiver) are happy at the general care and treatment or pediatric service, they should not be required to move to the SAAJ. Healthcare providers at Ponta Gêa noted that, for adolescents who started ART as children, transition to the SAAJ might be their second or third transition since starting treatment—and may be unwelcome.

Caregivers in all locations mentioned that they would like to stay involved in their adolescents' care and would not want to be cut off because adolescents are now being seen in the SAAJ.

> *"I don't think it is a good idea to take a child aged 10, 11 years alone to this SAAJ. At that age, we mothers must take serious responsibility for our child's treatment, because at that age the child doesn't even understand the illness they have."* (Caregiver, Ponta Gea)

Health and social care providers and key informants agreed that caregiver involvement, even after transition to adolescent care, is vital to ensure retention in care and treatment adherence. These groups suggested that adolescents should be gradually empowered to attend the SAAJ alone by the age of 15 years and that, even at that age, caregivers should continue to follow up on their children's care at home or at the health facility. Key informants noted that caregivers need to be reassured that they are welcome to come to the health facility and talk to healthcare providers about their children's care, even after children are attending the SAAJ on their own.

Most participants, across FGD groups, agreed that 24 years was an appropriate age at which to transition young adults back to general care and treatment services. Participants opined that 24-year-olds are "mature enough" to transition to adult services (*consulta de TARV geral*) without abandoning their treatment during the transition and can understand the importance of creating room in the SAAJ for new adolescents. However, some young adults from the Ponta Gêa health facility—a facility with a functional SAAJ—did not feel that transition at 24 years of age was appropriate and suggested postponing transition until the age of 30–35 years. These youth expressed hesitation and fear about moving back to general care and treatment services, where queues are long and services are less friendly.

> *"I think [the transition] can be a bit difficult, due to habits. We are already used to the SAAJ. At the SAAJ, we have this follow-up. There [general care and treatment], we won't feel at ease, starting with the nurses that receive you. If you are not patient, the normal thing to happen is that you are put aside. While, at the SAAJ, you receive all [services] in one single place."* (Female adolescent, Ponta Gêa)
>
> *"… We are used to there, the SAAJ. If we must leave there, some might give up [the ART], because they are used to there [the SAAJ]. You can go there anytime, while the adult care has another environment. … You ask yourself, 'Where am I going? I was used to my home (SAAJ).' … When you get there [adult care], it feels like a show, some peek at you, you peek too, that neighbor of mine is over there, the person might want to*

> *be transferred to another health facility, further away, where she is not known … So there will be people who will ask to be transferred to another health facility, and one of them will be me."* (Female young adult, Ponta Gêa)

There is a lack of clarity about where pregnant youth and young mothers should be seen. Key informants asserted that SAAJs should provide services to all female adolescents and young adults, regardless of whether they are pregnant or already mothers. Informants argued that this would increase positive prevention support and reinforce retention and adherence to ART.

Package of services

Key informants and healthcare providers explained that the SAAJ should be a one-stop shop (*paragem única*) for medical appointments, pharmacy pick-ups, and laboratory tests, including peer support groups (*grupos de adesão*), psychosocial support services, family planning services, and other sexual and reproductive health services. Key informants mentioned that peer support groups could be strengthened to work like community adherence support groups (*grupos de apoio e adesão comunitária*), in which group members pick up medication for one another in turns. Key informants unanimously noted the importance of counseling/psychosocial support services, explaining that, ideally, a psychologist (or other provider able to offer similar support services) should be available in every SAAJ. Informants also discussed the possibility of extending SAAJ hours to 1700 or 1730 (Currently, the hours are 0730–1530), or adding a Saturday clinic, to improve access to health and psychosocial support services. Overall, informants noted that the SAAJ model should allow for differentiated care, adapted to different stages of adolescence. They indicated that a fixed service approach may be a barrier to retention.

Discussion

Globally, approximately four million youth ages 15–24 years are living with HIV (UNAIDS, 2018b). Routine program and published data on treatment outcomes among adolescents and youth on ART show worse adherence, retention, and survival in these groups compared with older adults (e.g., Brown et al., 2018; Evans et al., 2013). Improving clinical outcomes among youth as they begin their sexual lives, and before they have children, is central to achieving epidemic control.

