

Paediatric Risk Of treatment failure: a guide to programmatic implementation

MSF

October 2018

Toolkit

Programmatic and Clinical Approach

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Introduction

Great strides have been made in the field of paediatric HIV over the last 15 years. Improvements in anti-retroviral treatment (ART) have enabled many children to reach adulthood and achieve their goals. However, many problems with paediatric HIV treatment remain, and often place children and adolescents at risk of failing their treatment. These problems include:

- The small number of available anti-retroviral medications (ARVs) for children.
- The poor palatability of existing ARVs.
- Dosing complications with paediatric ARVs.
- The many psychosocial issues surrounding the administration of chronic lifelong medication and maintaining long-term adherence.

Due to all these problems, it is not surprising that the treatment failure rate for children and adolescents with HIV is much higher than in adults.

What is paediatric HIV treatment failure?

Treatment failure in children with HIV can be categorized as virologic failure (having a high viral load), immunologic failure (having a low CD4 count), clinical failure (the development of opportunistic infections and other illnesses), or some combination of the three (Group et al., 2005). The definition of HIV treatment failure will vary depending on the HIV guidelines of the country where you are working and the resources that are available to you. In particular, the definition will differ depending on the availability of viral load testing:

- Without viral load testing:
In some locations, obtaining a viral load (to measure the level of HIV) is not available. In these situations, treatment failure in children and adolescents is defined either clinically (a persistence or development of clinical problems despite being on ARV treatment for more than 3 months), or immunologically (having any drop in CD4 count despite being on ARV treatment for more than 3 months).
- With viral load testing:
When viral load testing is available, the definition of treatment failure will depend in large part on the sensitivity of the viral load monitoring machines used in the country. It is best to check your national HIV guidelines as this will have an effect on how you approach a child with a detectable viral load. As an example, in South Africa treatment failure in children is defined as the child having two viral load values >1000 HIV RNA copies/ml on two consecutive occasions within 3 months.

What are the causes of paediatric HIV treatment failure?

When taken consistently, ARVs work very well in children and adolescents. In fact, the rate of *primary* ARV failure (failure due to resistance strains of HIV that have been passed from the mother to the child) is low. Instead, for most patients with treatment failure, the cause is *secondary ARV failure* due to **poor adherence**. Simply put, the patient is not taking his/her ARVs on a consistent enough basis to control his/her HIV. This leads to a high viral load. Moreover, ARVs are unfortunately very “unforgiving” medicines when it comes to adherence. They must be taken >90% of the time to adequately lower the viral load, and is the major reason for the treatment failure rate in children being so high.

What are the causes of poor adherence in children and adolescents?

There are numerous causes for poor adherence, including both “Patient-Related” and “Health System-Related” reasons. “Patient-Related” reasons are barriers based on the psychosocial situation of the patient and “Health System-Related” barriers to adherence are based on problems within the health care system that affect a patient’s ability to remain adherent to treatment. Below is a list of some causes of poor adherence:

Causes of Poor Adherence in Children and Adolescents

Patient or caregiver related factors	Regimen related factors	Health system related factors
Logistics <ul style="list-style-type: none"> Missing school or work to go to the clinic Travel outside of the area where medication is collected Stigma Issues with disclosure Lack of social support systems or a treatment supporter Mental health issues Substance abuse Violence and safety concerns or an unstable home environment Unwell or disinterested caregiver Treatment fatigue Competing priorities Food insecurity Unstable home life	Chronicity of medication Side effects Pill burden Complicated dosing regimens Poor palatability of medication	Poor access to facilities Inefficient services and long waiting times Poor HIV education Medication <ul style="list-style-type: none"> Stock outs Limited selection of medications available Negative staff attitudes Requirement for multiple visits

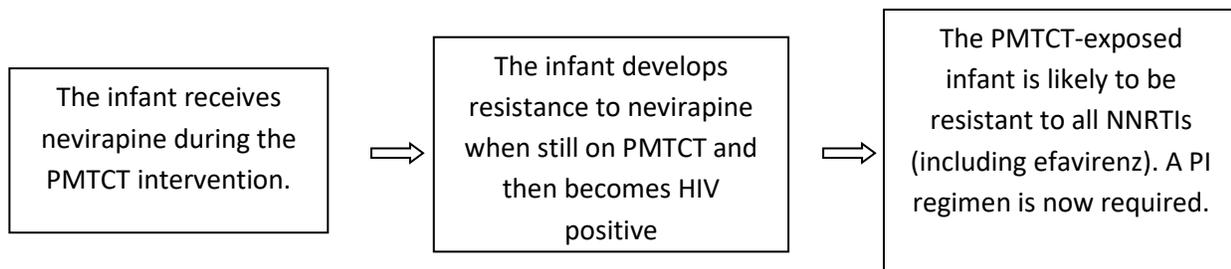
Why is having a high viral load detrimental for a child or adolescent with HIV?

Having a high viral load means that many copies of HIV are present in the blood. HIV affects every organ system in the body, not only his/her immunologic system. In particular, HIV affects the developing brain and the neurological system of children and adolescents, often resulting in neurodevelopmental impairment. The longer a child or adolescent remains with a high viral load, the greater the effects of HIV on the developing brain and body.

Furthermore, having a high viral load places the child at risk of developing **resistance** to ARVs. This means that the HIV will not be overcome by the specific ARVs the child is taking and resistance will occur.

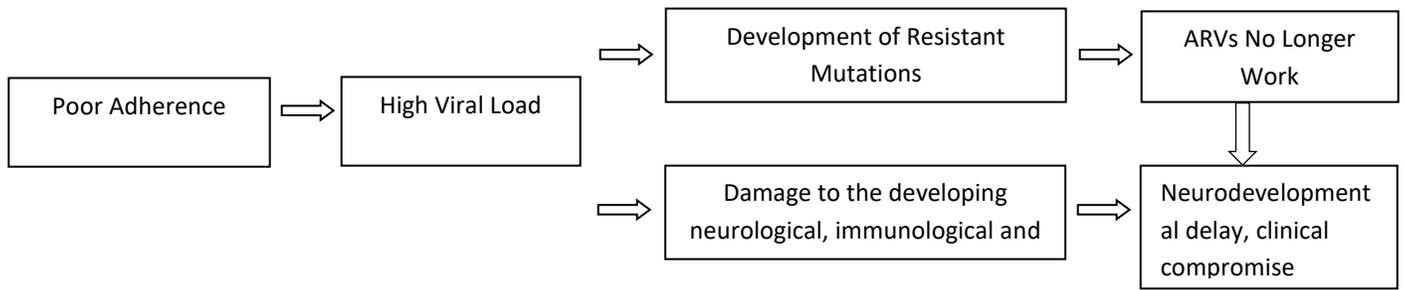
Why is the development of resistance a bad thing? One reason is that once resistance has developed to a specific drug, the drug will no longer work. The child will need to switch to an alternative ARV regimen (either 2nd or 3rd line depending on the current failing regimen.) Unfortunately, adherence to these regimens can be even more difficult as there is a higher pill burden and the 2nd and 3rd line medications may have additional side effects.

Moreover, *cross-resistance* may have developed to other drugs within the same ARV "class" (Non-nuclease reverse transcriptase inhibitors (NNRTI) class, protease inhibitors (PI) class etc.). This means that *none of the drugs in that entire ARV class* will work. Cross-resistance occurs, for example, when a child contracts HIV despite participating in a prevention of mother to child transmission program (PMTCT):



Given that, few ARVs are available for children, resistance and cross-resistance can potentially lead to a situation where *no effective ARV options* are left for the child. Such an extreme situation places the child at extreme risk of morbidity and mortality.

For these reasons, a high viral load in a child or adolescent should be considered an **emergency** and be addressed in a timely fashion – before any clinical compromise, neurodevelopmental delay, or resistance develops.



What is the purpose of this toolkit?

There are **two main purposes** of this toolkit:

1. To provide programmatic information and advice to assist you in starting a paediatric treatment failure program, *no matter what level of resources are available to you*.
2. To provide specific clinical patient management tools (such as scheduling and adherence tools) to help you manage children and adolescents who have high viral loads. In particular, the toolkit provides the *adherence counselling tools* needed to thoroughly address adherence.

What is included in this toolkit?

The following items will be found in the toolkit:

Programmatic information/advice on starting a paediatric treatment failure intervention

- a. Components of a paediatric treatment failure intervention. What is required and/or recommended to start an intervention?

Tools to monitor and evaluate your intervention Clinical patient management tools to address treatment failure in children and adolescents

- b. Baseline Patient Data Form
- c. Adherence Tools:
 - Adolescent Adherence Plan / Adolescent Adherence Session Form
 - Caregiver Adherence Plan / Caregiver Adherence Session Form
 - Adolescent Support Group Session – Facilitator Guide
 - Caregiver Support Group Session – Facilitator Guide
 - Community Care Worker Home Visit form
- d. Training tools
 - Nurse Paediatric HIV Treatment Failure Clinical Competency Checklist

Programmatic Information on Starting a Paediatric Treatment Failure Intervention

What components are required and/or recommended to start an intervention?

Note: Below is a discussion about specific programmatic aspects of a paediatric treatment failure program. While some of them are mandatory to have in order to run a successful program, others are not essential. *The components included in your intervention will depend on the resources available to you.* Even if you are not able to include all the components discussed below, your intervention can still be a success!

In addition, it is important to note that the services in the *intervention should be integrated within the existing services of the clinic* and should act as an augmentation of existing services, not one that acts as a parallel system outside the normal clinic structure.

Next to each component, we have written “Required” or “Recommended” as a guide to assist you when devising your intervention.

Department of Health and Clinic Support for the Intervention: (Required)

Before setting up a treatment failure intervention, if you are working for an organization outside of your country’s department of health, it is important to gather support and “buy in” from the key department of health (DoH) representatives where you work. Discussions with department of health officials, facility managers, and others will be necessary to alert them of your plan and gain support and consent for your project. In addition, once approvals have been obtained, it can be helpful to hold meetings *at the clinic* with the *entire staff* (including doctors, nurses, counsellors, clerks, security guards, etc.) to explain what you are planning to do. In addition to gaining buy-in, this also helps to identify problems you did not consider and gaps in the intervention of which you were not aware. Developing solutions with the clinic staff can help solve the issues in the most practical way for that clinic, as well as start to develop some ownership of the programme within the clinic.

Flagging System for High Viral Loads: (Required)

It is imperative to set up a system within your clinic to **flag high viral loads** in children and adolescents. Without a system to do this, it will be difficult to know who is failing treatment and needs enrolment into your program. To start a flagging system, the following is needed:

- A designated person to follow up viral load results for patients returning to the clinic. This may be anyone at the clinic (clerk, nurse, doctor etc.). Ideally, follow-up would occur on a weekly basis.
- A notification system to alert the clinician if the viral load is high. This can be done through simply marking folders of patients who have a high viral load with a pen.
- A referral system to schedule those patients with a high viral load to come to the treatment failure intervention.

