

# **Patient Support, Education and Counselling Guideline**

**For children and adolescents  
living with HIV**

Internal document

2018 Edition

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## Foreword

This guideline is designed to provide practical tools and guidance for staff providing patient support, education and counselling to children and adolescents aged between 0 - 18 years and infected with HIV. This guideline is built on experiences from MSF projects and recommendations from the literature. The guideline offers recommendations on both a minimum package versus a comprehensive package of activities for supporting children and adolescents living with HIV. It serves as a standard of activities to be put in place when dealing with HIV infected children and adolescents, but set-up should be adapted to the context and the human resources available. The guideline gives an overview of the activities to be put in place, while the annexes provide several practical tools from different MSF HIV projects.

This is the second edition of the guideline and it provides an up-to-date approach on education and counselling for children and adolescents infected with HIV. For general guidance on the implementation of Patient Support, Education and Counselling approaches please refer to the Patient Support, Education and Counselling Guideline for Adults Living with HIV and/or TB. Support to HIV-exposed infants of HIV-positive mothers is also covered in the guideline for adults.

The MSF AIDS working group, the Mental Health working group and the Patient Support, Education and Counselling focal points from OCB, OCG, OCBA, OCA and OCP contributed to the creation of the present guideline and validated its final version.

Please send feedback on the guideline to the respective focal points/referents of your Operational Centre, so we can continue to adapt the guideline to the realities in the field.

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## Glossary

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Consultation
ART	Antiretroviral Therapy
AWG	AIDS Working Group
CAGs	Community ART Groups
CD4	Immune system cell
CHW	Community Health Worker
EAC	Enhanced Adherence Counselling
FD	Full disclosure
FP	Family Planning
FU	Follow-up
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
HTS	HIV Testing Services
MSF	Médecins Sans Frontières
mHealth	mobile health
PD	Partial disclosure
PEC	Patient Education and Counselling
PEP	Post-Exposure Prophylaxis
PITC	Provider-Initiated Testing and Counselling
PLWHA	People living with HIV/AIDS
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
PSEC	Patient Support, Education and Counselling
PWG	Paediatric Working Group
Rx	Treatment
STI	Sexually Transmitted Infection
TB	Tuberculosis
ToP	Termination of Pregnancy
VCT	Voluntary Counselling and Testing
VL	Viral Load
WHO	World Health Organization

*Note:* The use of “he”, “him” and “his” refers to a person (adult or child) of unknown gender and is used to refer to both men and women.

# 1. The cascade of care for children and adolescents living with HIV

This guideline is designed to be used with children and adolescents living with HIV. A child is defined as a person up to the age of 10, while an adolescent is a person 10 to 19 years inclusive. The cascade of care<sup>a</sup> for children and adolescents living with HIV is marked by significant drops. Children and adolescents are underserved by HIV services, have a high risk to become lost to follow-up and often show suboptimal adherence<sup>1</sup>. Disclosure of HIV status to children and adolescents living with HIV remains a challenge in HIV care, with rates of disclosure in both high- and low-income countries remaining low.<sup>2</sup> Additionally adolescents face specific challenges related to their sexual and reproductive health and HIV.

Several factors influence children and adolescents being tested for HIV, being aware of their HIV-status, linking and retaining in care and adhering to their treatment.

## 1.1 Factors impacting on children and adolescents' adherence to treatment and retention in care

The factors influence adherence and retention of children and adolescents living with HIV can be split up in different categories, being characteristics of the caregiver, the child/adolescent, the medication and the health system.<sup>3,4,5,6,7,8</sup>

### 1.1.1 Characteristics of the caregiver

- Level of literacy and lack of knowledge about HIV and ART.
- Economic factors (e.g. lack of food or the lack of financial means to go to the clinic).
- Family dynamics (e.g. absent mothers, aging caregivers, frequently changing caregivers, adoptive families, denial of HIV amongst fathers, etc.).
- Language barriers.
- Inconsistent attendance of caregivers.
- Psychosocial problems of the caregiver (difficulty to deal with own illness, depression, substance use, etc.).
- Forgetfulness.
- Travel (e.g. caregiver who has to travel often due to work or family reasons might result in risk to child adherence).

#### Keep in mind

Caregiver's knowledge about antiretroviral therapy has been shown to improve adherence. Support to the caregiver and family are of fundamental importance for therapeutic success in children and adolescents living with HIV/AIDS.

<sup>a</sup> For a general explanation on these concept of the cascade of care, please refer to: *MSF Patient Support Education and Counselling Guideline for Adults with HIV and/or TB*. Médecins Sans Frontière, 2018

### 1.1.2 Characteristics of children and adolescents living with HIV

- Being assigned too much responsibility for medication-taking, in a way that is not adapted to his/her psychological maturity.
- Lack of family support (e.g. the caregiver being alone to care for the child, multiple caregivers, foster family, etc.).
- Discrimination by household members, resulting in isolation of child/adolescent.
- Gender and age of the child/adolescent (this can be context dependent and needs further analysis in the specific context of the project).
- Not knowing one's HIV sero-status.
- The wish to be like others e.g. not wanting to be seen as ill, or on medications.
- Psycho-social factors in the child/adolescent (depression, substance use, etc.).
- Refusal to take medication for diverse reasons (e.g. asymptomatic child/adolescent who does not feel the need to take treatment).
- Lack of an effective routine of taking medication (e.g. children who are sleeping at the time of taking medication or who vomit the medication).

#### Keep in mind

The predictors of better adherence include having a medication reminder strategy, regular clinic visits, and being aware of one's HIV status.

### 1.1.3 Medication characteristics

Burdensome ART regimens negatively influence adherence, such as:

- Bad taste of the medication.
- Pill burden.
- Difficulty for the caregiver to measure the correct dosage of syrups.
- ART formulations not adapted for children.
- The adverse effects of ART.
- Non-adaptation by prescribers or caregivers of weight-dependent doses for children.
- The use of traditional medicines (can be an issue when the treatments exclude the use of ART or create vomiting or diarrhea).

#### Keep in mind

Timely consultation including weighing of the child will aid the adaptation of the dose for the child. Formulations should be simplified when possible. Caregivers need to be trained to support the child in taking medication (e.g. swallowing).

### 1.1.4 Health system characteristics

Clinic context negatively impacting on children and adolescents' adherence:

- The lack of training and supervision of the staff in providing adherence counselling.
- Long waiting times at the clinic.
- Negative attitudes of the staff.
- Inefficient or inconsistent drug-delivery systems.



### **Keep in mind**

Healthcare providers and counsellors require regular trainings and supervision in adherence counselling for children and adolescents, support of caregivers, and timely disclosure of HIV status.

#### **1.1.5 Societal characteristics**

The following societal characteristics negatively influence adherence:

- Stigma-related issues (importance of keeping HIV status secret, exclusion, lack of disclosure, etc.).
- Negative perceptions of the illness (e.g. bewitchment).
- Rural versus urban settings (transport and distance to the clinic can be an issue in rural settings).

### **1.2 Factors influencing disclosure**

Children and adolescents not being aware of their HIV-status constitute a barrier to adherence to treatment and retention in care. Several factors influence the fact that a child or adolescent is aware of his own HIV-status.

#### **1.2.1 Barriers to disclosure**

Caregivers face several barriers to tell the child or adolescent about their HIV-status<sup>9,11</sup>. Barriers include:

- The fear of robbing their child of the happiness of living free of the knowledge about being HIV-positive.
- The fear of making their own HIV status known to more people.
- The fear of confrontation.
- The fear of creating conflict with their child.
- Feeling ashamed due to stigma and stereotypes associating HIV with sexual promiscuity, immorality, and death.

#### **1.2.2 Factors facilitating disclosure**

Disclosure is more common with older children and is largely driven by the caregivers' education and socioeconomic status<sup>10</sup>. The following factors contribute to the caregivers' decision to disclose to their children<sup>11,12,13,14</sup>:

- A supportive social environment.
- Structured interventions engaging caregivers in the process of disclosure in a manner suitable to the sociocultural context and developmental age and needs of the child such as:
  - A structured healthcare worker training in paediatric disclosure counselling.
  - A gradual, structured disclosure process (pre-disclosure intervention/education sessions for adolescents and for caregivers, disclosure session and post-disclosure support).
  - Providing caregivers with knowledge about HIV status disclosure approaches.
  - The delayed usage of HIV-specific terminology (HIV is mentioned when the child and the caregiver are ready for it).
  - Positive messaging (keeping the body strong, and having a future like other children, rather than the negative consequences of HIV).
  - The use of visual tools (associated with the structured approach).

## 2. Supporting children and adolescents living with HIV

*A package of care will need to be set up in every HIV Care program dealing with children and adolescents living with HIV in order to reduce the gaps in the cascade of care for this vulnerable population. The following activities need to be considered:*

- *Patient Education and Counselling* targeting all children/adolescents living with HIV and their caregivers. Patient education and counselling entails all educational and emotional support activities offered at health facilities or in the community for HIV-infected patients. The patient education and counselling activities along the cascade of care are further described in this guideline.
- *Patient Tracing* for children/adolescents living with HIV who missed an appointment. Patient tracing includes activities for supporting PLHIV to return to care after gaps or disengagement from care. Patient tracing strategies are the same for adults and children and are addressed in the *MSF PSEC Guideline for Adults living with HIV and/or TB*.
- *Patient Support* encompasses activities aiming to address the weak socio-economical support system of HIV infected children and adolescents in a punctual way. This can include socio-economical support, patient support groups, home visits and hospital visits. This is addressed in the MSF PSEC guideline for adults.
- *Mental Health Care* for HIV-infected children/adolescents includes screening, diagnosing and treating mental health issues among children and adolescents living with HIV. This is addressed in the *Mental Health and Psychosocial Support for Children Guideline, Médecins Sans Frontières – Mental Health International Working Group, January 2016*.
- *Health Promotion, Community Awareness and Social Mobilization* activities target the communities where children/adolescents living with HIV originate, and include awareness raising, HIV and STI prevention strategies, and promotion of the available HIV testing and medical services. This is addressed in the *MSF PSEC Guideline for Adults Living with HIV and/or TB*.