The situation in Mozambique is particularly concerning, as there is no sign of decreasing HIV incidence among youth and rates of clinical retention are particularly low, especially among adolescents (PEPFAR, 2018). The Government of Mozambique is committed to improving clinical outcomes among this population. Results are discussed in relation to the three objectives of this study:

- To catalogue the barriers and facilitating factors affecting retention in care and ART adherence
- To describe any services or innovations that may improve outcomes across the clinical cascade among youth ages 15–24 years
- To document the current status of viral load monitoring among youth ages 15–24 years
- To gather perspectives on a new adolescent/youth HIV care model under development by MISAU

Addressing the Clinical Cascade

This study assessed barriers and enablers affecting retention and adherence among youth, as well as services to support successful treatment outcomes among youth.

Barriers to retention and adherence

Barriers cited by respondents can be grouped into five categories:

1. Those related to stigma and discrimination (difficulty accepting HIV status, shame, privacy concerns, and lack of communication)
2. Lack of family support
3. Medication issues (side effects of medicine, changes in regimen, religious practices)
4. Inaccurate information
5. Health system barriers

Stigma and discrimination. The negative impacts of stigma and discrimination on all stages of the clinical cascade have been well documented (Ammon et al., 2018; Croomea et al., 2017; Ankrah et al., 2015), including a qualitative study in Mozambique (da Silva et al., 2015). Results from this study indicate that feelings of shame may increase as youth move through adolescence into adulthood, becoming increasingly conscious of the social meanings attached to HIV.

Lack of family support. Insufficient family support leads to late disclosure of HIV status and poor clinic attendance, especially as children need a caregiver to accompany them to the clinic and the pharmacy through adolescence. Improved family-centered counseling may be an important strategy for addressing these barriers. To improve adherence rates, Gross and colleagues (2015) suggest interventions to strengthen the parent-child dyad.

Medication challenges. Challenges related to medication are frequently cited as barriers to adherence (e.g., Ammon et al., 2018; Croomea et al., 2017; Ankrah et al., 2015). Religious fasting practices in the study population further complicate adherence.

Inaccurate information. FGD participants identified sources of misinformation and noted that family, friends, and community members often do not have accurate information on HIV, which leads to poor service uptake from testing through treatment. Further, some adolescents and young adults noted that they and their caregivers still see a positive HIV diagnosis as a death sentence, a finding echoed by a recent qualitative study in Mozambique (Bagnol et al., 2018). Information, education, and communication campaigns are needed, among both people living with HIV and others, to improve treatment literacy and knowledge about the meaning of an undetectable viral load (that an HIV-positive person with an undetectable viral load cannot sexually transmit the virus) and virologic failure.

Health system barriers. In FGDs, adolescents and young adults living with HIV identified several health system factors that affect their ability to stay on treatment, including difficulty accessing health services without a guardian, and a lack of trust in the health system and/or healthcare providers. Although FGD participants did not mention pharmacy stocks as either a facilitating factor or a barrier, pharmacy burden (as opposed to stocks) has been identified as a barrier to retention in Mozambique (Lambdin et al., 2011).

Gender. Gender also affects retention and adherence. FGD participants across all study populations suggested that male youth are more likely than female youth to struggle to stay in care; while pregnant women are more likely to stay in care than non-pregnant women. These findings echo those of a large multi-site cohort study conducted by Lamb and colleagues (2014), as well as recent analysis by Swannet and colleagues (2017), which found that rates of viral suppression were higher among pregnant and breastfeeding women. Specific efforts are needed to reach boys and men to keep them in care. Further, clinical guidelines around the care of new mothers should be reconsidered. In Mozambique, new mothers, regardless of age, are moved from the prenatal clinic to general care and treatment. This transition *out of* the one-stop shop services offered in SAAJs may work against retention objectives, especially for newly diagnosed clients.