Paediatric Adherence Tools: (Required)

As previously mentioned, poor adherence is the main cause of paediatric treatment failure. ***Thus, good adherence counselling is the most important intervention that takes place in a paediatric treatment failure intervention.*** In this toolkit, we have included comprehensive adherence documents that provide step-by-step guidance for counselling caregivers and adolescents about adherence to ARVs. Please see section below, “Clinical Patient Management Tools”, for an explanation of how to use the adherence tools.

Space for the Intervention: (Recommended)

Having a place to see patients is obviously a necessary component for the intervention. However, a *dedicated space* to provide paediatric treatment failure services can be particularly helpful. Integrating the paediatric risk of treatment failure programme with the paediatric services is advocated for, but having a paediatric consultation area separate from the adult services within the clinic allows you to design the space specifically for children and adolescents, with medical equipment that is geared towards children. Furthermore, a dedicated waiting room can allow you to provide paediatric information to patients while they wait for appointments and even hold support groups. ***However, while it can be beneficial to have a separate space for children, it is not necessary.*** Many clinics are extremely short of space, and it may be impossible to have a dedicated paediatric space.

Paediatric “Champions” and a Passionate Health Care Team: (Recommended)

The key to any successful program starts with dedicated and passionate people. A paediatric intervention will be much more successful if the people involved have a genuine interest in caring for children and adolescents. For example, in our treatment failure intervention in Khayelitsha, South Africa, we try to find clinicians who will act as “paediatric champions” for the intervention. These “champions” are staff members who are particularly passionate about child health and take the lead in scheduling the paediatric patients and overseeing the day-to-day organization of the intervention.

In addition to the “paediatric champion”, other passionate team members are also important. Below is an example of a list of staff members and their responsibilities in a treatment failure intervention.

Note: In this example, the “paediatric champion” is a doctor, but a nurse could also fulfil the role of Paediatric Champion. In many areas, doctors are not available. Additionally, a counsellor could also act as a paediatric champion and organize the services. However, the counsellor would need input and guidance from a nurse or doctor for the medical related aspects of the intervention.

Doctor (“Paediatric Champion”):

- Clinical care
 - Provide clinical care to patients when needed
 - Send, follow-up, and interpret labs including genotypes
- Patient adherence support
 - Teach the adherence modules to patients
 - Work with the counsellor to provide adherence support to patients
- Admin
 - Oversee the organization of intervention activities (daily clinic, support groups)
 - Complete intervention patient data forms
 - Oversee scheduling of patients and the follow up of patients who are lost to follow up
- Teaching and mentorship
 - Mentor nurse on the clinical care of the patients

Nurse:

- Clinical care
 - Provide clinical care to patients and refer to the intervention doctor with any questions (if doctor available)
 - Draw blood for laboratory testing
- Patient adherence support
 - Teach the intervention adherence modules to patients
- Admin
 - Schedule patients for clinic and follow up if patients are lost to follow up
 - Complete intervention patient data forms

Counsellor:

- Patient adherence support
 - Facilitate intervention support group meetings
 - Teaching the intervention adherence modules to patients
 - Assist doctor and nurse with translation (if needed)
- Admin
 - Scheduling of patients
 - Overall patient flow in the clinic

Support Groups: (Recommended)

Support groups can be a very powerful way for people to learn about HIV and troubleshoot problems related to ART administration. Led by a facilitator, these 30-40 minute sessions enable caregivers and adolescents to share their experiences with ART and learn from one another. In fact, during a productive support group, the participants do most of the talking among themselves with the facilitator speaking only infrequently to clarify any misconceptions. If possible, these sessions should be held on the day of their appointment before their individual sessions. The timing of support groups is dependent on the target audience. Holding support groups during weekday mornings works well for caregivers of younger patients, but this time is often not good for older children and adolescents due to school conflicts. For these older patients, *alternative scheduling* for support groups (for example once a month on a weekday afternoon) works better.

Adolescent Focused Services: (Recommended)

A combination of factors can make care for adolescents with HIV very difficult. Challenges include complex psychosocial dynamics, a propensity for “concrete thinking”, and a lack of foresight. As such, they require specific support services to help them through these turbulent years. We have found interventions such as monthly support groups to be helpful in providing additional assistance for these adolescents. During these sessions, adolescent specific topics are discussed such as peer pressure, alcohol and drugs use, dating, contraception, management of school and their ARVs, and others. In addition, scheduling the adolescents in your cohort to attend clinic on the same day (essentially creating “adolescent clinic days”) can aid in increasing peer support and educational opportunities.

Home assessment team (recommended)

During a home assessment, a community care worker or other local staff member visits the home of the patient to talk with the patient and family members and evaluate the patient's living conditions. Home assessments can provide important information that contributes to a thorough psychosocial assessment. By entering the home and seeing the domestic environment, community care workers or other local staff can gather information regarding barriers to adherence that may not be possible to obtain at the clinic or by only asking the patient or caregiver.

In our clinic, we perform an initial home assessment and then follow-up assessments at regular intervals if needed (Appendix 4).

Monitoring and Evaluation Tools

Paediatric Treatment Failure Intervention Monthly Data Collection Indicators

It is important to monitor a paediatric treatment failure intervention in order to assess whether it is working and to guide future adaptations to the program. Appendix 6 has a form which may be used for this purpose.

Clinical Patient Management Tools to Address Treatment Failure in Children and Adolescents

Overview of Visits

- The programme is comprised of two distinct "phases": the "Initial Phase" and the "Maintenance Phase." This "initial phase" is comprised of an *introductory visit and core adherence visits* where the majority of the adherence messages are given to the patient (or to the caregiver of a young child). At the appropriate time (according to local guidelines), a viral load is drawn and decisions are made regarding further management. If the viral load is still elevated, the patient repeats the previous initial phase visits to review the adherence messages. The patient continues to cycle through the PROTF system until the patient re-suppresses his/her viral load.
- Once a patient achieves a suppressed viral load, he/she moves to the "maintenance phase" of the intervention. The maintenance phase visits are shorter, and are essentially "check-ups" to review medication and investigate any new issues or problems. Once a patient has two suppressed viral loads (one in the initial phase to graduate to the maintenance phase, and one subsequently in the maintenance phase), the patient is discharged from the intervention. If the patient has rebounded, the patient returns to the initial phase to address existing adherence barriers.

Initial Phase Visits (3-4 visits)

- **Introduction visit** This visit takes place once the patient has been identified as having a high viral load. This visit takes place ideally on the same day as identification, but this is dependent on the patient. This is an introductory session during which the intervention is thoroughly discussed with the patient and caregiver(s). The staff of the programme is introduced, the programme schedule is discussed, and the goals of the intervention are explained. The **baseline patient data** form is completed (Appendix 1) and the major barriers to adherence are identified. The first individual adherence session will be started (see appendix 2).
- **Adherence visits** At this visit, the *individual adherence sessions* are continued (see Appendix 2). The patient also attends his/her *first support group* (Appendix 3 and 4). As discussed above, the support groups are facilitated by a counsellor. These sessions last approximately 30-40 minutes. During the support groups, a wide range of subjects are discussed with the overall aim to provide a safe space for parents and adolescents to discuss their barriers to adherence or other challenges they may be having. Of note, the timing of these support groups may need to be altered for adolescents due to school conflicts. For example an adolescent support group may be started one afternoon a month (and not necessarily on the same day as their clinic appointment). However, a concerted effort should be made to hold support groups for the caregivers of younger children *on the day of their clinic appointment*. This should be possible as there is usually more flexibility with school schedules for younger patients. The support groups can be done before or after the clinician visit, but before is preferable. At one of the adherence visits, usually visit 2 or 3 depending on local guidelines on the timing of VL, a VL is taken to assess whether the intervention has been successful in helping the patient suppress.
- **Results visit:** The support groups and individual sessions continue. The viral load result is discussed with the patient and decisions are made regarding medical and psychosocial management. In short, if the viral load is suppressed, the patient "advances" to the maintenance phase. If the viral load is still high, the patient's regimen will be switched and the patient returns to visit 1.

Maintenance Phase Visits (Appendix 2.1.4 and 2.2.3)

- The patient has now achieved a suppressed viral load, so the major adherence barriers have likely been addressed. However, continued follow-up is necessary to ensure a stable psychosocial situation and durable viral load suppression.
- **Follow-Up Visit 1:** The intervention is continued with an individual appointment to review any clinical issues and psychosocial barriers to adherence.
- **Follow-Up Visit 2:** The intervention is continued with an individual appointment to review any clinical issues and psychosocial barriers to adherence. **A viral load is drawn this visit or within 3 months of the last viral load.**
- **Follow-Up Visit 3:** Individual sessions continue. **The viral load result is discussed.** If the patient has achieved two consecutive suppressed viral loads, the patient is discharged from the intervention and returns to routine care. If the viral load is elevated, the patient has suffered viral load rebound and must return to the initial phase to intensify the addressing of barriers to adherence.

Note: In our intervention, we require the patient to *achieve two consecutive suppressed viral loads* prior to discharging him/her from the intervention. We feel that this indicates a more durable re-suppression with a more stable psychosocial situation. Such a requirement for discharge from your intervention may not be in keeping with your national guidelines. Hence, *discussions about discharge criteria for your intervention may be necessary.*

Note: A couple of questions that often arise are:

When do I switch regimens?

These can be a difficult question to answer, as each patient's history is different. *Therefore, an individual approach is needed.* In addition, national guidelines on treatment failure and when to switch medication regimens vary. Thus, your approach and decision-making will be affected by your local guidelines.

Despite this, some general points can be made:

If viral load (VL) > 1000, repeat within 3 months (during which there should be 2 months of intense adherence counselling, review of drugs tolerability/side effects/drugs interactions and assessment of any psychological issue).

If second VL>1000 copies/ml, manage as a virological failure and switch regimen.

VL#1 unsuppressed (at identification)

It is important to review the patient's **most recent CD4 count**, as this value will play a big role in deciding when to switch regimens. If the patient's CD4 count is low, we do not have time to wait to start the patient on an effective regimen. We do not have the "luxury" to work on adherence for several months only to find out later that the patient is resistant to the ARVs he/she has been taking. Therefore, the approach should be as follows: If the patient does not have a CD4 count within the previous 3 months before entering the intervention, obtain one at the introductory visit. Then, the management decision depends on whether the patient is on an NNRTI or PI based regimen:

- For patients enrolled on **NNRTI-based regimens**: if **the most recent CD4 count is less than 350, switch the patient to a PI based regimen immediately – even before beginning the adherence sessions.** The reason is that many children failing a NNRTI based regimen will already be resistant to the NNRTI when they entered the intervention. Of course, once the child is switched to a PI, it will be imperative to address the adherence issues so the patient does not fail the PI regimen. If the patient's CD4 count is more than 350, the patient can remain on the NNRTI, and the adherence sessions can proceed.
- For patients enrolled on a PI-based regimen: if the most recent CD4 count is <350, immediate switching to 3rd line is not necessary, as it is less likely that the patient will be resistant to the PI. However, obtain a genotype to check for resistance. If the CD4 count is >350, proceed through the adherence sessions.