The extent to which all of these activities will be put in place in a given project will depend on the set-up of the project, the characteristics of the target group, patient caseloads, and human resources available. Based on lessons learned in MSF projects and evidence from the research literature, alternatives of either minimum or comprehensive package of interventions have been identified. The minimum package of interventions is endorsed as compulsory to be implemented in all facilities providing care for children and adolescents living with HIV. In addition to this minimum package, a comprehensive package of interventions is recommended to be implemented in projects supporting children and adolescents living with HIV, particularly in high HIV prevalence settings.

### 3. The packages of PSEC interventions

#### 3.1 Minimum package of PSEC interventions to support children and adolescents living with HIV

<b>Activities</b>	
Patient education and Counselling	Patient centred and structured education and counselling sessions adapted to children/adolescents for : <ul style="list-style-type: none"> <li>- HIV testing.</li> <li>- Disclosure.</li> <li>- ART Initiation and early follow-up.</li> <li>- Long term follow-up on ART.</li> </ul>
Patient tracing	Children and adolescents should be traced by phone/SMS and/or home visits when they miss clinic appointments.
<b>Supportive measures</b>	
Patient file	An adapted patient file for patient support, education and counselling.
Tools	Use of a child/adolescent flipchart on HIV.
Training, mentoring, supervision and allocation of staff for child/adolescent support activities	<ul style="list-style-type: none"> <li>- On child friendly counselling techniques.</li> <li>- On the education and counselling models for children and adolescents.</li> </ul>
Booking of appointments	<ul style="list-style-type: none"> <li>- Children and caregivers on treatment to be booked on same days for refills or clinical follow-ups.</li> <li>- Adolescents to be booked together on same days to enhance peer support through group sessions.</li> </ul>

### 3.2 Comprehensive package of PSEC interventions to support children and adolescents living with HIV

In addition to the minimum package, the following interventions should be considered. The choice of interventions of this comprehensive package should be made according to the context and the needs of the target population.

<b>Activities</b>	
Patient Education and Counselling	Perform an initial needs assessment when the child/adolescent enters the program.
Mental health care	Screening, diagnosis and care or referral for mental health issues of children/adolescents living with HIV. See Annex 5 for a screening tool for depression in children/adolescents, age 8 - 18.
Social support	<ul style="list-style-type: none"> <li>- Home visits for patients failing treatment or experiencing adherence issues and children at risk (orphans aging caregivers, etc.).</li> <li>- Support groups for children and caregivers.</li> <li>- Children's "fun activities" at the clinic or in the community to strengthen the relation between clinic staff, children and caregivers.</li> </ul>
Other health promotion activities	<ul style="list-style-type: none"> <li>- Promotion of HIV testing for children in health facility/community.</li> </ul>
<b>Supportive measures</b>	
Clinic environment	Child friendly clinics/areas with paintings on the walls and play area (drawing material, dolls, games, small tables and chairs), etc. See Annex 6 for examples of child friendly areas.
Tools	<ul style="list-style-type: none"> <li>- Story books (about the visit to the clinic, taking treatment, HIV&amp;ART, etc. See Annex 7, 8, 9).</li> <li>- Educational videos (e.g. Annex 10 The Story of Bobo).</li> <li>- Posters and leaflets (to promote HIV testing of children and adolescents, to provide information about ART, sexual and reproductive health, etc.). (See health promotion toolkit).</li> <li>- Treatment follow-up tools such as pill boxes, the pill pathway (see Annex 11).</li> </ul>
Booking of appointments	<ul style="list-style-type: none"> <li>- Organisation of "paediatric days" at the clinic, whereby children and their caregivers are booked on the same day for ART refills and clinical consultations and group sessions.</li> <li>- Differentiated ART delivery models, grouping caregivers and their children or adolescents such as youth clubs, family clubs, Community Art Groups.</li> </ul>
mHealth interventions (mobile Health)	<ul style="list-style-type: none"> <li>- Sending treatment and appointment reminders by SMS to high risk groups.</li> <li>- Using adolescents friendly social media technologies (such as Whatsapp, Facebook groups) and adolescent-friendly websites.</li> </ul>

## 4. Specificities of patient education and counselling for children and adolescents living with HIV

Counselling children and their caregivers is about listening, understanding, supporting, imparting information and helping them make choices. The counsellor needs to create a trusted and respectful relationship with the caregiver and the child. The counsellor should remain neutral, empathic and able to tackle different topics with an open mind and a non-judgmental attitude. Some general recommendations on communication and counselling skills are provided in the *MSF Patient Support, Education and Counselling Guideline for Adults with HIV and/or TB*. Specific recommendations on child and adolescent counselling can be found in the MSF guideline *Mental Health and Psycho-Social Support for Children* (2016).

Patient education and counselling for children and adolescents living with HIV carries a number of specificities:

- It has to be adapted to the age, level of development and knowledge of the child (aware or not of his HIV status).
- It involves the child/adolescent as well as his caregivers.
- It must be provided by staff who have received specific training on support of children and adolescents.
- It requires the use of specific tools and activities.

### 4.1 Adapted to the understanding of the child/adolescent about health and diseases

General information of children and adolescent milestones can be found in the MSF guideline *Mental Health and Psycho-Social Support for Children*. Theories about the cognitive development of the child<sup>15,16,17,18,19,20,21,22</sup> help to understand the perception of the child regarding the causes of illness, though this can vary from one child to another and be influenced by cultural explanations of disease. According to these theories, most children develop their general conception of health and illness as follows:

#### Infants from 0 to 18 months

- An infant does not know how to communicate or to express what he feels. He does not understand the disease, he lives it.
- The child can feel pain. His suffering will be expressed through behaviours especially crying and irritability. If pain continues the infant can become increasingly withdrawn and avoid interactions with caregivers and others. The child can quickly go from crying to laughing as soon as the pain stops.

#### *Recommendations to care for infants from 0 to 18 months old*

- Facilitate the continual presence of a parent or main attachment figure.
- Be attentive to, evaluate, and treat pain.
- Put into place all means likely to reassure and soothe the child. Take into consideration that he cannot express himself in words. Look at him, smile at him, speak to him and cuddle him.

### **Children from 18 months to 3 years old**

- The child has no mental representation of internal organs. The illness is limited to that place which is hurting and at the moment it is hurting.
- The child perceives the disease as an external constraint that he can oppose. He can react strongly to the consequences of his illness and the disruption to his routine.
- With the progressive acquisition of language, the child becomes capable of expressing pain in other ways apart from crying, although the latter is still the main mode of expression.
- The child thinks that dead people are sleeping and are going to wake up. He fears separation from his caregiver.

#### *Recommendations to care for children from 18 months to 3 years old*

- Install routine, make treatment a “daily ritual” and respect the child’s routine as much as possible.
- Put into place all means likely to reassure the child that he is cared for and will get better.
- Give the child as much autonomy as possible in order to minimize the constraints of disease. Give him choices such as “would you like a story before seeing the doctor?”.
- Help caregivers to resist the control the child tries to impose upon them; caregivers’ anxiety and guilt often express themselves through excessive permissiveness. Saying “no” is necessary in certain situations as for all children of this age. Excessive permissiveness can derail normal development and result in behavioral problems.
- Be attentive to, evaluate, and treat pain.

### **Children from 3 to 6 years**

- The child is able to name his external but not his internal organs. He sees his body from the outside and is unable to represent the interior.
- The child’s vision of his disease is limited to painful areas and to when he has pain.
- From 3 to 4 years the child thinks that things around him are alive (e.g. “that chair hurt me”). There is a causal and artificial reason for everything. It is the period of incessant “why” questions.
- The child lives his disease on a day to day basis and does not project himself into the future.
- He may think that his disease is punishment for his bad behaviour or thoughts. His creative imagination can often be worse than reality. E.g. “They give me medicines to punish me”. “My mummy left home because she does not like me” (for instance when nobody told the child his mother died).
- From four years old, he may understand preventing symptoms that he has already experienced (e.g. wearing warm clothes to avoid falling sick when the weather is cold).
- Being weighed, measured and having blood taken may be interpreted as menacing and disturbing acts. The child confuses fear and pain and expresses them in the same way (crying).
- The child does not think of death as something definitive but as a temporary separation. Given his powerful imagination, the child may feel responsible for the deaths of others.
- The child’s thoughts are egocentric and he only can envisage things from his own point of view. If he knows he has HIV he thinks that everyone else knows it and can see it.
- The child tries to please the caregivers and staff. The child considers that an action is good if it is rewarded and is bad if it is punished.

#### *Recommendations to care for children from 3 to 6 years old*

- Install routine and ritualise treatments and respect the child’s routine as much as possible.
- Reassure the child that he will be cared for and his illness is not due to his behaviors.
- Keep giving the child a sense of autonomy by offering him choices.

- Use imagination to transmit ideas about the disease and treatment. Tell stories using analogies without lying to the child.
- Respect the child's imagination and lack of concept of limits about his future. For example, never say to a handicapped child "you will never be able to walk" when he talks about the desire to run and be a sportsman.
- Give information relevant in the short term (e.g. "Tomorrow, we will see the doctor").
- Involve the child in the consultations. Even if the child does not understand everything, he should be the center of the therapeutic relationship.
- Do not lie to the child.
- Maintain boundaries. Saying "no" is necessary in certain situations as for all children of this age.