Factors that support retention and adherence

Facilitating factors that support retention and adherence can be grouped into four categories:

1. External support (family, peer, and community support)
2. Individual factors (being disclosed to, acceptance of HIV status, and motivation to remain healthy)
3. Positive experiences at the health facility (being treated well by providers)
4. Adequate financial resources

External support. Family support and encouragement to continue treatment was the most commonly reported facilitator of retention and adherence—echoing findings from a recent systematic review of factors affecting ART adherence in sub-Saharan Africa (Ammon et al., 2018) and a recent qualitative study in Mozambique (Bagnol et al., 2018). Yet, caregivers spoke about crushing stigma that prevented some of them from supporting their children in their treatment journey to the best of their ability. A shame and fear-free environment at home, as a result of families' acceptance of youth's HIV status, was mentioned as a facilitator of adherence to ART.

Disclosure. Disclosure was a prerequisite for felt family support. Disclosure enables adolescents and youth to take part in their care and treatment and creates opportunities for them to access adherence and psychosocial support services (Mburu et al., 2014). Disclosure, both in general and before children reach 12 years of age, has been found to be correlated with higher adherence rates among adolescents (Cluver et al., 2015; Montalto et al., 2017). In Mozambique, caregivers are ultimately responsible for disclosing HIV status to their child. For those diagnosed in childhood, according to the National Psychosocial Support Guidelines (MISAU, 2015) the formal process of disclosure starts at eight years of age and may conclude at any age, depending on the child's cognitive skills and psychological maturity, as well as caregivers' decisions about the appropriate age for disclosure. For individuals diagnosed in adolescence, the disclosure process is more complex. National legislation states that citizens as young as 13 years of age can request an HIV test and obtain the results directly, even without parental permission (Government of Mozambique, 2014). However, HP+ found that, despite this legislation, providers may avoid direct disclosure of positive HIV test results to newly diagnosed adolescents—a finding that mirrors those of another recent study (UNICEF, 2018). HP+ found that disclosure practices vary across facilities and even among providers in the same facility.

Positive experiences in health facilities. Youth also spoke about the support of health and social care providers, saying that, if they trust providers, they are more willing to continue treatment. Youth saw counseling services, including appointment/medication pick-up reminders, as integral to their treatment success. These findings align well with those of a recent study conducted by Cluver and colleagues in South Africa, which identified five factors associated with improved retention: pharmacy stocks, providers having enough time to spend with adolescents, adolescents being accompanied to the clinic, adolescents having the financial means to travel to the clinic safely, and a perception that clinic staff are kind (Cluver et al., 2018).

Services to improve outcomes across the clinical cascade

Youth and their caregivers mentioned several support services that they were receiving, and which they perceived as enabling youth to stay on treatment—most prominently, counseling services from providers, client tracing, and appointment/medication pick-up reminders.

FGD participants also pointed out gaps in support services, namely the need for enhanced nutritional support, as well as for adolescent support groups (peer support groups). Some participants mentioned that these groups, rather than being HIV-focused, should address broader concerns affecting youth (e.g., employment). Other studies have identified the importance of support groups in improving enrollment, adherence, and even viral suppression (e.g., Ammon et al., 2018). A multi-country study (Côte d'Ivoire, Mozambique, South Africa, Tanzania, and Zambia) exploring factors facilitating pediatric enrollment in care (versus retention) found that clinics with linkages to associations of people living with HIV had higher enrollment rates (Adjorlolo-Johnson et al., 2013).

Some participants noted the need for new ART distribution modalities, such as community-based dispensing and a system that would allow clients to pick up their medication from any pharmacy (rather than only the one at their usual clinic) in case of travel. Also, youth and caregivers noted the need for community-wide sensitization campaigns on HIV, to address stigma and discrimination and gaps in knowledge.

Another study in Mozambique found that access to early infant diagnostic services was improved when social care workers accompanied mothers to the clinic (Ciampa et al., 2011; 2012). This technique is used often by clinical and community-based services in Mozambique (e.g., orphan and vulnerable children programs and "Mentor Mothers") and could be further tested for adolescents, especially considering that being accompanied to clinic has been found to be a facilitating factor for retention in the sub-Saharan Africa region (Cluver et al., 2018).