VL#2 unsuppressed

If a patient was enrolled into the intervention on an **NNRTI-based regimen** and still has a high viral load at second VL despite addressing adherence, switch the patient to second line treatment. A genotype is not needed to confirm resistance to the NNRTI before switching. **EVEN IF IT IS KNOWN THAT THE ADHERENCE IS STILL POOR, SWITCHING SHOULD STILL BE PERFORMED.** The reason for switching is that the child is most likely resistant to the NNRTI-based regimen and therefore will never achieve a suppressed viral load on the NNRTI regimen, even if the adherence is perfect. Once switched to a PI regimen however, adherence will need to be improved to avoid failure and development of resistance to the PI regimen. Remember: a child failing ART represents an **emergency that requires urgent care.** The adherence barriers must be addressed in a timely manner through the initial adherence counselling.

Viral Load Rebound: For the child enrolled on a NNRTI or PI based regimen who achieves a suppressed VL, but then has a high VL on a subsequent blood draw (rebounds), review the initial phase adherence barriers starting from Visit #1. Domestic circumstances are dynamic and frequently change, necessitating frequent review to identify barriers to adherence. Obtain another VL within 3 months and re-assess the situation. It is good practice to note somewhere visible in the file that this patient has been through PROTf so that subsequent clinicians are aware that the child and caregiver have struggled before. This will cause them to pay particular attention to adherence issues.

FOOTNOTES

1. Rapid switching

The data from MSF's implementation of this toolkit revealed that, of the children entering the programme on a failing NNRTI regimen, only 13% were able to achieve lasting suppression on the NNRTI, while the rest required a switch.

Genotypes that were done revealed 100% resistance to the NNRTI, showing that these children would never suppress regardless of improvements in adherence. Keeping children on a failing NNRTI regimen only facilitates the accumulation of mutations, jeopardising future ARV options, and causing discouragement to children trying hard to be adherent.

PIs are known to be more robust to the development of resistance. For this reason, and because of the high prevalence of resistance in children failing an NNRTI regimen, we recommend more rapid switching of children failing an NNRTI. Rather than delaying switch to address the adherence first, we suggest addressing adherence in tandem with a regimen change (see insert below).



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2. Indications for resistance testing?

Indications will differ according to your local setting.

In our program and based on Western Cape HIV PMTCT Guidelines (see below), we used the following criteria for genotyping:

- Infants < 2 years of age who are newly diagnosed as HIV positive if their mothers were exposed to PI-based ART during pregnancy or breastfeeding.
- Children on a PI regimen with virological non-suppression defined as at least three viral load measurements of ≥ 1000 copies/ml ($\geq \log 3$) at least 8-12 weeks apart after adherence has been addressed. Children <15 years of age should have received PI regimen for at least 1 year

3. Which second and third line regimens should be used?

This is very dependent on local guidelines and it is recommended that you follow your local guideline. In our case, we refer to the Western Cape HIV PMTCT Guidelines 2018 (inserted below).



2018 Western Cape
Consolidated Guidelin

How to support caregivers and patients appropriately?

Appendix 1 shows an example of a baseline data form to use in your intervention. As can be seen, the psychosocial history plays a significant role when performing an assessment of a child with treatment failure. As such, there are many questions related to the patient's family life and domestic situation.

While the patient’s psychosocial situation will be thoroughly evaluated during all the adherence sessions, it is important to begin to understand the main barriers to adherence during this baseline assessment. When taking an initial history from a patient with treatment failure, obtaining the following data is particularly helpful:

- **Document the viral load time-line:**
 - What are the results of all the patient’s viral loads in the past?
 - When did the patient start failing treatment?
 - How long has the patient been failing treatment?
 - Has the patient ever had a suppressed viral load?
 - Who has been living with the child when the child has been failing treatment?
 - Has there ever been a time when the child was completely off treatment (defaulted treatment)?
- **Establish the day to day schedule of the child:**
 - What exactly happens in the morning and in the evening?
 - Is it the same person taking care of the child in the morning and evening? Or is it a different caregiver?
 - Does an alternate person take care of the child during the weekends and/or school holidays?
 - Does the child move to someone else’s house during the weekend or during school holidays?
 - Does the child stay with someone else during school holidays?

It is helpful to ask about alternative caregivers. If there are others who take care of the child at times it is important to invite that person or persons to come to future visit. The more caregivers who are willing to learn about how to take care of the child and be treatment supporters, the greater likelihood of treatment success.

Importantly, **write down the contact information** of the caregivers and any potential treatment supporters. This includes all **addresses where the patient stays and phone numbers of everyone** who takes care of the child. Importantly, since addresses and phone numbers frequently change, clarify the contact information at each visit.

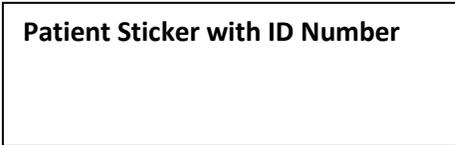
Note that counselling will differ depending on the developmental age of the patient:

- Children 0-5 years: The main caregivers, especially if it is the mother require careful support during the first year of a child’s life. Self-stigma, feelings of guilt, shame and her own health due to disease may complicate ensuring that the child remains adherent to treatment. Caregivers of children 3-5 need guidance and support to start the process of partial disclosure. Support groups for caregivers are designed to support this process and assist with empowering and motivate caregivers to ensure children adhere to treatment.
- Children 6-12 years: Caregivers of children aged 6-12 need guidance and support to continue the process from partial to full disclosure. **THIS IS THE REASON FOR NO DIRECT COUNSELLING TO THIS GROUP UNLESS A DISCLOSURE GUIDELINE IS FOLLOWED.**
Support groups for caregivers are designed to support this process and assist with empowering and motivating caregivers to ensure children adhere to treatment
- Adolescents: HIV positive adolescents face additional challenges besides puberty and a developing body and brain. Adherence to treatment is challenging and therefore counselling sessions re designed to empower and equip adolescents to deal with adherence barriers and development related challenges.

Adherence session guides are found in appendix 2, support group session guides in appendix 3 and a home visit guide in appendix 4.

Appendix 1: Patient Baseline Data

Paediatric Treatment Failure Intervention
Baseline Patient Data



Date	
Male or Female	
Date of Birth	

Vertical or Horizontal Infection?	
History of PMTCT?	
Date when started ART	
History of Defaulting?	
ARV Viral Load History/Timeline (Has Patient Ever Been Suppressed? How long failing on current regimen?)	
Current Line of ARV's (1 st , 2 nd , 3 rd)	
Current ARV's	
Other Medications	
Known Drug Allergies?	
History of Medication Side Effects	
History TB? If so, when? Treated?	
Current TB?	
Other Past Co-Morbidities	
Other Current Co-Morbidities	
Primary Caretaker/Contact Details	
Primary Caretaker HIV Status	
Who lives at home?	
Treatment Supporter? If so, who?	
Method for Remembering ARVs	
Disclosure Status	
Patient's Daily Routine (Who gives ARVs in morning and at night? Does situation change on the weekend?)	
Major Barriers to Adherence: 1. 2. 3. 4.	Additional Notes:

Appendix 2: Adherence Tools: Individual Sessions – Adherence Plan and Session Guides

- **Adolescent Adherence Plan and Adherence Session Guide** (Appendix 2.1)
- **Caregiver Adherence Plan and Adherence Session Guide** (Appendix 2.2)
- Accompanying each of the session guides is an **Adherence Plan**. This plan is meant to be used by the clinician during the corresponding adherence session and completed *by the caregiver or adolescent*. Through completing the adherence plan, the messages of the adherence sessions are reinforced. In addition, the caregivers and adolescents are forced to think about their psychosocial situation and

how the administration of ARVs fits in with their daily routine. Ideally, a copy of this plan is made, with the original kept in the patient's file at the clinic for documentation purposes and the copy given to the patient to use at home and bring to each appointment. If photocopying is not available, simply keep the adherence plan in the patient's file and review it with the caregiver or adolescent at each appointment.

- Before starting session 1, have the caregiver or adolescent write down their "3 Reasons to Stay Healthy". If you are counselling a caregiver, ask the caregiver, "What are 3 reasons you want your child to stay healthy?" or alternatively "What are 3 goals you have for your child?" If counselling an adolescent, ask him/her, "What are 3 reasons you want stay healthy?" or "What are 3 goals you have for your future?" Review the list with them at each clinic visit.
- A word about the length of the appointments: You will notice **that first three adherence sessions are longer than the latter ones**. This is done on purpose. We have found is that it is important to give the majority of the information early in the counselling process, and then to review the material at each subsequent appointment. Please try to be thorough when performing these adherence sessions. It is imperative to figure out what the main psychosocial barriers are to adherence. Unfortunately, this may take some time at the beginning of the process. However, time taken early in the intervention will reap benefits later on when the patient is re-suppressed and doing well, as these appointments can then be much shorter.
- Lastly, you will notice that the adherence sessions are **very detailed**. They go through the step-by-step process of how to be adherent to medication. Since just one small barrier can lead to poor adherence and a high viral load, it is important to be very specific in your adherence counselling. In short, "The devil is in the details" when it comes to paediatric HIV medicine. Be very detail-oriented when performing your adherence counselling, and make sure to follow-up any "red flag" responses with additional probing questions.

Appendix 2.1: Adolescent Adherence Plan

<u>Adolescent Adherence Plan</u>		
<u>My Three Life Goals:</u>		
1.		
2.		
3.		
Initial Phase		
<u>Session 1:</u>	Knowledge of HIV/Viral Load/ARV's	The reason my viral load is high:
	Dosing Time and Storage	Time I take my medication: Place I take my medication: Place I store my medication: Second "Emergency" storage location: _
	Missed Doses and Missed Appointments	Plan if I miss a dose of medication: My plan if my medication runs out before my next appointment: I get to my appointment by: My backup plan for getting to my appointments is:
<u>Session 2:</u>	Review	Any problem with taking my medication: My plan to fix the problem:
	Disclosure	People who know I am HIV positive: Who I would like to disclose to in the future:
	Support System	Members of my support system: Contact person in the program:
	Support when I go on holiday	Place I store my medication when I travel: Place I will keep my green card when I travel: Phone number of my clinic:
<u>Session 3:</u>	Review	Any problem with taking my medication: My plan to fix the problem:
	Substance Use/Peer Pressure/Stress	My plan to deal with my stress: My plan to deal with peer pressure: My plan to take ARVs when I feel peer pressure: My plan to take my ARVs if I go out drinking/using drugs: My other options to drinking when I am stressed:

Appendix 2.2.1: Adolescent initial adherence session 1

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed.