### **Children from 6 to 9 years old**

- Children at this age are able to imagine internal organs and actions. They think by analogy, comparing a heart with a pump or a stomach with a food basket. Death is considered as normal. All living things die one day. They refer to biological principles, like no breathing. They start wondering what happens after death.
- The concepts of being sick and having to take treatment are accepted. The child can understand the disease affecting him (for example sick means not being able to play).
- Schooling helps the child to organise his thoughts and his reason.
- Shorter term temporal landmarks may be given such as the fact that next Christmas he will still be taking his treatment or next holidays, or on his next birthday etc.
- Up until around seven years of age the child will continue to manifest colorful and representational thought processes. "Will the germ in my body wake up while I'm asleep?".
- The child has some capacity to imagine internal human organs. However, he thinks that the brain is only for thinking and his arms and legs move on their own.
- The child's desire for understanding ensure good exchanges with his environment and help him understand what he is going through. The child starts to question his surroundings (parents and caregivers).
- The representation of HIV disease is complex for asymptomatic children. As the child cannot feel the HIV in his body and has no symptoms, the disease lacks landmarks. It is difficult for the child to understand his disease and treatment given the abstract nature of the disease. Treatment may be problematic.
- Significant protective factors predicting the way the child will adapt to disease in adolescence include the acquisition of self-esteem through social activities, games and sports, putting some distance between himself and the family (investing elsewhere), and notions of autonomy.
- The first real fear of death is felt. The child understands three very important things about death; it is universal, irreversible and its cause is not linked to (imaginary) thoughts. Usually, this tends to happen between 8 and 10 years old.

### *Recommendations to care for children from 6 to 9 years old*

- Give the child information about his disease, as he needs landmarks. Analogies should be used to explain bodily functions that he can understand such as the heart is a pump; the stomach is a breadbasket, etc.
- Explain the disease, its chronicity and the treatment using analogies (blue soldiers keeping the red germ asleep/weak).
- Encourage the caregiver(s) to answer the child's questions and to disclose HIV status.
- Help the child to get organised in his daily routine, integrating the disease.
- It is important to consider the child as an active participant in his treatment.
- Promote contact with other young people with HIV disease if the child and caregiver so wishes.



### **Children from 9 to 12 years old**

- The child can understand the concept of illness and explain the symptoms of the disease on different organs and their function. He can express hypotheses as to the causes of the disease.
- The child is more and more conscious of the control he can have over the disease. His desire of autonomy allows rich exchanges and progressive taking of responsibility.
- An asymptomatic child can experience difficulties in understanding that he has a disease that requires treatment. This is further complicated when his questions have not been answered with clear and accurate information.
- School, social activities including clubs and sports result in increasing autonomy and self-esteem and help the child in dealing with a chronic illness.
- The child gradually becomes conscious of the chronic nature of his disease through daily treatment and the repetitive aspect of his care. This can lead to frustrations about taking treatment and coming to clinic visits.

#### *Recommendations to care for children from 9 to 12 years old*

- Give the child information about his disease. Illustrations of the body should be used to explain physiological mechanisms.
- Help the child understand that he has a lifelong illness that can be controlled by adherence to medical treatment.
- Encourage the parents to fully disclose if it has not been already done.
- Help the child to get organised in his daily routine, integrating the treatment.
- Encourage investment in activities outside of the family circle. Promote contact with other young people with HIV disease if the child so wishes.
- It is important to consider the child as an active participant in his treatment.
- Provide temporal landmarks that make sense such as “to enter into adult life”.

### **Adolescents from 12 years old**

The adolescent is capable of abstract thinking, of building hypotheses and experimenting with them. On the medical side, the adolescent makes hypotheses about the causes of the illness and makes the link between the symptoms and the function of the organs. He understands the chronicity of an illness and the concept of a life-long illness and treatment. If he is asymptomatic, the adolescent may experience difficulties with motivation to continue with treatment and be tempted to challenge the disease.

Adolescents will be concerned about being able to have romantic and sexual relationships, and if they can get married and have children.

Adolescents who are in opposition with their families or health-providers might stop the treatment to take risks and to see the results with cessation of treatment. Concerning death, the adolescent can be sceptical about going to heaven or any other theory given by adults on what happens after death but he will follow cultural beliefs.

#### *Recommendations to care for adolescents from 12 years old*

- All information should be provided to adolescents about HIV and ART.
- Promote activities outside of the family circle and contact with other young people living with HIV if the adolescent so wishes.
- Ensure to provide privacy to the adolescent through individual sessions. Discuss concerns about sexual activity, marriage, having children.



Considering the above information, the individual development and the culture of the child will guide the counsellor on how to adapt the language, the information, the process of disclosure and the tools to be used with the child.

Based on the developmental stages of the child/adolescents, several competencies can be identified that should be acquired by the child/adolescent living with HIV. See Annex 1 for the list of competencies.

## **4.2 Involving the child/adolescent and the caregiver**

### **The child as an actor in his own health**

Each child is an individual, having his own personality, temperament, his own specific needs, his own emotions, and ideas. He should be listened to, and involved in his own treatment and the management of his disease. It is important to involve the child as an actor in his own health and treatment from the beginning. Explanations concerning disease and treatment need to be adapted according to the child/adolescent's developmental level and cognitive ability.

The healthcare provider should not talk to the caregiver only. Beginning at the age when the child has developed expressive and receptive speech, usually about 3 years of age, the child should be progressively included in the conversation to establish a relationship based on simplicity, openness, trust and respect.

An appropriate consultation should start with a conversation with the child and the caregiver in order to establish a relationship of collaboration and communication. The actual situation and needs of the child will determine the appropriate actions to be taken in collaboration with the primary caregiver.

### **Close partnership with caregivers**

When admitting a child in the program, it is necessary to identify a caregiver who is committed to accompany and support the child in the management of his disease. This person should closely follow the treatment of the child at the clinic and at home and should be able to offer encouragement and emotional support to the child or adolescent. The caregiver should be someone who the child has experienced as caring and comforting. Ideally, it is a family member who has legal responsibility for the child.

In case children arrive in the program without any caregiver, the team must find the right solution to identify someone or an institution to support the child. Especially adolescents may present alone at the clinic and may not have a trusted person that is taking care of them. It is important in such cases to fully involve the adolescent in his care.

Supporting the child should involve a close collaboration between the project staff and the caregiver. Neither can succeed alone. It is essential that all team members give the same messages to the child and the caregiver. The staff should not be judgmental of the caregiver.

The complementarity resides in the fact that the patient support staff knows more about the illness, and the way to support children living with HIV and the caregiver knows more about the child's personality, and his physical and emotional needs.

It is important that the counsellor assesses the quality of the relationship between the caregiver and the child by observing the way they interact and by offering them individual sessions where they can feel free to express themselves.

Some tools to help identify mental health issues in caregivers can be found in the *MSF Patient Support, Education and Counselling Guideline for Adults with HIV and/or TB*. A caregiver

presenting mental health issues such as depression or substance use may need extra support to be able to care for the child. When the context allows it, caregivers presenting mental health issues should be referred to a counsellor separately in order to address issues beyond the care of the child/adolescent.

Based on the fact that both the child/adolescent and caregiver need to be involved, sessions may be done with the child and caregiver together, with child or caregiver separately or with a group of children/adolescents and caregivers.

#### **4.2.1 Sessions with the child/adolescent and the caregiver together or separate**

Small children may not be able to understand the information being presented or asked in the counselling sessions. Many aspects of care for the child will be the responsibility of the caregiver. The caregiver should help facilitate the child's understanding of his illness and treatment and repeat the messages at home.

The part of the session that the child cannot understand should be conducted with the caregiver alone. When providing information about HIV/ART or explaining the disclosure process the session should only involve the caregiver. Someone should be identified outside of the consultation room to care for the child during this part of the session.

It is generally recommended that younger children are seen with the caregiver (usually until 4 or 5 years of age). After that, depending on the identified needs, the counsellor can see each alone. The child may feel liberated by having the opportunity to talk to someone who is not a relative about topics that might be sensitive to discuss with the caregiver (e.g. family relations). The counsellor should ask the child if he agrees to be seen alone.

Beginning at age 12 years, most of the counselling work will be done with the adolescent alone. Teenagers may want to share things they want kept confidential with the counsellor or may want to ask questions they would not dare to ask to their caregivers (e.g. about sexuality). Counsellors must assure total confidentiality of what the adolescent says (including with caregivers) or negotiate with the adolescent what may be reported to the caregiver. Adolescents need to be informed that in the event that harm may come to them or others, healthcare providers are obliged to protect the patient first, in which case parents/adults may be informed (for instance, in case of suicidal or homicidal thoughts or plans).

It should be explained to the child/adolescent that, in case of refusal to take medication, hiding it or not swallowing it, the counsellor may decide to share the information with other members of the treatment team and/or the caregiver to avoid putting the health of the child in further danger. The counsellor should always try to negotiate with the adolescent and address the barriers to taking treatment and potential solutions before discussing with caregivers.

Even when seeing the child alone, it is still necessary to continue to involve the caregiver in support of the child or adolescent.

During partial disclosure, full disclosure and ART preparation the child and the caregiver should attend the session together (after a first session alone with the caregiver to agree on what can be explained to the child).

Behavioural or emotional problems of the child can also be discussed together with consideration that the counsellor needs to balance attention and support to both child and caregiver and not take sides.

Post-test counselling, full disclosure and enhanced adherence sessions should be done with the child and the caregiver and not in a group session, as the content addressed can be sensitive and evoke emotions in the child and the caregiver. It should be clarified with the caregiver as to how much information can be communicated to the child.

### 4.2.2 Group sessions with children/adolescents and caregivers

Sessions for pre-test, HIV&ART education, partial disclosure and sexual and reproductive health can be facilitated in children/adolescent groups. The groups should be organized according to the ages of the children and should never mix children who are fully disclosed with others who are not or partially disclosed.

Group sessions can also be organized for caregivers. A group can mix the caregivers of disclosed and non-disclosed children. This could help the caregivers of non-disclosed children to learn how to progress with disclosure by listening to peers' experiences.