Viral Load Monitoring

Routine viral load testing was introduced in Mozambique in late 2016/early 2017 and the requisite expansion of laboratory services and alignment of lab information systems is still ongoing. Key informants and providers noted progress in viral load monitoring at clinic level (ordering tests and using results for clinical decision making), but also described shortcomings. While providers in all three health facilities stated that they routinely order viral load tests, the focus for these tests is on new clients. Also, not all providers follow protocols in relation to ordering second viral load tests in cases where a client has been found to have a high viral load. Further, providers may be hesitant to move clients to second-line ART regimens due to the extra burden this poses for clients (taking more pills, often more times per day) and the associated adherence challenges. Indeed, another study in Mozambique found that only one-third of clients experiencing virologic failure had been moved to second-line treatment (Swannet et al., 2017). Healthcare providers in this study underlined the important role of the provincial ART committee in helping making regimen change decisions. Healthcare providers, clients, and caregivers also described challenges with viral load testing and results return, including laboratory delays in processing blood samples and issuing test results.

Efforts are underway to address these challenges, such as expansion of the laboratory network and development of a new electronic clinic-laboratory interface called DISALink. In areas where DISALink has been rolled out, it has reduced results return delays. Improving coordination between laboratories and clinics with respect to scheduling and streamlining procedures for results return at the clinic level will be vital to maximize the utility of viral load testing.

Importantly, few youth and caregivers were able to definitively say whether they (or their child) had received a viral load test. Moreover, many adolescents who had received a viral load test perceived the test to be in response to a poor clinical indicator (e.g., weight loss), rather than part of the routine standard of care. This may reflect the phased rollout of viral load testing (at the time of sampling, viral load testing uptake was under 30 percent in all health facilities per CHASS data) and a focus on new clients. However, it may also suggest poor communication between providers and clients/caregivers, as well as low levels of direct communication with adolescents themselves. This finding is in line with those of another study in Mozambique (UNICEF, 2018). Many health and social care providers expressed a preference for speaking with caregivers, rather than adolescents, for fear that adolescents either could not digest, or should be protected from, information about their health/healthcare. By avoiding direct communication with adolescents, providers miss an opportunity to build adolescents' treatment literacy and empower them to become more independent in managing their care. Guidelines and job aids for engaging adolescents may help providers better support treatment literacy among adolescents living with HIV, which may lead to improvements in retention and adherence.

Perspectives on Adolescent Care and Transition

Adolescents and young adults who had attended a SAAJ reported having very positive experiences. They also expressed hesitation, even at 24 years of age, to transition to general care and treatment services. Those who were not familiar with SAAJs were very supportive of them as a concept. Providers' and key informants' main concern about SAAJs related to human resources—whether SAAJs could be adequately staffed with trained providers to address the demand for services, especially with increasing numbers of HIV-positive children aging up into this youth cohort (HP+, 2018). To ensure that SAAJs are functional, and not overcrowded and under-financed, the government may need to prioritize subpopulations of adolescents and youth for treatment in SAAJs.

Participants described several factors that they felt should determine eligibility to transition—being disclosed to, being capable of remembering appointments and picking up medication, and age. Most FGD participants felt that 10 years of age was too young to transition to a SAAJ and saw adolescents between 13 and 15 years of age as more likely to have the maturity needed to transition. Providers and key informants stressed the importance of transition counseling and recommended that adolescents and youth be accompanied to their new clinic by a health facility staff person for a time during the transition process. Caregivers expressed a desire to stay involved in their children's care after transition. Healthcare providers, social care providers, and key informants agreed that caregiver involvement is crucial to ensuring good retention and adherence outcomes. At the time of drafting this report, the Government of Mozambique was finalizing transition guidance that will address some of these issues.

Health and social care providers and key informants also emphasized that transition should not be mandatory and that the number of transitions in and out of the SAAJ should be limited. It is possible for a female HIV-positive youth to have started care in a pediatric clinic, then been moved to a general adult clinic, then to a SAAJ, and then—when pregnant—to a prenatal clinic, after which—according to current guidelines—she would be expected to move back to the general adult clinic, even if she were still an adolescent. The large number of transitions increases the risk of attrition, especially among new mothers. This is particularly worrying, given that Nuwagaba-Biribonwoha and colleagues (2018) recently found adolescence and pregnancy to be potential risk factors for attrition.