Barrier: Lack of knowledge about HIV and ARVs

<p>Review 3 reasons to stay healthy</p>	<p><i>“In your initial visit at the intervention, we discussed your 3 reasons to stay healthy. Let’s go through these goals for the future now. We will put a sticker on your adherence plan to help you remember them.”</i></p>
<p>Knowledge of HIV/Viral Load/ARVs</p>	<p>Discuss the adolescent’s general knowledge about HIV and ARVs.</p> <ul style="list-style-type: none"> • <i>“It is important for you to understand how HIV can affect your health and how the medicines that he/she is taking (the anti-retrovirals or ARVs) can help you stay healthy. Let’s review these things. Also, there are a lot of myths about HIV and ARVs. Let’s talk about these so that you have a good understanding of HIV and ARVs.”</i> • <i>Do you know what the following terms mean? (Ask the adolescent to explain these terms to you.)</i> <ul style="list-style-type: none"> ○ Viral load ○ High viral load ○ Undetectable viral load. • <i>Do you know what happens if your viral load is high?</i> <ul style="list-style-type: none"> ○ The higher their viral load, the greater chance you will become ill. ○ The main job of ARV’s is to lower the viral load. ○ ARV’s work best if they are taken at the same time every day. However, there is some flexibility with the times you take the medicine. (This will be discussed further below). <p>Discuss the adolescent’s reasons for having a high viral load and how we will work together to help him/her.</p> <ul style="list-style-type: none"> • <i>Why do you think your viral load is high?</i> • <i>What makes it difficult for you to take the medication as prescribed?</i> <ul style="list-style-type: none"> • Responses may include: <ul style="list-style-type: none"> • “I forget to take the medicine” • “I don’t want anyone to know I take the medicine” • “I run out of medicine” <p>Discuss the following with the patient:</p> <ul style="list-style-type: none"> • The reason you have been referred to this clinic is that the viral load is high. We need to address this so that you will remain healthy. • It can be difficult to remember to take ARVs. It can be overwhelming. However, with practice it can become part of your everyday routine. • We are here to help you figure out ways for you to remember to take your ARVs and keep your viral load low.

<p>Timing, dosages and Storage</p>	<p>Review the time and place the medication is taken:</p> <ul style="list-style-type: none"> • <i>“What time do you take your medication?”</i> • <i>“Where do you take the medication? At home? At school?”</i> • <i>“Is this different on weekends?”</i> <ul style="list-style-type: none"> ○ Establish the times and place(s) they take their medication. ○ If they are having problems with the time and place the medication is given, establish more appropriate times and locations. ○ Discuss the flexibility with taking the medication. It is no longer necessary to take ARVs at the exact same time every day. They do not need to be taken exactly 12 hours apart (e.g. 7 in the morning and 7 at night). There can be flexibility of a few hours. The most important thing is not to miss/skip any doses entirely. ○ Discuss how ARVs can be taken at different times on the weekends if their schedule is much different on weekends (for example they may sleep until 10am on weekend days, so the times they give the ARVs will be different. This is ok to do if necessary. ○ Remind the adolescent that if they do forget a dose, they should take the dose as soon as they remember it, no matter how many hours later. The next dose should then be taken at the normal/usual time. <p>Discuss where and how they store the medication:</p> <ul style="list-style-type: none"> • <i>“Where do you keep the medication?”</i> <ul style="list-style-type: none"> ○ Help the adolescent to identify a place in the home where they are going to keep the medication. If they are afraid of people finding the medication, then brainstorm a good place to hide them. <p>Help the adolescent decide where to keep extra/emergency doses:</p> <ul style="list-style-type: none"> • <i>“It is important to have extra doses/emergency doses of medication available. Do you keep an extra dose somewhere?”</i> • <i>“If so, where do you keep it?”</i> <ul style="list-style-type: none"> ○ Discuss the importance of keeping an extra supply of tablets in specific places. ○ Help the adolescent to identify where they can keep an extra supply of medication in case they are not at home when it is time to take the medication (for example a girl might keep extra tablets in her handbag). ○ These tablets would only be used in emergency cases when they are not at home in time to give the dose.
<p>Missed Doses</p>	<p>Discuss missing doses:</p> <ul style="list-style-type: none"> • <i>“How often do you miss a dose of medicine?”</i> • <i>“What do you do when you miss a dose of medicine? Do you wait until it’s time to take the next dose?”</i> • <i>“What are the reasons you miss doses?”</i>

	<ul style="list-style-type: none"> ○ Discuss with the adolescent what to do if they miss a dose of medicine. <u>If a medication dose is missed, they should take the dose as soon as they remember, no matter how late it is. The next dose should be taken at the normal/regularly-scheduled time.</u> ○ Discuss what led to the interruption. This can provide important information to the adolescent so that the interruption can be prevented in the future. ○ It is important to tell the adolescent not to beat himself/herself up. Normalise the interruption. They need to tell themselves that they are only human and mistakes happen. ○ Stress that the important thing is to learn from the mistake. This will help them to prevent it from happening again. ○ Tell them that If they continue making mistakes and missing doses, they need to let us know so that we can address the problem together.
<p>Missed appointments</p>	<ul style="list-style-type: none"> ● <i>How often do you miss appointments?</i> ● <i>What are the reasons you miss appointments? School? Transportation problems? Forgetting?</i> <ul style="list-style-type: none"> ○ Help the adolescent identify barriers to getting to his/her appointments. ○ Help the adolescent problem-solve ways to overcome these barriers to getting to the appointments. <ul style="list-style-type: none"> ▪ For example, if they tend to forget, receiving a text message the day before may help to remind them. ▪ For example, the days and times of their appointments can be altered if they conflict with school duties. ○ Make a plan for getting to the appointments: <ul style="list-style-type: none"> ▪ Ask how they get to the medical appointments. ▪ Ask what they would do if their usual way of getting to their appointment was not available (for example if they usual take the train to get to their appointments and the train was not running). What is their backup plan? Is there anyone who can help them get to their appointments?
<p>At the end of the session, make sure the adolescent completes the adherence plan</p>	

Appendix 2.1.2: Adolescent initial adherence session 2

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed.

Barrier: Disclosure

Review 3 reasons to stay healthy	<i>In your initial visit at the program, we discussed your 3 reasons to stay healthy. Let's go through them now. We will put a sticker on your adherence plan to help you remember them.</i>
Review adherence challenges	<p><i>Have you had any difficulties taking your medication since your last appointment?</i></p> <p><i>Do you think your adherence has improved?</i></p> <ol style="list-style-type: none"> <i>a. Enquire if any doses have been missed.</i> <i>b. Discuss ways to overcome any difficulties that may have been encountered.</i>
Disclosure	<p>Discuss the benefits of disclosure:</p> <ul style="list-style-type: none"> • <i>What do you think are the benefits of disclosure?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> • The person you discuss with could be someone you can talk to • The person you disclose to can help you remember to take your medication • The person you disclose to can help you if you are ever ill <p>Discuss why disclosing to people can be difficult:</p> <ul style="list-style-type: none"> • <i>Why can disclosure be difficult? What do you think are the barriers to disclosure?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> ▪ Fear of rejection ▪ Fear of stigma ▪ Fear of violence <p>Discuss to whom they have disclosed:</p> <ul style="list-style-type: none"> • <i>Who have you disclosed to?</i> • <i>What was their reaction?</i> • <i>How did their reaction make you feel?</i> <p>Discuss how they disclose to people:</p> <p>Discuss how they disclose to people. Once they have decided to disclose, it is important for them to think carefully about the following:</p> <ul style="list-style-type: none"> ○ Who do you want to tell and why ○ Disclosing is your choice and right ○ You should trust your instincts ○ You don't need to apologize for having HIV ○ It may be hard for someone else to hear you have HIV – especially if they care about you. Remember how you felt when you first heard about your status. Remember that others may also be saddened or upset for a while. Try to understand this.
Support System	<p>Discuss the support system of the adolescent:</p> <ul style="list-style-type: none"> ○ <i>Who lives do you live with?</i> ○ <i>Do the other people in the household know that you are HIV positive?</i> ○ <i>Do they help you with taking your medication?</i>

	<ul style="list-style-type: none"> ○ Discuss how difficult it is to consistently take the medicine without the help of others. Suggest to the adolescent that he/she enlists the support of family members and friends in reminding him/her to take the medication. <p>Discuss the need to have a support system if/when they move:</p> <ul style="list-style-type: none"> ● <i>Have you moved often in the past and/or are there plans for you to move in the future?</i> <ul style="list-style-type: none"> ○ Stress the importance of forming a new support system if/when they ever move to a new house. They should always have someone close to them that knows they are HIV positive and can provide support and help them with taking the medication.
<p>Adherence during holidays</p>	<p>Discuss preparing for times when on holiday or not at home:</p> <p><i>Will you be going on holiday this year or spending any time away from home?</i></p> <ul style="list-style-type: none"> ● Holidays are difficult times to remain adherent to medication. Encourage the adolescent to plan for holidays and travel. The adolescent can ask the clinician for enough medication to last for the time away from home even if it is longer than 1 month. It is important to pack enough medication to last the entire trip. ● Advise the adolescent to have all relevant information on his/her green card – most importantly the home clinic’s phone number and their patient number at the clinic. It also helps to put these numbers onto their phone. The adolescent can also ask the clinician to ensure that the adolescent’s current medication regimen and doses, latest viral load, and latest CD4 count are also reflected on their green card. ● Explain to them that if they are ever away from home and they run out of medicine that they must go to the nearest ARV clinic and show their green card, even if that clinic does not use green cards. Hopefully, the clinic can help them and give them medication. If the clinic wants to check that the adolescent is taking ARV’s, the nurse should call the clinic phone number on the green card. If the clinic can’t help, they should contact (name of relevant doctor or nurse) for help. <p>Discuss with the adolescent if the people whom they will be visiting know if they are HIV positive. If not, discuss if this will be a problem and if so how they will approach the situation.</p> <p>Discuss the importance of coming to the clinic before their medication runs out – even if they cannot make their scheduled appointment.</p> <ul style="list-style-type: none"> ● <i>It is important for you to come back to clinic before you run out of medicine. Even if it is not the scheduled day for your appointment, come to the clinic to get more medication. We will ensure that you are seen and receive the medication.</i>
<p>Obtaining the adolescent’s viral load (if 3 months since last VL)</p>	<p><i>We are going to draw your blood today to check your viral load.</i></p> <ul style="list-style-type: none"> ● Remind the adolescent that the time has come to repeat their viral load. <i>We will discuss your result at your next visit.</i> ● <i>We need to know if your HIV is increasing or decreasing so that we can plan a way forward”</i>
<p>At the end of the session, make sure the adolescent completes the Adherence Plan!</p>	

Appendix 2.1.3: Adolescent initial adherence session 3

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed.