Adolescents are a very vulnerable group and should be involved in peer support strategies when coming to the clinic. It is recommended to book all adolescent patients on similar days to enhance the peer support component through interactive group counselling sessions. To keep the peer –dynamic going outside of the group sessions, programs can consider using technologies commonly used by adolescents, and agree on social media networks such as “whatsapp”, or other mobile-Health strategies to support linkage and retention in care.

#### Recommendations for grouping children, adolescents and caregivers based on their needs

Type of session	Children/adolescents	Caregivers
HTS (VTC and PITC)	Group of children for Pre-test education counselling based on: - the age and level of understanding. - what caregiver agrees to tell (no/partial/full disclosure).  Post-test counselling should always be done individually.	Group of caregivers bringing their child or being referred for HTS.
Partial disclosure	Group of children based on: - the age and level of understanding. - the caregiver agrees to proceed with partial disclosure.	Group of caregivers who agree for the child to go through partial disclosure. These groups can also mix caregivers of partially disclosed children and caregivers of fully disclosed children to enhance peer support and experience sharing on ways to proceed to full disclosure.
Full disclosure	It is recommended to do the first full disclosure session (FD1) individually. If this is not possible (due to work load), then proceed as follow. Group of children based on: - the age and level of understanding. - the caregiver agrees to proceed with full disclosure.  For the session on SRH (FD2), group of boys and girls should be separated depending on the context.	Group of caregivers who agree for the child to go through full disclosure. These groups can also mix caregivers of partially disclosed child and caregivers of fully disclosed child to enhance peer support and experience sharing.

### Recommendations for grouping children, adolescents and caregivers based on their needs (continued)

Type of session	Children/adolescents	Caregivers
ART Initiation and early follow-up	Group of children/adolescents who need education on HIV and ART.  Group children based on: - the age and level of understanding. - level of disclosure (information to be adapted).	Group of caregivers for education on HIV and ART to support children/adolescents initiating treatment.
Long-term follow up on ART	Group children/adolescents with adherence issues or adverse results for education on results and counselling on adherence based on: - the age and level of understanding. - what caregiver agrees to tell (no, partial or full disclosure).  Individual session should take place to identify specific needs.	Group caregivers of children/adolescents with adherence issues or adverse results for education on results and to enhance peer support and discuss adherence strategies.

The ideal number of participants depends on the objective of the group. Group counselling is best done with 8 to 12 participants. Patient-education can be done in larger groups.

The group should be a “safe environment” with some rules (such as confidentiality, respect and voluntary participation) permitting the children to feel comfortable and free to express their thoughts and feelings. A support group session is NOT a school session. Don’t teach the children but use playing tools and activities to transmit information. The group should always remain an attractive place, not a boring or compulsory place to go. Annex 12 provides guidance on the way to organize and facilitate a group session for children and caregivers.

#### 4.3 Provided by trained staff

Patient support, education and counselling for children and adolescents living with HIV can be provided by specific PSEC staff or can be integrated in the tasks of staff performing other duties. For more information on staffing models, refer to the *MSF PSEC Guideline for Adults living with HIV and/or TB*.

It is important that anyone involved in supporting children and adolescents living with HIV received specific training on support of children and adolescents. Through training they will start feeling comfortable working with children and adolescents.

An example of a training package on supporting HIV-positive children and adolescents is provided in Annex 2.

#### 4.4 Using specific tools and activities

Counsellors need to adapt their counselling techniques and strategies to meet the child where he is by using verbal and non-verbal communication as appropriate. E.g., some children might be more willing to talk while others might express themselves easier through playing,

drawing and other non-verbal techniques. Counselling techniques need to take into account developmental capacities of the child (e.g. a 6 year old child with cognitive and speech delays might relate more like a 3 year old child).

Providing support to HIV infected children/adolescents thus requires a number of specific tools and activities. The selection of such tools is dependent on the goal of the session and the developmental stage of the child. Some tools will be ideal for educational purposes, other for expressing feelings, developing life skills or just for fun.

The following type of tools and activities can be considered:

- Flipcharts with images and educational messages. This is part of the minimal package and every counsellor should have this tool available (Annex 13).
- Books and booklets (Annex 7, 8, 9).
- Treatment follow-up tools.
- Poster and leaflets.
- Activity sheets with colouring figures, drawings.
- Workbooks.
- Films, movies (Annex 10).
- Performances.

## 5. Patient support, education and counselling sessions for children and adolescents along the cascade of care

Steps in the cascade of care	Session	Topics	Transversal disclosure sessions
<b>HIV Testing services</b>	Pre-test information.	Benefits of HIV testing. Education on HIV transmission & prevention, testing procedures & preparation on possible results.	Adapt the regular sessions based on the context, the age and the development of the child. For non- or partially disclosed children, sessions should provide PSEC to caregivers individually before facilitating the session with the child.
	Post-test counselling.	Emotional support in case of HIV+ result. Education & support on how to stay negative (harm reduction skills).	
<b>Entry into care</b>	Initial assessment of patient's needs understanding.	Explore educational, emotional, social and behavioral needs.	An <b>assessment of disclosure status and caregiver support</b> has to take place prior to the disclosure process.
<b>Follow-up for patients not yet eligible for ART</b>	Pre-ART session.	Education on HIV & ART. Counselling to ensure clinical FU.	<b>Partial disclosure to be started approx. around the age of 5-6:</b>
<b>ART initiation and early follow-up</b>	HIV/ART education session.	Education on HIV & ART. Counselling on motivations for Rx, support system, appointments attendance and readiness to start ART.	Two sessions explaining the visit to the clinic, the immune system and the red germ without naming HIV.
	ART initiation session.	Education & counselling on Rx schedule, side effects, Rx reminders, storing of Rx and missed doses.	<b>Full disclosure to be started approx. around the age of 9-10. HIV status to be disclosed to all children &gt;12 if not previously done:</b>  Session explaining that the red germ is HIV and ways of transmission & prevention.
	Adherence follow-up counselling at month 1 on ART.	Education: Assessment of prior knowledge retention and revision. Counselling: assessment on the implementation of the adherence strategies. Creation of new strategies in case of substance use or travelling. Communication between caregiver and child.	
	Adherence follow-up counselling at month 3 on ART.	Education on Viral load test. Counselling to set treatment goals.	
Adherence follow-up counselling at month 6 on ART.	Revision of information on viral load test and treatment goals. Information on the differentiated models of ART delivery.		

Steps in the cascade of care	Session	Topics	Transversal disclosure sessions
<b>Long-term follow-up of patients on ART</b>	Evaluation of adherence at every visit.	Through patients' self-reporting.	
	PSEC session for patients with an adherence issue or who missed an appointment.	Identify the adherence issue and find an appropriate solution.	
	Enhanced Adherence Counselling sessions.	Education on VL result and the most common reason for high VL. Counselling to assess patients' adherence barriers and support the identification of strategies to overcome them.	
	PSEC for 2 <sup>nd</sup> /3 <sup>rd</sup> line ART initiation.	Education on 2 <sup>nd</sup> line/3 <sup>rd</sup> line ART. Revision of adherence strategies.	



## 6. HIV testing services (HTS) for children/adolescents

HIV testing may be initiated by the caregiver/adolescent (client-initiated HIV testing or “opting-in” approach) or proposed by health care providers to children/adolescents attending health care facilities as a component of medical care (Provider-initiated HIV testing and counselling, abbreviated as PITC, or “opt-out” approach). *The MSF Paediatric HIV Handbook* (2015) provides recommendations regarding offering an HIV test to children and their caregivers. It also provides guidance on consent and refers to the 5 “Cs” that should be observed when offering HIV testing services: informed Consent, Counselling, Confidentiality, Correct test result, and Connection to HIV prevention, treatment and care. For more information on testing in nutrition and paediatric programs, consult “*MSF Intersectional Directives for Integration of HIV care as part of Nutrition and Paediatric Programs* (combined position of the Paediatric, AIDS, Nutrition and PSEC Working Groups, Médecins Sans Frontières, July 2014).

**HIV testing should never become mandatory and should not be done without the informed consent of the caregiver (or the adolescent of legal age to provide informed consent).**

### 6.1 Consent for HTS

National legislation and/or policies related to consent and age of consent need to be consulted in each context. If the national legislation or cultural norms block testing despite the best interest of the child, discuss with HIV advisor. Verbal informed consent is usually adequate. In all cases, even if a child is too young to give legal consent, obtain the assent of the child to be pricked (e.g. get the willingness of the child/adolescent to test, do not force them).

Confidentiality of the parent’s HIV status should be guaranteed. Children should not be told they are being tested because their mother is HIV+ unless the mother has given her consent. In some cases the HIV status of the parents may be unknown and the child will be the first family member to be tested.

#### Children < 10-12 years old

- Consent is usually obtained from a parent or legal guardian and the child should be tested in his presence (that is, do not test children brought by a suspicious neighbour). Usually consent from one parent is sufficient, but local cultural norms may require paternal consent.
- If there is no parent or legal guardian (e.g. orphans, street children etc.), check any existing national legislation. A decision will need to be taken by the health care provider to decide if performing an HIV test is in the best interests of the child or adolescent. The medical referent or the project coordinator should be involved in making this decision. Explain to the child according to his/her level of maturity.
- The child can be given partial but truthful information for the reason of testing: for example, that the test can identify a germ that might make them sick and that needs special treatment.



**Children > 10-12 years old**

- Are usually able to give fully informed consent for testing but legally a guardian could be required to give consent.
- Explain they are being tested for HIV to assess their health status; most of them will have some knowledge of what HIV is.
- Adolescents coming on their own for HIV testing should not be denied access to testing. Counselling is a good opportunity to discuss safer sex strategies with them. In general, when adolescents seek STI, FP, ANC or ToP services, HIV test is proposed regardless of legal age of consent. However, pre-test counselling must include identification of a supportive adult, and assess the adolescents' readiness to receive a HIV+ result.