Offering diverse services at the SAAJ is important to youth. FGD participants liked the one-stop shop model, in which adolescents and youth can obtain a wide range of health and social services in one place, at one time. Key informants also noted the importance of offering differentiated care models and adolescent support groups. Lamb and colleagues (2014) found that attrition rates among adolescent-friendly clinics in Kenya, Mozambique, Tanzania, and Rwanda differed based on service offerings. For instance, clinics that offered condoms and adolescent support groups experienced lower attrition but, surprisingly, clinics offering adolescent-specific hours, experienced moderately higher attrition. Determining the most appropriate mix of services and operating procedures will be important to ensuring the success of the SAAJ.

Recommendations

This study was undertaken to provide Mozambique's government with information that can help improve care for youth living with HIV. Based on the study's findings, HP+ offers the following recommendations:

Improve treatment literacy and address knowledge gaps around viral suppression and failure and viral load monitoring through information, education, and communication strategies. There is a need to increase knowledge about the benefits of viral suppression—the individual health benefits of having an undetectable viral load (that a person living with HIV who has an undetectable viral load cannot transmit the virus), as well as its public health importance, including that of community viral load suppression. Strategies should use all available communication modalities, such as radio and social media, and make use of existing information, education, and communication materials on viral suppression and viral load testing. Initiatives to reduce misinformation are also required, including targeted initiatives to engage influential stakeholders, role models, and gatekeepers. Engaging faith-based organizations and traditional leaders as change agents is particularly important.

Expand peer support interventions for adolescents. Youth emphasized the importance of peer support in enabling them to stay on treatment. Peer support groups/interventions should be scaled up to build treatment literacy and self-efficacy skills among youth and empower youth to become able in managing their care. Groups may be based in health facilities, the community, or schools and should provide peer support on living with HIV and supporting family members with HIV.

Enhance disclosure and peer support for caregivers. Peer support services (one-on-one or group-based) for caregivers should be created to offer caregivers opportunities to discuss their concerns and develop and share solutions.

Enhance training for health and social care providers in working with adolescents and youth. HP+ recommends building providers' skills in an assets-based approach to engaging adolescents and youth—enabling providers to communicate with adolescents and youth about their health and healthcare in ways that put them at ease and can be easily understood. Further, providers should receive training on how to support caregivers through disclosure processes and new strategies should be used to incentivize providers for their important work in engaging and empowering adolescents.

Improve healthcare provider training in viral load monitoring. Specifically, providers should be trained in using viral load test results in patient care decision making (including when to order first tests and follow-up tests) and explaining the significance of viral load test results to patients (especially that having an undetectable viral load means that they cannot transmit the virus).

Address facility-level factors that delay viral load testing and results return. Health facilities should streamline procedures for carrying out and returning the results of viral load tests, including scaling up DISALink, improving commodity tracking, and aligning appointments across hospital services.

Reconsider SAAJ eligibility criteria. The age of entry for SAAJs should be increased to at least 12 years. Further, adolescent mothers should be made eligible to receive services in the SAAJ, regardless of their number of children.

Implement SAAJ transition guidelines and pre-transition counseling guidance. In addition to full-scale implementation of these guidelines, these policies should specify a mechanism for continued caregiver involvement in adolescent care in the SAAJ and for accompanied visits; transition to a SAAJ should be optional; and efforts should be made to minimize the number of transitions between clinics.

Standardize policies for HIV testing, disclosure, and involving adolescents in their care. Clinical policies, including the age of consent for results disclosure and treatment, should reflect national legislation and be posted publicly in all health facilities. Health and social care providers should be reminded of the age of consent and trained to rapidly assess subjective consent criteria (individual readiness) and to involve adolescents in their care.

Identify and scale up models for customized care for youth. HP+ recommends offering flexible, differentiated care models for adolescents, such as evening clinics and differentiated drug distribution modalities.

Study "positive deviants." To unlock successful strategies and explore the importance of linked interventions delivered at the community level or in school settings, there is a need for focused research on individuals who have successfully navigated social, community, and clinical issues that many have struggled with, especially male youth who have stayed on treatment and caregivers who have successfully disclosed to their children in early adolescence.

Build and review a policy scorecard. To hold stakeholders accountable, a policy scorecard should be designed and used, beginning with scanning pediatric and adolescent policy and guidelines to unpack the status of priority guidelines from conception to implementation.