Barrier: Stress, peer pressure and substance use. Viral load results.

<p><i>Introduction:</i></p> <p>Review 3 Reasons to Stay Healthy</p>	<p><i>In your initial visit at the program, we discussed your 3 reasons to stay healthy. Let's go through them now. We will put a sticker on your adherence plan to help you remember them.</i></p>
<p><i>Review adherence challenges</i></p>	<ul style="list-style-type: none"> • <i>Have you had any difficulties taking your medication since your last appointment?</i> • <i>Do you think your adherence has improved?</i> <ul style="list-style-type: none"> ○ Enquire if any doses have been missed. ○ Discuss ways to overcome any difficulties that may have been encountered.
<p><i>Stress and adherence</i></p>	<p>Discuss the causes of stress in the adolescent's life, the effects of stress, and coping mechanisms for stress:</p> <ul style="list-style-type: none"> • <i>What causes stress in your life?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> ▪ Stress about school ▪ Stress about a boyfriend or girlfriend ▪ Stress about disclosure ▪ Stress about a family situation • <i>What happens when you feel stressed?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> ▪ I feel mad, sad, violent, upset, anxious • <i>What do you do when you feel stressed?</i> • <i>What are some good and bad ways to cope with stress?</i> <ul style="list-style-type: none"> ○ Good coping examples: listen to music, exercise, talk to someone about the source of stress ○ Bad coping examples: becoming violent, yelling a people, drinking alcohol, doing drugs ○ <i>What have you learned in your support group with the counsellor about coping mechanisms?</i> <ul style="list-style-type: none"> ▪ Explore coping mechanisms that will work for the adolescent.
<p><i>Peer pressure and adherence</i></p>	<p>Discuss how peer pressure can affect the adolescent's life and their adherence, and ways they can deal with peer pressure:</p> <ul style="list-style-type: none"> • <i>What would be an example of peer pressure?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> ▪ <i>Being pressured to go out when you don't have your ARV's with you</i> ▪ <i>Feeling pressure that you can't talk about having HIV.</i> • <i>How can peer pressure negatively affect your life?</i> • <i>Do you think peer pressure could be a barrier to taking your ARV's?</i> • <i>How do you deal with peer pressure?</i> <ul style="list-style-type: none"> ○ Examples include: <ul style="list-style-type: none"> ▪ Giving in to the peer pressure ▪ Ignoring the peer pressure ▪ Becoming angry or sad • <i>What plan can we make to help you deal with peer pressure?</i> <ul style="list-style-type: none"> ○ Strategize ways the adolescent can address peer pressure
<p><i>Substance use</i></p>	<p>Discuss if/how substance use or abuse affects their life and their adherence. Explore ways to address this issue:</p> <ul style="list-style-type: none"> • <i>How do you think substance use or abuse may affect your ARV medication and your adherence?</i> <ul style="list-style-type: none"> ○ Taking alcohol or drugs makes it difficult for you to remember to take treatment. If possible it is best to limit your use, but if you are planning to take any alcohol or drugs,

	<p>perhaps at a party, it is important to plan ahead so that you don't forget to take your treatment.</p> <ul style="list-style-type: none"> • <i>How often do you use alcohol and drugs (assess if more than 3 times a week, and how much)</i> • <i>Has this had any effect on adhering to your medication in the past 2 weeks?</i> • Make a plan: • <i>In case you are going to drink alcohol or use drugs, what could you do to make sure you remember to take your treatment?</i> <ul style="list-style-type: none"> ○ For example: take your ARV's before you go out drinking. ○ If you are already out, ask a friend who is not drinking to make sure you take your treatment.
<p>Viral load results</p>	<ul style="list-style-type: none"> • <i>"We drew your last month to check your viral load. I want to discuss the result with you."</i> <p>Use the following as a guide depending on his/her result:</p> <ul style="list-style-type: none"> ○ Viral Load <400 → <ul style="list-style-type: none"> ▪ <i>"Your next visit to the intervention will be in 1 month. You will only see a nurse at that time."</i> ▪ Congratulate the adolescent on doing a great job! Well done! You have been working incredibly hard to make sure you take your ARV's correctly. Be proud! Now the goal is to keep up the good work for the long term. ○ Viral Load > 400 → <ul style="list-style-type: none"> ▪ The plan for the adolescent will depend on how high the result is: ▪ If the viral load has decreased significantly but is still detectable: <ul style="list-style-type: none"> • Congratulate the adolescent on doing a good job! • <i>We realize that taking ARV's is a very difficult thing to do. You have been working incredibly hard to make sure you take your ARV's. Be proud! Now the goal is to keep up the good work for the long term.</i> • <i>Your next visit to the intervention will be in 1 month. You will continue seeing a doctor and nurse at that time.</i> ○ If the viral load has not come down significantly: <ul style="list-style-type: none"> • <i>We realize that taking ARV's is a very difficult thing to do. The important thing is to not become unmotivated at this point. Sometimes it can take longer to get this right and for the viral load to become undetectable. We will continue to work together to find ways to help you in taking the ARV's.</i> • <i>Your next visit to the intervention will be in 2 weeks. You will continue seeing a doctor and a nurse at that time.</i>
<p>At the end of the session, make sure the adolescent completes the Adherence Plan!</p>	

NOTE RE SUBSTANCE USE: Please note that for adolescent substance use does the following:

- It affects their growth and development, especially brain development.
- It coincides with other risky behaviors, such as unprotected sex and dangerous driving.
- It can contribute to the development of adult health problems, such as heart disease, high blood pressure, and sleep disorders.

- If the adolescents start using substance at a young age they have a greater their chances of continuing to use substances and developing substance use problems later in life.

If substance use intervention referral resources are available, please refer adolescents who are motivated to change.

See: <https://www.cdc.gov/features/teen-substance-use/index.html>

Appendix 2.1.4: Adolescent maintenance adherence sessions

Maintenance Phase	
Session #1	
<p>Review three goals for the future!</p>	<p>Review the following:</p> <p>Review adherence challenges</p> <ul style="list-style-type: none"> • <i>Have you had any difficulties taking your medication since your last appointment?</i> • <i>Do you think your adherence has improved?</i> <ul style="list-style-type: none"> ○ Enquire if any doses have been missed. ○ Discuss ways to overcome any difficulties that may have been encountered.
Session#2	
<p>Review three goals for the future!</p> <p>Preparing the adolescent for viral load</p>	<p>Review adherence challenges</p> <ul style="list-style-type: none"> • <i>Have you had any difficulties taking your medication since your last appointment?</i> • <i>Do you think your adherence has improved?</i> <ul style="list-style-type: none"> ○ Enquire if any doses have been missed. ○ Discuss ways to overcome any difficulties that may have been encountered. <p>Obtaining the adolescent’s viral load:</p> <ul style="list-style-type: none"> • <i>We are going to draw your blood today to check your viral load.</i> <ul style="list-style-type: none"> ○ Remind the adolescent that the time has come to repeat their viral load. We will draw blood today and will discuss your result at your next visit. ○ “We need to know if your HIV is increasing or decreasing so that we can plan a way forward.”
Session # 3	
<p>Review three goals for the future!</p> <p>Giving the adolescent for viral load results</p>	<p>Review three goals</p> <ul style="list-style-type: none"> • <i>Let’s review your three goals for the future!</i> <p>Review adherence challenges</p> <ul style="list-style-type: none"> • <i>Have you had any difficulties taking your medication since your last appointment?</i> • <i>Do you think your adherence has improved?</i> <ul style="list-style-type: none"> ○ Enquire if any doses have been missed. ○ Discuss ways to overcome any difficulties that may have been encountered.

Discussing the adolescent's viral load:

- *"We drew your last month to check your viral load. I want to discuss the result with you."*

Use the following as a guide depending on his/her result:

- Viral Load <400 →
 - *"Your next visit to the intervention will be in 1 month. You will only see a nurse at that time."*
 - Congratulate the adolescent on doing a great job! Well done! You have been working incredibly hard to make sure you take your ARV's correctly. Be proud! Now the goal is to keep up the good work for the long term.
- Viral Load > 400 →
 - The plan for the adolescent will depend on how high the result is:
 - If the viral load has decreased significantly but is still detectable:
 - Congratulate the adolescent on doing a good job!
 - *We realize that taking ARV's is a very difficult thing to do. You have been working incredibly hard to make sure you take your ARV's. Be proud! Now the goal is to keep up the good work for the long term.*
 - *Your next visit to the intervention will be in 1 month. You will continue seeing a doctor and nurse at that time.*

If the viral load has **not** come down significantly:

- *We realize that taking ARV's is a very difficult thing to do. The important thing is to not become unmotivated at this point. Sometimes it can take longer to get this right and for the viral load to become undetectable. We will continue to work together to find ways to help you in taking the ARV's.*
- *Your next visit to the intervention will be in 2 weeks. You will continue seeing a doctor and a nurse at that time.*

Appendix 2.2: Caregiver Adherence Plan

	<p>My Three Goals for my child's future:</p> <p>1.</p> <p>2.</p> <p>3.</p>	
Session 1	Caregiver knowledge of HIV/Viral Loads/ARVs	The reason your viral child's viral load is high:
	Medication Administration and storage	<p>Time you give your child medication:</p> <p>Place you give your child medication:</p> <p>Place your store your child's medication:</p> <p>Second EMERGENCY storage location:</p>
	Missed Doses	<p>Plan if my child missed a dose of medication:</p> <p>Plan if my child misses a clinic appointment:</p>
	Side Effects of Medication	<p>Plan if minor side effect arises:</p> <p>Plan if a serious side effect arises:</p>
	Missed Appointments	<p>How you get to your child's appointments:</p> <p>Alternative way of getting to your child's appointment:</p> <p>Contact person in the clinic:</p>
Session 2	Review	<p>Any new problem with giving my child medication:</p> <p>My plan to fix the problem:</p>
	Disclosure	Level of disclosure of my child:
	Support system	Members of my support team:

		People who know my child is HIV positive: People who help me to remember to give the medication:
Session 3	Review	Any new problem with giving my child medication: My plan to fix the problem:
	Preparing for holidays	My plan to fix the problem: Place I store my child's medication when I travel: Place I will keep my child's green card when I travel: Phone number of my home clinic: My child's viral load:

Note: Review adherence challenges during follow-up appointments in the Maintenance phase

Follow-up Sessions :

Review:

Any new problem with giving my child medication: _____

My plan to fix the problem: _____

Appendix 2.2.1: Caregiver initial adherence session 1

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed.