**6.2 Pre-test education**

Pre-test education can be provided individually or in group, depending on the number of children/adolescents to be tested. Informed consent should always be sought individually, as much as possible in private.

The MSF Children & Adolescent Flipchart for HIV testing, Disclosure & Adherence Counselling (pages 2-4) (Annex 13) should be used as visual support to provide information to the child, adapting the explanations to his age and developmental level.

**6.2.1 Caregiver or adolescent alone (individual or group)**

Counsellors should first speak with the caregiver(s) alone. Meanwhile, the child should be welcomed and someone should be identified to take care of the child outside of the consultation room.

In case an adolescent is coming alone, the pre-test counselling session should be done anyway. The provision of the test will be based on the country legal guidelines regarding age of consent, and MSF adaptation to the context regarding such cases.

The following topics should be addressed:

- 1) Introduction: the counsellor should welcome the caregiver or the adolescent, introduce himself, explain his role, and the procedure of counselling and testing, find out if it is a voluntary or referred visit, explain the principles of confidentiality (about what patients say, and the HIV test result).
- 2) **In case of provider initiated testing and counselling (PITC)**, explain the reason why the test is recommended, the benefits of testing and the care available in case of an HIV positive result. Inform about the right to refuse the test, without this affecting the access to services that do not depend upon knowledge of the child's HIV status.
- 3) **In case of voluntary counselling and testing (VCT)**, explore the reason for coming for HIV-testing.
- 4) Ask what the caregivers/adolescents know about HIV/AIDS and fill the gaps if necessary.
- 5) Explain the HIV testing process (finger-prick or drawing blood and timing of result).
- 6) Explain the meaning of a positive and negative HIV test result.

7) Provide education on ways of transmission and prevention of HIV- flipchart pages 15 and 16.

8) With caregivers (not for adolescents on their own).

- Assess:

- The family situation: has the caregiver been tested? Is there a HIV positive parent in the family? Is the mother alive?
- What does the child know concerning his health and the reason of his visit?
- What is the maturity and developmental level of the child (through simple conversation about age, going to school, speaking about health at home, child's reactions when being sick, how child expresses emotions, ...)?
- How much information can be given to the child in pre-test & how can a possible positive result be announced to the child (immediate total disclosure, partial disclosure)?

This will determine how to continue the second part of the counselling when working with the child and the caregiver. The caregiver should feel confident that you will not tell things to the child if the caregiver does not feel ready for the child to know his HIV status.

- Discuss the importance for the caregiver and siblings to test in case of an HIV-positive test result of the child.

9) Ask who the caregiver/adolescent could get support from in case of an HIV positive test result.

10) Determine whether caregiver is the parent or legal guardian of the child. If so, get consent from the caregiver/adolescent to proceed with the HIV test.

### 6.2.2 Caregiver and child

The child will be asked to join his caregiver and the counsellor. Explanations should be provided to the child/adolescent based on his developmental stage, his understanding of illness/HIV/AIDS and the caregiver's readiness to give information.

- **In case of young children, below 6 years**, there will generally be no need to explain the HIV test prior to getting the results. It is recommended to provide information easy to understand on how blood is drawn (using analogy such as a bird that pricks the arm/finger with its beak). The focus should be on making the child feel at ease as much as possible.
- **In case of children between 6 and 12 years**, all options are possible. Before the age of 10, it is recommended to start with simple explanations, e.g. *"We will take blood to check how strong the body is or to see if there are any germs"*. After 10 years old, if the caregiver wishes, an explanation about HIV testing can be provided to the child.
- **In case of adolescents, above 12 years**, everything can be openly discussed: why the child has been referred for an HIV test, assess knowledge and perception about HIV/AIDS and ways of transmission, clarify misconceptions, provide opportunities for questions, explain the testing procedure and possible results, assess emotional situation, prepare for getting possible positive result, reassure on available treatment and provision of MSF support.

It is important to keep in mind that with some children more information can be imparted at a younger age than with other children. Context and culture also plays an important role in what information a caregiver will agree to share with a child.

### 6.3 Post-test counselling

The post-test counselling should always be done individually, whatever the HIV test result. It should be done as much as possible by the same counsellor who did the pre-test counselling.

Unless the caregiver is opposed, the post-test counselling can be done directly with the adolescent. For children under 12 years old, the result will first be announced to the caregiver alone, and then the child will be asked to join his caregiver and the counsellor.

### 6.3.1 Giving an HIV-negative result

- Ask the caregiver / the adolescent if he is ready to receive the result.
- Give the result simply and clearly.
- Explain the meaning of the result.
- Explain the window period and recommend re-testing for adolescents who could have been exposed to HIV in the preceding 3 months (or in case of sexual violence).
- Discuss any other immediate concern the person might raise.
- With adolescents, discuss the importance of staying HIV-negative. Provide condoms and guidance on the way to use them (with a demonstration).
- When available, recommend medical male circumcision to HIV-negative males (insisting on continued use of condoms for adolescents). Propose PEP for adolescent at risk.

### 6.3.2 Giving an HIV-positive result

#### Caregiver alone (or adolescent alone):

- Ask the caregiver/adolescent if he is ready to receive the result.
- Give the result simply and clearly, and give the person time to consider the result.
- Check with open-ended question that the person understands the meaning of the result.
- Allow the patient to ask questions.
- Ask the caregiver/adolescent how he feels about the result?
- Encourage the caregiver/adolescent to talk about his feelings about the result.
- Leave space for emotions and normalize the caregiver's/adolescent's reaction, e.g. *"It is normal to have difficulty accepting the result or to be in shock/angry/sad/ confused"*.
- Ask about any immediate concern, including personal safety (suicide, depression, violence, etc.).
- Discuss eventual disclosure of the result to the child/adolescent and/or to another trusted person.
- Check whom might be available to offer immediate support (in family and friends).
- Describe follow-up support available in the health facility, especially access to life-saving ART.
- Arrange specific date and time for follow-up counselling visit and medical care.
- Emphasize that the child/adolescent can live a long healthy life if he is starting treatment as recommended. Talk about the importance of linkage to care.
- Assess the potential barriers for the caregiver/adolescent to link to care and support him to find solutions.
- For an adolescent, discuss about protection of sexual partners. Provide condoms and guidance on the way to use them (with a demonstration).
- For the caregiver, discuss again how much information can be given to the child and how to announce a positive result (immediate full disclosure or partial disclosure). Ensure the caregiver has enough time to express emotions and get support before including the child.
- When a child has tested HIV positive, it is necessary to encourage HIV testing of parents and siblings.

### Caregiver and child

After the result is discussed with the caregiver alone, the child is asked to join the caregiver and the counsellor.

- **In case of young children, below 6 years**, the diagnosis will not be announced to the child. However, it is important to explain basic things, e.g. *“that blood we took, we looked at it to see how strong your body is”, “now you will go and see the doctor”,* etc. Engage in friendly discussion about going to the doctor. The main idea is to make the child feel comfortable and include him in the discussion. He should not feel excluded. Do not forget he will feel the sadness or other emotional reactions of the caregiver.
- **In case of children between 6 and 12 years**, it is recommended to start with partial disclosure (see further information on disclosure). Full disclosure will be done only if the child was aware that the test was for HIV.
- **In case of adolescents, above 12 years**, it is recommended to proceed immediately with full disclosure, including specific discussion on emotional situation, relationships, modes of transmission and condom use.

### 6.4 Cases of sexual abuse

If the child or adolescent has been brought or presented within 72 hours after a sexual assault, it is advised to offer HTS at the first contact. The reasons for the test need to be explained to the caregiver and child/adolescent (if developmental level is sufficient for understanding). More detailed HIV counselling can be done in the following sessions.

In case the child’s environment may put him at risk further of sexual violence, the staff should address the issue with the project coordinator to find a solution in the best interest of the child. More information is available in the *MSF Policy for Reproductive Health and Sexual Violence Care* by the MSF International Working Group for SRH (2014) and in the *Nurse guide; To welcome children under 12 victims of sexual violence and give them psychological support. MSF OCP, June 2016.*

## 7. Initial assessment of patient's needs

This patient needs assessment is optional and may not be offered in every program. According to the characteristics of the project's target group, patient loads, resources available, and implementation of WHO's ART initiation recommendations, one may consider doing an initial assessment of the child/adolescent's needs at the patient's entry into the HIV program. Often this is done in projects with groups at high risk of being lost to follow-up, or having problems to adhere, or where there is a time delay between screening, diagnosis and treatment initiation.

This assessment can however also be done for a restricted group of patients or for patients facing a specific problem such as patients with a high viral load or hospitalised patients. Ideally the assessment is done on the first contact with the patient, after HIV testing and counselling. If this is not possible, it can be done during later sessions or over several sessions.

Annex 3 proposes an example of initial needs assessment of the caregiver and the child which can be adapted to the target population and the context.

The aims of this initial assessment for children/adolescents and caregivers are:

- To establish a trustful relationship with the child and the caregiver (or adolescent alone).
- To assess the psychosocial environment of the child/adolescent and the relationship with the caregiver.
- To assess the child's level of development.
- To assess for past psychiatric history and present psychiatric symptoms.
- To assess what the child and the caregiver know about HIV (level of disclosure of the child).
- To let the child and caregiver express their needs and plans.
- To engage the caregiver and the child in a process of patient-centred education respecting the development of the child.
- To identify the specific needs of the child and the caregiver to support the child/adolescent living with HIV.
- To assess patient's abilities to learn and self-manage.
- To identify potential barriers to disclosure and treatment adherence in order to offer adequate support to the child/adolescent and the caregiver.

## 8. Disclosure

Disclosure is the process by which children learn about their HIV/AIDS status. It is a transversal process that can happen at any step of the cascade of care from the moment the child tests HIV-positive up to when the child is already on treatment for some time. The age, the developmental stage and the questions asked by the child as well as the wishes of the caregiver will determine when to proceed with partial or full disclosure. WHO<sup>23</sup> recommends that children of school age should be told of their HIV-positive status because of health benefits. A process-oriented approach to disclosure, consistent with the child's developmental capacities, adapted to the cultural context should be used.