Annex A. Demographic Characteristics of Respondents

Adolescents (Ages 15–19 Years)

Twenty-nine adolescents (ages 15–19 years) participated in FGDs across the three health facilities. A majority (72 percent) had secondary education. Around one-third (31 percent) reported that they had known that they were HIV positive for less than one year, 52 percent reported that they had known they were HIV positive for between one and four years, and 17 percent reported that they found out they were HIV positive more than five years prior to the study. Just over one-quarter (28 percent) had been on ART for less than one year, nearly half (45 percent) had been on ART for between one and four years, and 28 percent had been on ART for more than five years. Two-thirds (66 percent) reported perfect adherence to their treatment, with the rest reporting that they sometimes miss pills. Only three respondents (10 percent) reported receiving their HIV treatment in a SAAJ (see Table A1).

Table A1. Demographic Characteristics of Adolescent FGD Participants (Ages 15–19 Years)

Characteristic	Sofala (Beira) n=8		Manica (Chimoio) n=12		Niassa (Lichinga) n=9		TOTAL n=29
	Females (n=4)	Males (n=4)	Females (n=6)	Males (n=6)	Females (n=5)	Males (n=5)	
Age (Years)							
15	–	1	1	2	–	1	5
16	2	–	–	–	2	1	5
17	–	2	1	1	1	–	5
18	2	1	1	1	–	2	7
19	–	–	3	2	2	–	7
Highest Level of Education							
Primary	1	1	3	2	–	–	7
Secondary	3	3	4	3	5	3	21
Technical	–	–	–	–	–	1	1
Higher education	–	–	–	–	–	–	–
For how many years have you known you have HIV?							
Less than 1	1	1	3	–	3	1	9
1–4	3	2	3	3	2	2	15
5–9	–	1	–	2	–	1	4
10–15	–	–	–	–	–	–	–
More than 15	–	–	–	1	–	–	1
How many years ago did you start ART?							
Less than 1	1	–	3	1	2	1	8
1–4	3	–	3	3	3	1	13
5–9	–	2	–	2	–	2	6
10–15	–	–	–	–	–	2	2

Characteristic	Sofala (Beira) n=8		Manica (Chimoio) n=12		Niassa (Lichinga) n=9		TOTAL n=29
	Females (n=4)	Males (n=4)	Females (n=6)	Males (n=6)	Females (n=5)	Males (n=5)	
How would you describe the frequency with which you take antiretroviral medication?							
Every day	3	1	3	6	4	2	19
Often, but miss a few	1	3	3	–	1	2	10
Occasionally	–	–	–	–	–	–	–
Stopped ART	–	–	–	–	–	–	–
Where do you have your consultations and receive your ART?							
SAAJ	2	–	–	–	1	–	3
General (adult) clinic	–	4	5	6	4	4	23
Other	2	–	1	–	–	–	3

Young Adults (Ages 20–24 Years)

Thirty-nine young adults (ages 20–24 years) participated in FGDs across the three health facilities. Around one-third (31 percent) had only primary education, 51 percent had secondary education, and 18 percent had higher education. Around one-third (31 percent) reported that they had known that they were HIV positive for less than one year, 63 percent reported that they had known they were HIV positive for between one and four years, and 21 percent reported that they found out they were HIV positive more than five years prior to the study. Just over one-quarter (28 percent) had been on ART for less than one year, half (51 percent) had been on ART for between one and four years, and 21 percent had been on ART for more than five years. Ninety percent of young adults reported perfect adherence to their treatment, with the rest reporting that they sometimes miss pills. Just over one-quarter of participants (28 percent) reported that receive their HIV treatment in a SAAJ (see Table A2).