Barrier: Lack of knowledge about HIV and ARVs

<p>Review 3 goals for the child's future</p>	<p><i>"In your initial visit at the intervention, we discussed the 3 reasons you want your child to remain healthy. Let's go through these goals for the future now. We will put a sticker on your adherence plan to help you remember them."</i></p>
<p>Care giver knowledge of HIV/Viral Load/ARVs</p>	<p>Discuss the caregiver's general knowledge about HIV and ARVs.</p> <ul style="list-style-type: none"> • <i>"It is important for you to understand how HIV can affect your child's health and how the medicines that he/she is taking (the anti-retrovirals or ARVs) can help him/her stay healthy. Let's review these things. Also, there are a lot of myths about HIV and ARVs. Let's talk about these so that you have a good understanding of HIV and ARVs."</i> • <i>Do you know what the following terms mean? (Ask the caregiver to explain these terms to you.)</i> <ul style="list-style-type: none"> ○ Viral load ○ High viral load ○ Undetectable viral load. • <i>Do you know what happens if your child's viral load is high?</i> <ul style="list-style-type: none"> ○ The higher their viral load, the greater chance he/she will become ill. ○ The main job of ARV's is to lower the viral load. ○ ARV's work best if they are taken at the same time every day. However, there is some flexibility with the times you take the medicine. (This will be discussed further below). <p>Make sure the caregiver understands the following:</p> <ul style="list-style-type: none"> • If you child takes the ARV's as prescribed the viral load will remain low. • The reason your child has been referred to this clinic is that the viral load is high. We need to address this so that your child will remain healthy. • It can be difficult to remember to give your child ARVs. It can be overwhelming. However with practice it can become part of your everyday routine. • We are here to help you figure out ways for you to remember to give your child his/her ARVs and keep his/her viral load low. <p>Discuss the caregiver's reasons for the child's high viral load and how we will work together to help improve the situation:</p> <ul style="list-style-type: none"> • <i>Why do you think your child's viral load is high?</i> • <i>What makes it difficult for you to give the medication as prescribed?</i> <ul style="list-style-type: none"> • Responses may include: <ul style="list-style-type: none"> • "I forget to give the medicine" • "I don't want anyone to know my child takes the medicine"

	<ul style="list-style-type: none"> • “I run out of medicine” <p>Review the child’s “journey” in the clinic. – there are frequent appointments, each appointment starts with a support group session with the counsellor, a viral load will be drawn at 3 months, and the child’s course in the clinic will depend on the result of this viral load. If it is undetectable, then the child will return each month for another three months at which time a second viral load will be drawn. If this second viral load is again undetectable, then the child will be discharged from the PACC to an adherence club. If the child’s viral loads continue to be detectable, a different visit plan will be discussed with the doctor.</p>
<p>Medication Administration and Storage:</p>	<p>Review your 3 goals for your child for the future.</p> <ul style="list-style-type: none"> • <i>“In your initial visit at the intervention, we discussed the 3 reasons you want your child to remain healthy. Let’s go through these goals for the future now. We will put a sticker on your adherence plan to help you remember them.”</i> <p>Review the time and place the medication is given:</p> <ul style="list-style-type: none"> • <i>“What time do you give the child the medication?”</i> • <i>“Where do you give the medication? At home? When you are out?”</i> • <i>“Is this different on weekends?”</i> <ul style="list-style-type: none"> ○ Establish the times and place(s) they take their medication. ○ If they are having problems with the time and place the medication is given, establish more appropriate times and locations. ○ Discuss the flexibility with taking the medication. It is no longer necessary to take ARVs at the exact same time every day. They do not need to be taken exactly 12 hours apart (e.g. 7 in the morning and 7 at night). There can be flexibility of a few hours. The most important thing is not to miss/skip any doses entirely. ○ Discuss how ARVs can be taken at different times on the weekends if their schedule is much different on weekends (for example they may sleep until 10am on weekend days, so the times they give the ARVs will be different. This is ok to do if necessary. ○ Remind the caregiver that if they do forget a dose, they should give the dose as soon as they remember it, no matter how many hours later. The next dose should then be taken at the normal/usual time. <p>Discuss what the caregiver does if the child refuses to take the medication or vomits the medication:</p> <ul style="list-style-type: none"> • <i>“What do you do if your child refuses to take the medication?”</i> <ul style="list-style-type: none"> ○ Provide the caregiver with a few ideas of how they can motivate the child, for example they can get a toy if they take their medicine perfectly for the month. • <i>“What do you do if your child vomits the medication?”</i> <ul style="list-style-type: none"> ○ Remind the caregiver that if the child vomits the medication, the dose should be given again.

	<p>Discuss where and how they store the medication:</p> <ul style="list-style-type: none"> • <i>“Where do you keep the medication?”</i> <ul style="list-style-type: none"> ○ Help the caregiver to identify a place in the home where they are going to keep the medication. If they are afraid of people finding the medication, then brainstorm a good place to hide them. ○ If their child is taking a medication that needs to be kept cool, then ask the caregiver how they are doing this. If the house has no refrigerator, suggest that the caregiver could place the medicine in a clay pot and place the pot onto the floor (or dig a shallow hole if possible). <p>Help the caregiver decide where to keep extra/emergency doses:</p> <ul style="list-style-type: none"> • <i>“It is important to have extra doses/emergency doses of medication available. Do you keep an extra dose somewhere?”</i> • <i>“If so, where do you keep it?”</i> <ul style="list-style-type: none"> ○ Discuss the importance of keeping an extra supply of tablets in specific places. ○ Help the caregiver to identify where they can keep an extra supply of medication in case they are not at home when it is time to give the medication (for example a woman might keep extra tablets in her handbag). ○ These tablets would only be used in emergency cases when they are not at home in time to give the dose.
<p>Missed Doses</p>	<p>Discuss missing doses:</p> <ul style="list-style-type: none"> • <i>“How often do you miss a dose of medicine?”</i> • <i>“What do you do when you miss a dose of medicine? Do you wait until it’s time to take the next dose?”</i> • <i>“What are the reasons you miss doses?”</i> <ul style="list-style-type: none"> ○ Discuss with the caregiver what to do if they miss giving a dose of medicine. <u>If a medication dose is missed, they should give the dose as soon as they remember to give it, no matter how late it is. The next dose should be given at the normal/regularly-scheduled time.</u> ○ Discuss what led to the mistake. This can provide important information to the caregiver so that the mistake can be prevented in the future. ○ Stress that mistakes are normal and a part of life. The important thing is to learn from the mistake so that it does not happen again. ○ It is important to tell the caregiver not to beat himself/herself up about making a mistake. They need to tell themselves that they are only human and mistakes happen, but that they must continue giving the medication to the child. If they continue making mistakes and missing giving doses, they need to tell the clinic about this so any problems can be addressed.

Side Effects to medication	<p>Discuss the side effects of the medication:</p> <ul style="list-style-type: none"> • Discuss what the caregiver will do if the child experiences a minor side effect of the medication. • Discuss what the caregiver will do if the child experiences a serious side effect of the medication.
Missed appointments	<ul style="list-style-type: none"> • <i>How often do you miss appointments?</i> • <i>What are the reasons you miss appointments? Transportation problems? Forgetting?</i> <ul style="list-style-type: none"> ○ Help the caregiver identify barriers to getting to his/her appointments. ○ Help the caregiver problem-solve ways to overcome these barriers to getting to the appointments. <ul style="list-style-type: none"> ▪ For example, if they tend to forget, receiving a text message the day before may help to remind them. ▪ For example, the days and times of their appointments can be altered if they conflict with work or other obligations. ○ Make a plan for getting to the appointments: ○ Ask how they get to the medical appointments. ○ Ask what they would do if their usual way of getting to their appointment was not available (for example if they usual take the train to get to their appointments and the train was not running). What is their backup plan? Is there anyone who can help them get to their appointments?
Forward planning to prevent running out of medicine	<p>Discuss the importance of coming to the clinic before the child’s medication runs out – even if they cannot make their scheduled appointment.</p>
<p>At the end of the session complete an adherence plan</p>	

Appendix 2.2.2: Caregiver initial adherence session 2

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed. Barrier: Disclosure and support structure

Review 3 goals for the child’s future	<i>Can you remind me of the 3 reasons why you want your child to remain healthy.</i>
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Review adherence challenges	<p><i>Have you had any difficulties giving the medication since your last appointment? Do you think your adherence has improved?</i></p> <ul style="list-style-type: none"> ▪ Enquire if any doses have been missed. ▪ Discuss ways to overcome any difficulties that may have been encountered.
Disclosure	<p>Ask about disclosure of HIV:</p> <ul style="list-style-type: none"> • Have you disclosed to your child his/her HIV status? Is it full or partial disclosure? <ul style="list-style-type: none"> ▪ Mention the process of disclosure and how we will be working on this throughout the child's time in the intervention. ▪ Discuss how disclosure plays a role in adherence and how problems with disclosure can decrease adherence.
Support System	<p>Discuss the support system of the caregiver and child:</p> <ul style="list-style-type: none"> ▪ <i>Who lives with the child and caregiver?</i> ▪ <i>Do the other people in the household know that the child is HIV positive?</i> ▪ <i>If they do know the child is HIV positive, do any of them help you to remember to give the medication?</i> <ul style="list-style-type: none"> ○ Discuss how difficult it is to give the medicine consistently without the help of others. Suggest to the caregiver that he/she enlists the support of family members and friends in reminding him/her to give the medication. <p>Discuss alternative caregivers:</p> <ul style="list-style-type: none"> • <i>Are there other people who help to take care of the child and help with giving the medication?</i> <ul style="list-style-type: none"> ▪ Explain that there should be one clearly assigned <u>alternative caregiver</u> to give medication when the primary caregiver is not there. Ask if there is any other person (family member or friend) who is willing to give the medication if the primary caregiver is not able to do so. ▪ If not, discuss if an alternative person can be found and entrusted to give the medication to the child. <p>Discuss the need to have a support system if/when they move:</p> <ul style="list-style-type: none"> • <i>Have you moved often in the past and/or are there plans for you to move in the future?</i> <ul style="list-style-type: none"> ▪ Stress the importance of forming a new support system if/when they ever move to a new house. They should always have someone close to them that knows their child is HIV positive and can provide support and help them with giving the medication.
Obtaining the child's viral load	<p>Remind the caregiver that the time has come to repeat their child's viral load. Check the caregiver's understanding of viral load.</p> <ul style="list-style-type: none"> • <i>We need to know if the child's HIV is increasing or decreasing so that we can plan a way forward.</i>
<p>At the end of the session complete the adherence plan</p>	

Appendix 2.2.3: Caregiver initial adherence session 3

Facilitated by Doctor and/or Nurse with Counsellor assistance when needed.