*What and when to disclose?* When working with children under 12, MSF recommends progressive disclosure. Progressive disclosure is the process of gradually informing children about what is happening in their body, to the endpoint of naming the disease.

A first step in progressive disclosure is partial disclosure, which is providing information about what is happening in the body, without naming the disease. Partial disclosure should begin when the child is able to understand concepts of illness (often around the age of 5–6 but it could be done earlier).

Later on full disclosure will be done, which means naming the virus and providing information on the modes of transmission, prevention and sexual and reproductive health. Full disclosure can mostly be done around 9–10 years old or when the child is asking questions about the name of the infection or treatment, suggesting the child is ready for full disclosure. Full disclosure should be done at the latest before the age of 12, when the child reaches adolescence. At this stage, keeping the secret has too many negative consequences on the adolescent's treatment and emotional wellbeing.

*Why to disclose?* Research has shown that disclosure leads to improved health benefits for the child. There is little evidence of psychological or emotional harm from disclosure of HIV status to HIV-positive children and immediate emotional reactions dissipate with time and respond to program interventions<sup>22</sup>. It is important to tell the truth to the child and answer his questions with sincerity, adapting the explanation to his understanding. Even when the child is very young, it is good to explain things in an honest and open manner. Hiding the truth always brings long term damages to the caregiver-child relationship.

*Who should disclose?* The disclosure process should be conducted by someone the child trusts and respects, usually the caregiver. Counsellors should help the caregiver feel more comfortable about the disclosure process. Counsellors can also directly assist in the disclosure process with the caregiver. Ideally, disclosure takes place in a supportive environment through collaboration and cooperation between the caregiver and counsellor. Some caregivers may not want their adolescents above the age of 12 to be disclosed about their HIV status. When this happens, the caregiver requires counselling sessions to help him work through the reluctance to disclosure and to reinforce the importance of full disclosure to an adolescent. If the caregiver remains reluctant or disagrees to disclose the HIV status to the adolescent, the medical team should take the responsibility for disclosing to the adolescents above 12 years of age. Counsellors should inform caregivers that they will proceed with disclosure, based on the argument that non-disclosure has negative consequences for the adolescent's health and wellbeing. However, if it is determined, based on assessment of caregiver, adolescent, and social situation, that disclosure without caregiver consent will have greater and ongoing negative consequences for the adolescent than non-disclosure, then don't do the disclosure. Instead, continue to work with the caregiver about importance of full disclosure for adolescents.

*How to record disclosure?* The disclosure status of a child/adolescent should be indicated on the file using a sign (e.g. empty circle for ND, half circle for PD or full moon circle for FD) or initials (e.g. ND, PD and FD) to alert the team if the child is not at all, partially or fully disclosed.

The whole team should know how far the child is in the disclosure process and address him accordingly to avoid accidental disclosure.

How to disclose? The child and adolescent flipchart (see Annex 13) is to be used to conduct the below disclosure sessions. Additional story books can be used as well (see Annex 7, 8 and 9).

## 8.1 Partial disclosure

Partial disclosure can be started when the child is asking questions about the visit to the clinic or about taking treatment every day. It is recommended that the counsellors pro-actively start with partial disclosure around the age of 5-6 years. Depending on the developmental stage of the child, the counsellor can address some topics earlier/later and answer the child's questions to help him understand the reason for visiting the clinic, taking ARV's, etc.

### 8.1.1 Caregiver alone (individual/group)

- Assess knowledge about HIV/AIDS and correct misconceptions.
- Assess what the caregiver has told the child about coming to the clinic, drawing blood, taking treatment, etc.
- Explain the process of disclosure: Explain that partial disclosure should begin by the time the child starts to understand concept of illness (around 5-6 or before based on development) and provide information about what is happening in the body without naming the disease. Then, mention that full disclosure will consist in informing the child about his HIV+ status and is recommended around the age of 9 or 10 or before if the child asks questions or suspects he has HIV). Explain to the caregiver that it is ill-advised to delay full disclosure once the child is 12 years of age or older - Flipchart page 1 on progressive disclosure.
- Explain the advantages of progressive disclosure:
  - The child can speak openly about his feelings. Children who can express themselves are more able to cope with difficult situations.
  - The caregiver conveys an image of the adult who has authority and can be trusted.
  - It helps to build a constructive relationship, in which the caregiver can help the child to become strong and learn to live with the condition.
  - It allows giving appropriate information to the child, adapted to his age. The child will not remain with erroneous and dangerous fantasies.
  - The child is conscious about the importance of medical care, adherence to the treatment and of protecting himself and others.
- Explain the risk of late or non-disclosure
  - The child will guess that there is a secret regarding his illness. It can lead him to inventing his own explanation which can be worse than the reality.
  - Children can feel different and isolated.
  - Children can learn inaccurate or incomplete information about HIV/AIDS in the media, in the community or at school.
  - The accidental discovery of his status without appropriate support has worse consequences than a well-organized progressive disclosure.
  - When the child finds out that he has HIV, he can feel that he has been deceived about his true medical condition.
  - These factors can lead to emotional problems (anxiety, depression, aggressiveness), troubles at school and relational or social disorders.



- Assess the readiness of the caregiver to proceed with partial disclosure, **reassuring that the term HIV will not be mentioned in this session**. If the caregiver agrees, explain the topics that will be discussed and then start partial disclosure with the child present.
- If the caregiver refuses, assess the reason for refusing and propose another session to support finding solutions to overcome the barriers to disclosure.

### 8.1.2 Caregiver and child (or child alone)

The process of partial disclosure is usually done over two sessions, when the child is attending the clinic for medical visits. For older children, one session may be sufficient. The two sessions can be offered at consecutive or non-consecutive visits. The number of sessions and the interval between them should be adapted based on the specific needs of the child.

#### Session 1 (individual or group)

- Help the child to feel comfortable and express himself by asking questions about his friends, his favorite game, his favorite food, etc.) – Flipchart page 2.
- Invite the child to express how he feels today- Flipchart page 3.
- Ask the child what happens when he comes to the clinic. Explain the different activities taking place in the clinic– Flipchart page 4.
- Assess what the child already knows about the human body. Talk about the human body from the outside and from the inside with the blood system, explaining all the little tubes that carry the blood thru the body- Flipchart page 5.
- Explain that there are green soldiers inside the blood, in order to protect the body-Flipchart page 6.
- Explain the immune system: The green soldiers are there to protect us against the yellow germs- Flipchart page 7.
- Discuss with the caregiver and the child about who they want to tell that they are coming to the clinic or taking treatment. Flipchart page 17.
- Assess if there are any concerns or questions.

#### Session 2 (individual or group)

- Assess what the child remembers from session 1 with open ended questions and complete or correct information reviewing the flipchart pages 5, 6 and 7.
- Explain that the red germ is a special germ in his body and that it is different from the other yellow germs- Flipchart page 8.
- Explain that the red germ attacks the green soldiers/ in the blood. At the beginning, the soldiers can still protect the body but as time pass, if we don't do anything to stop the red germ, the green soldiers won't be able to protect the body anymore. The yellow germs will enter the body and make the child sick- Flipchart page 9.
- Explain that luckily there is a treatment to keep the red germ asleep/weak. When keeping the red germ asleep, the green soldiers can become strong again. With the treatment, the green soldiers are able to protect the body against other diseases. This treatment has to be taken every day; otherwise the red germ will wake up and fight the green soldiers again- Flipchart page 10.
- Talk about the importance to take treatment as advised. Some children will have to take treatment once a day around the same time every day. Some others may have to take it twice a day – Flipchart page 11.
- Assess what the child thinks would happen if he stops or forgets to take the treatment regularly. Explain the risk of poor adherence: being sick and getting a germ that becomes different, the purple germ which the actual treatment can no longer protect against– Flipchart page 12.
- Assess if there are any concerns or questions.



## 8.2 Full disclosure

The full disclosure should be done when the child is asking questions about the name of his infection or treatment. In most cases, the child will have reached this developmental level by the age of 9 or 10 years old, though some children could be younger.

### 8.2.1 Caregiver alone

- Assess how things are going with the child, if he asks questions about the visit to the clinic or the treatment. Assess if the caregiver has provided any information to the child about his HIV status.
- Assess how the child takes the treatment.
- Assess the readiness of the caregiver to announce to the child that he is infected with HIV.
- If the caregiver doesn't feel ready, assess the reason and explain the advantages of disclosure.
- If the caregiver feels ready, agree with him on who will announce the HIV status to the child. Encourage the caregiver to do it. If the caregiver does not feel able, propose to do it together. Call the child and proceed with full disclosure.

### 8.2.2 Caregiver and child

- Assess what the child remembers from the partial disclosure session(s) and complete the information- Flipchart pages 9 to 12.
- Ask the child if he knows the name of the red germ.
- Based on what has been agreed, the caregiver or the counsellor tells the child/adolescent that the red germ is HIV.
- Ask the child/adolescent what he knows about HIV and correct misconceptions.
- Invite the child to express how he feels now that he knows his HIV status- Flipchart page 3. Recognize and normalize any emotion the child could express (numb, in shock, angry, sad). Let the child/adolescent know that it is normal to feel such emotion and that he might also experience other emotions in the coming days/weeks. Let the child/adolescent know that you will be there to support him if he wants to talk about how he is feeling.
- Talk about the ways of transmission and the ways HIV cannot be transmitted- Flipchart page 15.
- Discuss about sexual violence, emphasizing that it is never the child's fault when it happens and the importance of being able to talk to a trusted adult about it- Flipchart page 16.
- Discuss about who to tell. Invite the caregiver and the child to agree on who they can tell and who they shouldn't tell. Explain that some people still have misconceptions about HIV and that it is important to identify someone they trust. Flipchart page 17.
- According to age provide information about prevention and condom use.
- Assess if there are any concerns or questions.