Table A2. Demographic Characteristics of Young Adult FGD Participants (Ages 20–24 Years)

Characteristic	Sofala (Beira) n=17		Manica (Chimoio) n=12		Niassa (Lichinga) n=10		TOTAL N=30
	Females (n=8)	Males (n=9)	Females (n=7)	Males (n=5)	Females (n=7)	Males (n=3)	
Age (Years)							
20	1	2	3	1	–	1	8
21	1	1	–	–	1	–	3
22	1	2	2	2	2	1	10
23	2	3	1	1	4	1	12
24	3	1	1	1	–	–	6
Highest Level of Education							
Primary	1	1	6	1	3	–	12
Secondary	6	3	1	4	4	2	20
Technical	1	4	–	–	–	1	6
Higher education	–	1	–	–	–	–	1

Characteristic	Sofala (Beira) n=17		Manica (Chimoio) n=12		Niassa (Lichinga) n=10		TOTAL N=30
	Females (n=8)	Males (n=9)	Females (n=7)	Males (n=5)	Females (n=7)	Males (n=3)	
For how many years have you known you have HIV?							
Less than 1	2	4	–	2	3	1	12
1–4	5	4	3	3	3	1	19
5–9	1	–	2	–	1	1	5
10–15	–	1	1	–	–	–	2
More than 15	–	–	1	–	–	–	1
How many years ago did you start ART?							
Less than 1	3	2	–	2	3	1	11
1–4	6	4	3	3	1	3	20
5–9	–	1	3	–	1	1	6
10–15	–	1	1	–	–	–	2
How would you describe the frequency with which you take antiretroviral medication?							
Every day	8	9	7	4	6	1	35
Often, but miss a few	–	–	–	1	1	2	4
Occasionally	–	–	–	–	–	–	–
Stopped ART	–	–	–	–	–	–	–
Where do you have your consultations and receive your ART?							
SAAJ	4	7	–	–	–	–	11
General (adult) clinic	3	2	5	5	6	3	24
Other	1	–	2	–	1	–	4

Caregivers

Forty-two caregivers participated in this study, all but one of whom were female. Around one-third (31 percent) were 30 years of age or younger, 48 percent were between 31 and 40 years of age, 21 percent were 41 years of age or older. Five percent reported no education, 43 percent had only primary education, 45 percent had secondary education, and 7 percent had higher education. Seventy-one percent cared for one HIV-positive child living with HIV and 29 percent cared for more than one HIV-positive child living with HIV. Half of caregivers reported that there was an adult living with HIV in the household. Half of caregivers had been caring for HIV-positive children for five or more years, 38 percent for between one and four years, and 12 percent for less than one year (see Table A3).

Table A3. Demographic Characteristics of Caregivers of Adolescents Living with HIV

Characteristic	Sofala (Beira) n=14	Manica (Chimoio) n=13	Niassa (Lichinga) n=15	TOTAL N=42
Sex				
Male	–	–	1	1
Female	14	13	14	41
Age (Years)				
Less than 20	–	–	1	1
20–30	6	4	2	12
31–40	6	5	9	20
41–50	–	4	1	5
51 or more	2	–	2	4
Marital Status				
Single	4	6	10	20
Cohabiting	7	3	1	11
Married	3	1	1	5
Divorced	1	1	–	2
Widow/Widower	–	2	2	4
Highest Level of Education				
No education	1	–	1	2
Primary	7	5	6	18
Secondary	6	8	5	19
Higher Education	–	–	3	3
How many children/adolescents living with HIV do you care for?				
1	11	8	11	30
2	2	2	3	7
3	1	2	–	3
4 or more	–	1	1	2
For how many years have you cared for children/adolescents living with HIV?				
Less than 1	–	2	3	5
1–4	7	6	3	16
5–9	6	4	5	15
10–15	–	1	4	5
More than 15	1	–	–	1
Are children/adolescents under your care on ART?				
Yes	14	13	14	41
No	–	–	1	1

Characteristic	Sofala (Beira) n=14	Manica (Chimoio) n=13	Niassa (Lichinga) n=15	TOTAL N=42
Are there any adults living with HIV (20 years or older) in your household?				
Yes	10	7	4	21
No	4	5	10	19
Do not know	–	1	1	2

Social Care Providers

Thirty-seven social care providers participated in FGDs across the three health facilities. Almost four-fifths (78 percent) were female and 73 percent were ages 30 years or younger. Eight percent had only primary education, 84 percent had secondary education, and eight percent had higher education. Thirty percent had worked with people living with HIV for less than one year, 41 percent had worked with people living with HIV for between one and four years, and 30 percent had worked with people living with HIV for more than four years. Forty-three percent worked in the community, 35 percent worked in clinical services, and 22 percent reported working in other locations (see Table A4).