Barrier: Planning for travel

Review 3 goal for the child's future	<i>Can you remind me of the 3 reasons why you want your child to remain healthy.</i>
Review adherence challenges	<p><i>Have you had any difficulties giving the medication since your last appointment?</i></p> <p><i>Do you think your adherence has improved?</i></p> <ul style="list-style-type: none"> • Enquire if any doses have been missed. • Discuss ways to overcome any difficulties that may have been encountered.
Disclosure	<p>Ask about disclosure of HIV:</p> <ul style="list-style-type: none"> • Have you disclosed to your child his/her HIV status? Is it full or partial disclosure? <ul style="list-style-type: none"> o Mention the process of disclosure and how we will be working on this throughout the child's time in the intervention. o Discuss how disclosure plays a role in adherence and how problems with disclosure can decrease adherence.
Support System	<p>Preparing for times when on holiday or not at home:</p> <ul style="list-style-type: none"> • <i>Will you be going on holiday this year or spending any time away from your home?</i> <ul style="list-style-type: none"> o Holidays are difficult times to remain adherent to medication. Encourage the caregiver to plan for holidays and travel. The caregiver can ask the clinician for enough medication to last for the time away from home even if longer than 1 month. It is important to pack enough medication to last the entire trip. o Advise the caregiver to have all relevant information about the child on his/her green card – most importantly the clinic's phone number and the child's patient number at the clinic. It also helps to put these numbers onto the caregiver's phone (assist caregiver to do this). The caregiver can ask the clinician to ensure that the child's current medication regimen and doses, and the latest viral load and CD4 are also reflected on the green card. o Explain to them that if they are ever away from home and they run out of medicine that they must go to the nearest ARV clinic and show the child's green card even if that clinic does not use green cards. Hopefully, the clinic can help them and give them medication. If the clinic wants to check that the child is taking ARVs, the nurse should call the clinic phone number on the green card. If the clinic can't help, they should contact (name of the intervention nurse or doctor) for help. o Discuss with the caregiver if the people whom they will be visiting know if the child is HIV positive. If not, discuss if this will be a problem and if so how the caregiver will approach the situation.

<p>Giving the child's viral load results</p>	<ul style="list-style-type: none"> • <i>We drew your child's blood last month to check his/her viral load. I want to discuss the result with you.</i> <p>Use the following as a guide depending on his/her result:</p> <ul style="list-style-type: none"> ○ Viral Load <400 → <ul style="list-style-type: none"> ▪ <i>Congratulations! Well done! You have been working incredibly hard to make sure your child takes his/her ARVs correctly. Be proud! Now the goal is to keep up the good work for the long term.</i> ▪ <i>Your child's next visit to the intervention will be in 1 month. You will only see a nurse at that time.</i> ○ Viral Load > 400 → <ul style="list-style-type: none"> ▪ The plan for the adolescent will depend on how high the result is: ○ If the viral load has decreased significantly but is still detectable: <ul style="list-style-type: none"> • <i>Congratulations on doing a good job!</i> • <i>We realize that taking ARV's is a very difficult thing to do. You have been working incredibly hard to make sure you take your ARV's. Be proud! Now the goal is to keep up the good work for the long term.</i> • <i>Your next visit to the intervention will be in 1 month. You will continue seeing a doctor and nurse at that time.</i> ▪ If the viral load has not come down significantly: <ul style="list-style-type: none"> • <i>We realize that taking ARVs is a very difficult thing to do. The important thing is to not become unmotivated at this point. Sometimes it can take longer to get this right and for the viral load to become undetectable. We will continue to work together to find ways to help you in taking the ARVs.</i> • <i>Your next visit to the intervention will be in 2 weeks. You will continue seeing a doctor and a nurse at that time.</i>
<p>At the end of the session complete the adherence plan</p>	

Follow-up Sessions : Review adherence challenges during follow-up appointments in the Maintenance phase

Any new problem with giving my child medication: _____

My plan to fix the problem: _____

Discuss viral load results when appropriate.

My child's viral load: _____

Appendix 3 Support Group Sessions – Facilitator Guide

Note: This appendix shows examples of guides used by facilitators of support groups for caregivers and adolescents. While the forms do mention major themes for discussion, they are intentionally less detailed and thorough than the individual adherence counselling tools. The idea is for the facilitator to start discussions through the introduction of major topics, but then allow the participants to share their experiences and voice their concerns. It is through sharing their own experiences and learning about others' difficulties and successes that participants gain the support of their peers.

- 3.1 Adolescent Support Group Session – Facilitator's Guide
- 3.2 Caregiver Support Group Session – Facilitator's Guide
- 3.3 Other resources

Appendix 3.1 Adolescent Support Group Session – Facilitator’s Guide

Adolescent Support Group (SG) Session	
Target group	All Adolescent patients (12- 19 years)
Timing	Immediately upon arrival: 12:30pm
Duration	45 min
Mode	Group
Tools	Agree/disagree signs for the wall

Step 1: Introduction:

- Introduce yourself as the facilitator
- Explain to patients why they are in the support group:
“All of us here have one thing in common and that is that we all have a high viral load.”
- Explain:
“As young people, it can feel very difficult to take your ARVs every day for many reasons. We hope that through these group sessions and your individual discussions with your doctor and nurse, we can help to make it a little bit easier.”
- *“Some of you have been to the support group before and for others this is your first time. At each session, we will discuss general subjects surrounding adherence. However, each time new topics will arise and there will be new things to share.”*
- Ask the adolescents who have attended previous sessions to help you with the new members – they can help orient the new members and provide support.
- Assure the adolescents that they will have their individual clinical consultation with the doctor and nurse after the support group.
- Assure confidentiality by yourself, the nurse, the doctor and between patients attending the group.
- Support group members should be non-judgmental towards each other.

Step 2: Discuss Flexibility in Taking ARVs:

- *“Taking ARVs every day is hard. The good news is that the times during the day when you take your medicine has become more flexible. It is no longer necessary to take your ARVs at the exact same time every day (for example at 7am and 7pm). There can be an hour or two of flexibility.” Also, if you want to change your schedule on the weekends you can do so (for example if you tend to sleep late on weekend days). However, it is still important to take your medicine each day and not to miss doses.*

Step 3: Discuss Barrier: Mixing Social Life with Taking ARVs:

- Explain:
“We are all young people here, our lives are different from our parents and our older sisters and brothers. Many of us are in school, have many friends, are dating, like going out and socialising”
“Our lives are often complicated which can make taking ARVs more difficult.”
- Discuss social situations that make it difficult to take their ARVs.
“What social situations make it difficult to take your ARVs?”
(If no one gives an example, ask about going out with friends and taking ARVs.)
- Discuss relationships:
“Many of us have boyfriends or girlfriends. We change our partners when we are not happy with our relationship or we meet someone that we like more.”
“How could having a boyfriend or girlfriend make it difficult to take your ARVs?”
“What plans have you made in the past to help?”

Step 4: Discuss Barrier: Stigma and Coping with Stress:

- Introduce ‘agree’ or ‘disagree’ game: We are going to take part in an activity where you let your feet do the talking. You will notice on one side of the room we have a sign saying ‘Agree’ and on the other side a sign saying ‘Disagree’. Let us all come to the middle and when I ask a question, you let your feet answer the question.
 - *Do you feel there is discrimination against young people with HIV?*
 - *Is discrimination based on HIV status fair?*
 - *Have you ever felt discriminated against for any reason?*
 - *Have you stopped a friendship because you thought that the person was discriminating against you?*
- Back in seated group, ask:
 - *“What is stigma?” “What is discrimination?”*
 - *“In what ways is it possible to be discriminated against?”*
 - *“Discuss how it feels to be discriminated against.”*
 - *“What can we do to fight against stigma and discrimination due to your HIV status?”*

Step 4: Plan the Way Forward:

- Explain again that after the session all patients will see the doctor and nurse individually in the clinic.
- Explain that they will attend this support group each time they come to the intervention. Each time they come they will first attend the support group and then be seen individually by the doctor and nurse.
- Ask the new patients to stay behind after the group.
- End the session with a positive, reinforcing message.

Guiding Points for Group Facilitation:

- It’s important for patients to feel that the session is a learning experience and a time when they can share their feelings and concerns. It is not a time for blaming and finger pointing.
- Try not to put new patients on the spot. Do not ask a new patient “What have you been doing wrong?” It is possible to identify a problem without blame or such a direct question.
- **Let patients do most of the talking.**

Extra Step with New Programme Patients:

- Explain the following:
 - “You are new patients to this clinic. You will be seeing the doctor and nurse after this short session. The team will help you with any difficulties you may be having with taking your treatment and discuss a number of steps that may help you plan for taking your treatment.”*
 - “We would like you to prepare a little while you wait.”*
 - “We can sometimes struggle with negative thoughts when we are taking treatment every day for a long time. It can help to think of the positive things in your life and your dreams for the future when you take your treatment.”*
 - “While you wait, please can you think about:*
 - ***What you would like to do when you are older.***
 - ***What are three things that you want to do in the future?***
- Close with an encouraging message:
 - “This is the beginning of a journey to work together to make taking ARV treatment a little easier, we are here to help and support you as much as you need us.”*

Note: The counsellor should not discuss these questions with the patient. These are questions that will be discussed individually with the doctor/nurse.

Appendix 3.2: Caregiver Support Group Session – Facilitator Guide

Target Group	All Caregivers of Patients 0-12 Years Old
Timing	Immediately Upon Arrival: 8:00am
Duration	45 Minutes
Mode	Group
Tools	None

Step 1: Introduction

- Introduce yourself and other facilitators (if present)
- Explain to the caregivers why they are in a support group (they all have something in common – a child with a high viral load).
“All of us here have one thing in common and that is that we all are caring for a child who has a high viral load.”
- Explain:
“As caregivers, it can feel very hard to give ARVs every day. There can be many reasons for this. We hope that through these group sessions and your individual discussions with your doctor and nurse, we can help to make it a little bit easier.”
- Ask the caregivers who have attended previous sessions to help you with the new members – they can help orient the new members and provide support.
- Assure them that they will have an individual adherence meeting with the doctor and nurse after the support group.
- Assure confidentiality by yourself, the nurse, the doctor and between patients attending the group.

Step 2: Rules of ARV’s:

- Open by saying we have all been taught the “rules” of taking ARV’s. These rules can sometimes be hard to follow.
- Ask caregivers to share with the group the basic rules they have learned for taking ARVs (not individual problems at this time).