## 8.3 Unacknowledged disclosure<sup>24</sup>

This category represents those youth who have come to know their HIV-status or disease through an unplanned and unsupported disclosure. This disclosure might occur suddenly and unexpectedly without explanation, and could even involve words that insult or hurt. Unacknowledged disclosure can occur in different circumstances and they do not necessarily have the same psychological impact for the child. We may encounter the following situations:

- **Involuntary disclosure** : this is the child/adolescent who comes to a clinic and sees posters about HIV/AIDS. He can read these posters and understand the messages. This can be also the child/adolescent who hears adults speaking about HIV/AIDS or who sees the name of his medications and has a friend who takes the same medications for AIDS.

- The disclosure **made in a moment of crisis**, under the influence of strong emotions. This situation is often encountered when the child is reluctant to take ARVs. Some parents, frustrated and short of arguments, suddenly announce the diagnosis without providing the appropriate education and assurance.
- A **disclosure made voluntarily to harm the child**. For example, a neighbor who announces: “Anyway, you have AIDS, you are going to die like your mother.”

The counsellor needs to be alert for children/adolescents who give signals that they know something about their HIV status/disease but this is not acknowledged by caregivers. The counsellor might be solicited by a parent following an unacknowledged disclosure. Discussion then needs to take place with the caregiver about the importance of full disclosure with an appropriate explanation, and the negative impact on the child and the caregiver-child relationship if there is not open discussion.

It will be necessary to first determine with the caregiver the circumstances of this unacknowledged disclosure (and possibly the words that were used). Then offer to resume the guided disclosure with the child or adolescent, taking into account the age, the cognitive abilities of the child, the family context, and the relationship to the person who made the unacknowledged disclosure. The interview should ideally be conducted by an experienced counsellor known to the child if possible. After welcoming the child and his/her caregiver, begin by exploring what the child understood, by asking him to tell what he heard: “Your mother said that you heard (or that someone told you) about your health issue. Can you tell me what happened, what you understood? ” . If the child is in shock, offer him some help: “I see it is hard to talk about this. If you want, I can help you. I will tell you what I have been told, and you will just tell me if it happened that way. Are you OK with this? ”. Once the dialogue has started, the counsellor follows the steps of a planned disclosure.

### 8.4 Sexual and reproductive health session (individual or group)

This session is done without the caregivers of the fully disclosed adolescent. It can be done individually or in group. In case of a group session, boys and girls can be split (depending on the context) to make sure they feel comfortable to discuss intimate topics with peers. The groups can mix again at the end of their respective session, deciding in advance the feedback they want to give in the mixed group.

- Assess what the adolescent knows about the changes happening in the bodies of boys and girls when they grow up. Ask about emotional changes (feelings for others). Explain that often adolescents begin to experience sexual feelings, and sexual interest in others. They may feel desire to engage in sexual contact with others. They may even feel they are ready to engage in sexual intercourse- Flipchart page 18.
- Talk about the importance of using condoms to avoid transmitting HIV to sexual partners and to prevent other STI's. -Flipchart page 19. Carry out a condom demonstration.
- Provide information about the menstrual cycle and a woman's sexual and reproductive organs and reproductive options, including how to prevent unplanned pregnancy- Flipchart page 20.
- Provide information about a man's sexual and reproductive system. Talk about how conception occurs. Talk about prevention of unplanned pregnancies and condom use- Flipchart page 21.
- Assess if the adolescent has any questions.

Tools other than the flipchart may be used to discuss the growing body, sexuality and HIV, such as Aunt Stella (Annex 14) or the Love Check Game (Annex 15).

## 9. Follow-up for children/adolescents not yet eligible for ART

Very few projects will have children and adolescents not yet eligible for ART in their program, as since 2016 WHO recommends that children/adolescents be initiated on ART regardless of their CD4 cell count. In the few projects where these recommendations have not yet been implemented, counselling and education should be provided to caregivers of children and adolescents not yet eligible for ART.

<b>When</b>	At day of defining non-eligibility for treatment.
<b>Mode</b>	Individually or in group.  This session could be spread over different sessions, depending on patient's needs.  Caregivers of non-fully disclosed children should attend most of this session alone. The counsellor should first receive the child and the caregiver to welcome them and establish contact with the child. Then someone should be identified to stay with the child outside of the consultation room. A separate session will take place with the child to work on partial and full disclosure based on his age and developmental level and willingness and desire of the caregiver.
<b>Duration</b>	30 minutes.
<b>Tools</b>	Child and adolescent flipchart (Annex 13).
<b>Objectives</b>	Education on HIV and ART, disclosure, identification of the support system, importance to attend future appointments and assessment of readiness to start treatment as soon as the child/adolescent will be eligible for ART.

### 9.1 Caregivers alone or with fully disclosed children/adolescents

#### Education about HIV and ART

The counsellor should ask the following questions to evaluate the knowledge the caregiver and/or the child/adolescent have about HIV/AIDS and treatment, correct misconceptions and complete the information (as recommended below).

What is HIV?

- *The **immune system** defends us against diseases (TB, flu, etc.) and is made of CD4 cells (CD4 cells=soldiers of the body) - Flipchart pages 6 and 7.*
- ***HIV** is a virus that attacks this immune system and CD4 cells. As the CD4 cells are attacked there are less of them to protect against illness and the body will slowly become weaker. All kinds of diseases will be able to enter the body: fever, diarrhea, TB, mouth sores - Flipchart pages 8 and 9.*
- *The diseases that enter the body when the immune system is destroyed by HIV are called **opportunistic infections**. The most common is TB.*
- ***HIV turns into AIDS** when the immune system has become weak and there is a diagnosis of HIV-related opportunistic infections.*

What are the modes of transmission and of prevention of HIV?

Modes of transmission	Modes of prevention
Through unprotected sex.	Condom use.
From mother to child (during pregnancy, delivery or breastfeeding).	Test for HIV and take ART if HIV+ (PMTCT).
By sharing sharp materials that had contact with HIV infected blood (this mode of transmission is not frequent).	Avoid sharing sharp objects. Sterilized or single-use instruments for medical procedures.

How is HIV treated?

- *There is special treatment for HIV called anti-retrovirals or **ARVs**. Without ARV treatment, HIV will keep on multiplying and destroying the CD4 cells – Flipchart page 10.*
- *Once started, the treatment should be taken every day for life to keep control of the virus, or make HIV “sleep” in the body. If the treatment is stopped, the virus will multiply again – Flipchart page 11.*
- *Along with ARVs, children might also be given an antibiotic to prevent other infections.*

When should the treatment be started?

- *The treatment should be started as soon as it is recommended by the clinician.*
- *If the treatment is not yet started (due to health policies applied in the context recommending to start from a certain CD4 threshold), it is very important to come for check-ups as advised (every 3 or 6 months) to get a CD4 count. The CD4 count will measure the amount of CD4 (soldiers) in the body and will determine the best time to start the treatment.*

#### **Education on progressive disclosure (for caregivers of non-disclosed children)**

- Remind the caregiver that the child can have a healthy future if he comes for regular check-ups and starts medication when advised by the clinician.
- Explain to the caregiver that he doesn't have to tell the child that he is HIV positive now if he is not ready for that, but that he shouldn't lie to him either. It is counter-productive to deceive or mislead him about the reality of his condition.
- Explain to the caregiver that children are more cooperative about taking their treatment when they understand the illness, e.g. have been partially or fully disclosed regarding their HIV+ status – Flipchart page 1.

#### **Counselling (individual)**

- 1) Identify the motivations to come for follow-up visits and CD4 count check.
  - Help the caregiver/adolescent to talk about what dreams/goals he may have for the child's/his future. Write down 2 or 3 main dreams that will help motivate them to come for follow-up.
- 2) Identify supports in the child's and caregiver's environment.
  - Help the caregiver/adolescent to identify someone to whom he can disclose the HIV status.
  - Remind the caregiver/adolescent that it is their choice to disclose and to whom.
  - Ask if they would agree to have a community health worker visiting them at home in case it is needed or if they would like to join a support group (where available).
  - Explain ART refill options where available (e.g., ART refills in group and/or in the community).
- 3) Planning for future appointments.
  - Explain that it is very important that the child attends the clinic appointments so he can receive the best medical care possible and get his CD4 count done regularly.
  - Ask what might cause the child/adolescent to miss appointments.
  - Assess how the caregiver/adolescent travels to the clinic and help them make a plan in case of unforeseen events such as: no transport money, rain, having a sick child at home, etc.

4) Readiness to start the treatment when it will be advised by the clinician.

- Explain that starting ARVs as soon as it will be advised by the clinician will help the child to stay healthy and live a good life.
- Ask what could keep them from starting ARVs when the clinician will recommend doing so.
- If the caregiver/adolescent has obstacles to start treatment, explore the concern and support the caregiver/adolescent to think of solutions to the obstacles.

## **9.2 Non fully disclosed child**

If the child was not in the session, thus has not yet been disclosed, invite him to join the session to provide information according to his age, understanding and the caregiver's readiness to disclose HIV status to the child (refer to the chapter on disclosure for content).

## 10. ART Initiation and early follow-up

With WHO's 2016 recommendations to start ART regardless of CD4 count, all children/adolescents will be offered to start ART immediately at diagnosis. The counsellor will have to support the child and the caregiver to start a lifelong ARV treatment. For young children, maintaining good treatment adherence will be the responsibility of the caregiver. He needs to understand the potential complexities in a drug regimen and assist the child with the drug administration. Older children/adolescents should take responsibility for managing their own health and understand the requisite aspects of treatment although they will still require support from a caregiver.

The ART initiation and adherence sessions include both information on HIV&ART and skill-building so ART suits the patient's life, motivations and future aspirations.