Table A4. Demographic Characteristics of Social Care Providers

Characteristic	Sofala (Beira) n=7	Manica (Chimoio) n=10	Niassa (Lichinga) n=30	TOTAL N=37
Sex				
Male	2	3	3	8
Female	5	7	17	29
Age (Years)				
Less than 20	1	1	1	3
20–30	4	4	16	24
31–40	2	3	2	7
41–50	–	1	1	2
51 or more	–	1	–	1
Marital Status				
Single	4	6	10	20
Cohabiting	7	3	1	11
Married	3	1	1	5
Divorced	1	1	–	2
Widow/Widower	–	2	2	4
Highest Level of Education				
No education	–	3	–	3
Primary	5	7	19	31
Secondary	2	–	–	2
Higher Education	–	–	1	1

Characteristic	Sofala (Beira) n=7	Manica (Chimoio) n=10	Niassa (Lichinga) n=30	TOTAL N=37
Occupation				
Activista	–	3	8	11
Other	7	7	12	26
For how many years have you worked with people living with HIV?				
Less than 1	1	2	8	11
1–3	4	2	10	15
4–10	2	–	2	4
More than 10	–	7	–	7
What clinical context do you work in?				
General care and treatment	1	3	–	4
Antenatal clinic/prevention of mother-to-child transmission	–	3	3	6
SAAJ	3	–	–	3
Other	–	1	7	8
Community work	3	3	10	16

Healthcare Providers

Twenty-eight healthcare providers participated in focus groups across the three health facilities, 64 percent of whom were female. Half of the providers were between 20 and 30 years of age. Fourteen percent had only secondary education; the rest had higher education. Forty-three percent were nurses, 32 percent were general medical technicians, 11 percent were doctors, one was a psychologist, and three reported other professions. The majority of respondents (61 percent) reported having been working with people living with HIV for four years or more. Seven percent reported having less than one year of experience working with people living with HIV. Only one respondent worked in a SAAJ (see Table A5).

Table A5. Demographic Characteristics of Healthcare Providers

Characteristic	Sofala (Beira) n=7	Manica (Chimoio) n=10	Niassa (Lichinga) n=11	TOTAL N=28
Sex				
Male	1	7	2	10
Female	6	3	9	18
Age (Years)				
20–30	6	4	4	14
31–40	1	5	4	10
41–50	–	–	3	3
51 or more	–	1	–	1

Characteristic	Sofala (Beira) n=7	Manica (Chimoio) n=10	Niassa (Lichinga) n=11	TOTAL N=28
Highest Level of Education				
Secondary	1	2	1	4
Technical	5	3	7	15
Higher Education	1	5	3	9
Occupation				
Nurse	4	3	5	12
General medical technician	2	2	5	9
Doctor	1	1	1	3
Psychologist	–	1	–	1
Other	–	3	–	3
For how many years have you worked with people living with HIV?				
Less than 1	–	1	1	2
1–3	5	3	1	9
4–10	1	4	6	11
More than 10	1	2	3	6
What clinical context do you work in?				
General care and treatment	3	4	6	13
Antenatal clinic/prevention of mother-to-child transmission	–	–	4	4
SAAJ	–	–	1	1
Other	3	5	–	8
More than one	1	1	–	2

Key Informants

HP+ interviewed 10 key informants—two in each province and four at the national level. Four of these informants (a.k.a. policymakers) worked for MISAU and six worked for an implementing partner. All respondents had at least four years of experience working in the HIV field (see Table A5).

Table A6. Demographic Characteristics of Policymakers/Informants

Characteristic		TOTAL (N=10)
Sex	Male	7
	Female	3
Province	Sofala (Beira)	2
	Manica (Chimoio)	2
	Niassa (Lichinga)	2
	N/A (Headquarters)	4
Type of Agency	MISAU	4
	NGO	6
Current Position	Provincial supervisor	3
	Team lead	5
	Director	2
Years Working in Current Position	Less than 1	2
	1–4	8
Years Working in the Field of HIV	4–10	6
	More than 10	4

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