Step 3: Discuss the Flexibility of ARVs:

- Counsellor now has the opportunity to explain common misconceptions about taking ARVs. Explain the flexibility when taking ARV.
“Giving ARVs everyday is hard. The good news is that the times during the day when you give the medicine have become more flexible. It is no longer necessary to give the ARVs at the exact same time everyday (for example at 7am and 7pm). There can be an hour or two of flexibility. Also, if you want to change your schedule on the weekends you can do so (for example if you tend to sleep later on weekend days). However, it is still important to give the medicine everyday as prescribed.”

Step 4: Discuss the Caregiver’s Own Experiences:

- Ask caregivers about their difficulties in giving their child ARVs. Let caregivers share their experiences and solutions. Examples of problems that may be brought up are:
 - I forget to give the medicine. I don’t have a good way to remember to give it.
Explain to the group:
“It can be difficult to remember to give the medicine to your child. It is important to find a method for remembering that works for you. Some good ways to remember are to use the alarm on a cell phone, an alarm on a watch, or the alarm on a TV. It is also helpful if someone else knows about giving the medicine and helps you to remember.”
 - My child refuses to take the medicine because he/she says it tastes bad and/or my child spits out the medicine or vomits the medicine.
Explain to the group:

“Some of the ARVs have a very bitter taste. It can be helpful to give the medicine with something sweet, such as peanut butter or juice. If your child continues to refuse to take the medicine, keep trying different foods to give with them until one works. If he/she spits out the medicine or vomits it up, give it again.”

-I don't want anyone to know that I give my child medicine.

Explain to the group:

“This is a difficult issue. It is closely related to disclosure and your support structure. Let's ask other members how they dealt with this issue.”

-I miss giving doses because of my busy schedule.

Explain to the group:

“It is important to find a way to fit giving the medicine into your routine schedule. Make giving the medicine part of your normal morning and evening routine when caring for your child. This will make it easier to remember to give them. If it is not possible to fit giving the medicine into your routine, then a second caregiver must be found to give the medicine.”

Step 5: Plan the Way Forward:

- Explain again that after the session all patients will see the doctor/nurse/counsellor individually in the intervention..
- Explain that they will attend this support group each time they come to the intervention. Each time they come to the PACC they will first attend the support group and then be seen individually by the doctor and nurse.
- Ask the new patients to stay behind after the group.
- End the session with a positive, reinforcing message.

Guiding Points for Group Facilitation:

- It's important for caregivers to feel that the session is a learning experience and a time when they can share their feelings and concerns. It is not a time for blaming and finger pointing.
- Try not to put new caregivers on the spot. Do not ask a new caregiver “What have you been doing wrong?” It is possible to identify a problem without blame or such a direct question.
- **Let caregivers do most of the talking.**

Extra Step with New Patients:

- Explain the following:
 - “You are new patients to this clinic. You and your child will be seeing the doctor and nurse after this short session. The team will help you with any difficulties you may be having with giving the treatment to your child and discuss a number of steps that may help you plan for giving the treatment.”*
 - “We would like you to prepare a little while you wait.”*
 - “We can sometimes struggle with negative thoughts when we are giving the treatment every day for a long time. It can help to think of the positive things in your life and the dreams you have for your child when you give the treatment.”*
 - “While you wait, please can you think about:*
 - ***“What are three things that you would like to see your child do in the future?”***
- Close with an encouraging message:
 - “This is the beginning of a journey to work together to make giving ARV treatment a little easier. We are here to help and support you as much as you need us.”*

Note: The counsellor should not discuss this question with the patient. This question will be discussed individually with the doctor/nurse.

Appendix 3.3: Links to alternative adolescent counselling tools

1. MSF Patient Support, Education & Counselling Guideline for Children and Adolescents Living with HIV



PSEC_Children and adolescents.pdf

2. South African Clinician's Society Guideline: Adherence to antiretroviral therapy in adults and young children July 2017



Adolescent (SHORT)_WEB2.pdf

3. WHO Guidance for HIV testing and counselling and care for adolescents living with HIV



WHO Guidance for testing and counsellin

4. Western Cape Counselling Guidelines for Children



PARTIC 0 to 18 months_final.doc



PARTIC 18mt to 5yrs _final.doc



PARTIC 6 to 12 yrs _final.docx

Appendix 4: Home Assessment Form

Home Assessment Form Children and Adolescents

Initial Assessment

Patient's Name and Surname: _____

Folder Number: _____

Address and Telephone Number: _____

Alternative Address: _____

Person Interviewed: _____

I would like to ask you a few questions to find out more about the child/adolescent's situation so that the health team can best support him/her and you.

It is important to know some information about the people who live with the child/adolescent and who is responsible for taking care of him/her.

1. How many people live in the home?

Children under 5 _____ Children 5 -15 _____ Adolescents/Adults older than 15 _____

2. Who is the primary person who takes care of the child/adolescent? _____

3. Does anyone else help take care of him/her at home? Yes No

If yes, who? _____

4. Does anyone else in the neighborhood help to take care of the child? For example a family friend?

Yes No

If yes, who? _____

5. Does someone help give the medicine to the child? Yes No

If yes, who gives the medicine to the child? _____

6. Are there other people living in the house who are HIV-positive? Yes No

If yes, who?

People who are HIV-positive: _____ People who are HIV-negative: _____

7. Does anyone living in the house smoke dagga or use alcohol? Yes No

If yes, who?

People who smoke dagga: _____ People who use alcohol: _____

8. Does anyone who lives in the home work?

If yes, who?

Person/People who work _____

What is the person/people's job(s)? _____

9. Does anyone living with the child have TB? Yes No

It is also important to understand who knows that the child/adolescent is HIV positive.

10. Does everyone living in the house know that the child/adolescent is HIV positive? Yes No

If not, who knows and who does not know?

People who know status: _____ People who do not know status: _____

We would also like to know some information about the ARVs the child is taking.

11. Where are the medicines stored in the house? _____
12. Are pill-boxes being used with the medicines? Yes No
13. Do you keep an "emergency" supply of medicine Yes No
14. How are you remembering to give the medicine? (Alarm clock? Phone? Etc.) _____

I have a few more questions about your house.

15. Is there electricity in the house? Yes No
16. Does the house have running water? Yes No
17. Does the house have a heater? Yes No

I have a couple of other questions:

18. Do you bring the child/adolescent to a traditional healer? Yes No
19. Are you planning on traveling with the child/adolescent any time soon? Yes No
If yes, where? _____

For the CCW to complete. Please give your impression:

20. Do you (the CCW) think there is enough food in the house? Yes No
21. Do you (the CCW) think the child has enough warm clothing? (Ask to look where the child keeps his/her clothing)? Yes No
22. Do you think the child is receiving his/her ARV medication every day? Yes No

Name of Person Performing Assessment: _____ Date: _____

Note: This home assessment form was used in the MSF clinic as it has more details relevant to the assessment of the child or adolescent living with HIV. If preferred, it may be adapted for use with your local home assessment form. The Western Cape form is attached below:



WC CCW Household
Assessment (Form A).



ccw home
assessment form.pdf

Appendix 5: Staff Assessment Form: PROTF Nurse Clinical and Adherence Competency Assessment

Nurse's NAME :

DATE:

Clinical Competencies	Not Competent	Needs Supervision	Acceptable	Advanced
HIV Management				
Understands Viral Load measurement – can define “undetectable viral load”, “high viral load”				
Able to summarize patient ART and VL history				
Understands schedule of VL monitoring (follows national guideline)				
Understands CD4 monitoring schedule (follows national guidelines)				
Can identify virological/immunological/clinical failure in a paediatric patient				
Recognizes and manages common ART side-effects				
Identify and manage common drug interactions, HIV/TB co-infection				
Able to identify and manage/appropriately refer paediatric OIs				
Knows 1 st and 2nd paediatric ARV regimens (follows national guidelines)				
Knows national guidelines on when to switch from 1st to 2nd line ART				
Selects appropriate 2nd line ART and baseline bloods				
Adequately performs 2nd line preparation counseling – importance of adherence				
Understands 2nd line drugs’ dosing schedule, side-effects, contra-indications				
Understands routine blood and VL monitoring for 2nd line				
Understands when to seek advice from doctor regarding need for genotype and 3 rd line ART				
PROTF Adherence Support Competency				
Follows session plans: Session 1				
Session 2				
Session 3				
Session 4				
Session 5				
Session 6				
Session 7				
Session 8				

Clinical Competencies HIV Management	Not Competent	Needs Supervision	Acceptable	Advanced
Exhibits an encouraging, supportive, understanding attitude				
Completes the adherence session plan in the patients file				
Facilitates the patient completing the "Patient Adherence Plan"				
Understands the major barriers to adherence for paediatric and adolescent patients				
Understands basic approaches to addressing adherence barriers (importance of treatment supporters, flexibility of ART, need for method of remembering ART, plan if patient vomiting medication, etc.)				
Provides continuity of care - follows the patient through all the sessions				
Routine Care / Every Visit				
Able to measure paediatric vital signs				
Able to perform growth monitoring and plot measurements correctly on appropriate growth charts				
Able to perform complete paediatric physical examination, including basic neuro-developmental exam				
Recognizes signs/symptoms of common paediatric illnesses (respiratory, skin, ENT, GI)				
Understands how to treat common paediatric illnesses (respiratory, skin, ENT, GI)				
Correctly performs TB screening/diagnosis/management				
Recognizes warning signs for PCP, TBM, KS, candida, herpes zoster				
Investigates weight loss/gain				
Appropriate Cotrimoxazole use				
Appropriate MVT, deworming, and vitamin A prescribing				
Ensures contraception for sexually active adolescents				
If any 'Not competent' or 'Needs supervision' state reasons here:				

Assessment done by _____

If nurse is found 'Not competent' or 'Needs supervision' on any of the competencies, continue tailored mentoring before allowing independent nurse management of ROTF patient.

Appendix 6: Monitoring and Evaluation of the Paediatric Treatment Failure Program

Paediatric Treatment Failure Monthly Data Collection		
Month:	Year:	Clinic:
New patients enrolled this month:		Total patients in programme:
Change in enrolment since last month	Number:	Percentage:
Number of patients by age	This month	Total
0-5 years		
6-14 years		
15-19 years		
Number of patients stratified by ARV regimen		
First line:	Second line:	Third line:
Regimen change	This month	Total
Resistance tests done		
Number changed to 2 nd line		
Number changed to 3 rd line		
Co-infection rates		
Number diagnosed with TB		
Viral load monitoring		

Number of viral loads done		
Number of suppressed VLs		
Number of raised VLs		
Additional indicators		
Disclosure stratified by age	Full disclosure total	Full disclosure percentage
0-5 years		
6-14 years		
15-19 years		
Average age of patients in intervention		
Number of patients with a change in caregiver		

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