A frame for rapid ART initiation is proposed below. For processes for ART initiation at the day of HIV diagnosis (same-day initiation), check the *MSF PSEC Guideline for Adults Living with HIV and/or TB*.

### 10.1 HIV/ART education session

**Focus on** Education on HIV and ART, disclosure, identification of the support system, importance to attend future appointments and assessment of readiness to start treatment.

**Duration** 30-60 minutes.

**Tools** Child and adolescent flipchart (Annex 13).  
Optional: video the Story of Bobo (Annex 10).  
Patient file / Adherence plan (Annex 4).

**Mode** Caregivers of non-fully disclosed children should attend most of this session alone, except in the case of infants. The counsellor should first receive the child and the caregiver to welcome them and establish contact with the child. Then someone should be identified to stay with the child outside of the consultation room. A separate session will take place with the child to work on partial and full disclosure based on his age and developmental level.

#### 10.1.1 Caregivers alone or with children/adolescents fully disclosed

##### Education (individual or group)

1) Education about HIV and ART:

The counsellor should ask the following questions to evaluate the knowledge the caregiver and/or the child/adolescent have about HIV and ART, correct misconceptions and complete the information (as recommended below).

What is HIV?

- The **immune system** defends us against diseases (TB, flu, etc.) and is made of CD4 cells (CD4 cells=soldiers of the body)- Flipchart pages 6 and 7.

- **HIV is a virus that attacks this immune system and CD4 cells. As the CD4 cells are attacked there are less of them to protect against illness and the body will slowly become weaker. All kinds of diseases will be able to enter the body: fever, diarrhea, TB, mouth sores.** – Flipchart pages 8 and 9.
- **The diseases that enter the body when the immune system is destroyed by HIV are called opportunistic infections. The most common is TB.**
- **HIV turns into AIDS when the immune system has become weak and there is a diagnosis of HIV-related opportunistic infections.**

What are the modes of transmission and of prevention of HIV? - flipchart page 15

Modes of transmission	Modes of prevention
Through unprotected sex.	Condom use.
From mother to child (during pregnancy, delivery or breastfeeding).	PMTCT.
By sharing sharp materials that had contact with HIV infected blood (this mode of transmission is not frequent).	Avoid sharing sharp objects sterilized or single-use instruments for medical procedures.

How is HIV treated?

- *There is special treatment for HIV called anti-retrovirals or **ARVs**. Without ARV treatment, HIV will make more of itself (multiply) and destroy the immune system so the CD4 cells can't protect the body against diseases.* – Flipchart page 10.
- *HIV cannot be cured; the treatment should be taken **every day for life** to keep the HIV "asleep" in the body. If the treatment is stopped, HIV will multiply again.* – Flipchart page 11.
- *Along with ARVs, children might also be given an antibiotic to prevent other infections.*

2) Education on progressive disclosure (for caregivers of non-disclosed children) – Flipchart page 1.

- Explain that it is important that the child has some understanding of why he needs to start taking medication every day.
- If the child understands the importance of taking medication he will be more willing to take it.
- Remind the caregiver that the child can have a bright future if he starts medication timely and takes it every day.
- Explain to the caregiver that he doesn't have to tell the child that he is HIV positive now, but that he shouldn't lie to him either.
- If the child meets the criteria for disclosure (age and development stage), provide the session on partial disclosure to the caregiver.

### Counselling (individual)

The counsellor should help the caregiver/patient to develop adherence strategies to overcome the most common barriers to adherence.

1) Identify the motivation for treatment.

- Help the caregiver/adolescent talk about what goals he may have for the child's/his future. Write down 2 or 3 goals that will motivate the caregiver/adolescent to start the child/himself on ART.

2) Identify support in the child's/adolescent's environment.

- In case of several caregivers, identify who will administer the treatment.
- Explain that it is good to have someone to talk to about the child's HIV status. This person could help to give ARVs or take the child to clinic appointments.
- Assess what could be the main barriers to disclose the child's status.
- Help the caregiver/adolescent to identify someone to whom he can disclose the HIV status.



- Remind the caregiver/adolescent that it is their choice to disclose an HIV+ status, and to whom (though it is important to encourage adolescents to disclose their HIV+ status to sexual partners).
- Ask if they would agree to have home visits (in case it is needed) or if they would like to join a support group.

3) Planning for future appointments.

- Explain that it is very important that the child/adolescent attends the clinic appointments so he can receive the best medical care possible.
- Ask what might cause the child/adolescent to miss appointments.
- Assess how the caregiver/adolescent travels to the clinic and help them make a plan in case of unforeseen events such as: no transport money, rain, having a sick child at home, etc.

4) Readiness to start the child on treatment.

- Explain that starting ARVs as soon as possible will help the child stay healthy and live a good life.
- Ask what could keep them from starting the child on ARVs.
- If the caregiver/adolescent does not feel ready to start treatment, explore the concern and support the caregiver/adolescent to think of solutions to any obstacle. Plan extra sessions to provide further support and re-assurance until the caregiver/adolescent feels ready to begin ART.
- If the caregiver/adolescent feels ready, plan the session for initiation on ART (to avoid delaying initiation, ideally, this should occur within one week once patient expresses readiness to start ART).

### 10.1.2 Non fully disclosed child

If the child wasn't in the session, thus has not yet been disclosed, invite him to join the session to provide information according to his age, understanding and what has been agreed with the caregiver (refer to the chapter on disclosure).

## 10.2 ART initiation session

**Focus on** The medication schedule, explanation on how to administer/take medication, treatment reminders, what to do in case of missed doses, maintaining daily treatment, dealing with side-effects and the importance of an open and honest communication between child and caregiver.

**Duration** 30-60 minutes.

**Tools** Patient file/adherence plan (Annex 4).  
Medication samples.

### 10.2.1 Caregivers and fully disclosed child/adolescent

Review the motivation to start treatment:

- Ask the child what he would like to do in the future (e.g. goals e.g. hobbies, talents, work).
- Mention the caregiver's goals for the child's future (from previous session).
- Remind the caregiver and the child of the importance of taking treatment in order to reach these goals.

Find out if the caregiver has disclosed the child's status to someone who could support them. Encourage him to do so while remaining non-judgmental and understanding if he did not manage to do so.



Assess what the caregiver remembers from the previous session and if he still agrees that the child starts ARVs today. Assure that the team will support them to deal with the treatment.

Continue to identify adherence strategies and educate the caregiver/adolescent regarding the following common barriers to adherence:

### 1) Medication schedule and administering medication.

(Before providing explanation on treatment, the counsellor should get information from the clinician about the treatment prescribed and the recommendations for administering it).

- Make sure the person accompanying the child is the caregiver in charge of administering the treatment.
- According to the regimen prescribed, educate on how to take/give ARV treatment. Demonstrate how to use dispersible tablet, a syringe if syrup has been prescribed, measuring spoons, cutting and crushing tablets (Aluvia=Lopinavir+Ritonavir should never be cut or crushed), with or without food, mixed with beverage.
- Explain that the caregiver/adolescent should make sure he takes the correct amount of ARVs around the same time, once/twice every day.
- For caregivers of children not yet on an adult dose, educate that, as the child grows, the medication will change according to his weight. It is therefore important to bring the child to appointments so that the nurse can weigh him and prescribe the correct dose.
- Assess if there might be difficult times during the day to give/take ARV.
- Support the caregiver/adolescent to decide the best time to give/take the treatment (based on their daily schedule/routine).
- Support the caregiver to administer medication encouraging them to make medication times a positive experience for the child. Annex 16 provides some tips for giving medicines to infants and toddlers.
- Explain that if the child/adolescent vomits within 30 minutes of taking the ARVs, he should give/take the dose again.
- If the caregiver/adolescent experiences ongoing problems with giving/taking the ARVs, they should come and talk to the nurse.

### 2) Create strategies to remember the time to take treatment.

- Explain to the caregiver/adolescent that reminders can help to remember when to give/take the treatment. The reminders can also be linked to the child/adolescent's goal (as a "positive thinking strategy").
- Help the caregiver/adolescent to think about what could help them remember to take the treatment (attach a piece of fabric close to where the caregiver/adolescent usually is at the time of taking medication, set an alarm in the phone, a daily TV program, a daily habit like fetching water,...).
- Recommend the caregiver/adolescent to think (and repeat with the child) about the dreams for the future when it is the time to take treatment.
- If available, the counsellor can propose to give reminder tools to the caregiver/adolescent such as dot stickers and help them to identify where to put them (on phone, TV, wall, etc.).

### 3) Managing missed doses.

- Assess what are the situations in which the caregiver/adolescent could forget (or be unable) to give/take treatment.
- Ask what he would do if he forgets to give/take the treatment.
- Explain that the caregiver/adolescent should give/take the medication as soon as he remembers, up to 12 hours later for ART taken once a day and up to 6 hours later for ART taken twice a day. After giving/taking the late dose, he should go back to the usual medication time. For more information on exact timing to take missed doses, refer to the *Patient Support, Education, and Counselling Guideline for Adults Living with HIV and/or TB*.
- Encourage the caregiver/adolescent to let the counsellor or the nurse know in case he misses doses.

4) Storing medication and keeping extra doses.

- Explain that it is important to identify a convenient place to store the medication and to carry some with them in case they can't get home on time.
- Assess if there is a cool place to keep the medication at home (e.g. a clay pot).
- Ask where the caregiver/adolescent could carry extra doses in case he does not make it home on time for the scheduled dose e.g. in the pocket of your jacket or bag that they usually use when going out (not applicable for syrup).

5) Dealing with side-effects – Flipchart page 14.

- Explain that the medication may cause some side effects such as nausea, vomiting, diarrhea or a rash. If the child/adolescent has difficulty breathing, is very pale, bruises easily, develops a rash, or develops yellow eyes they should come immediately to the clinic.
- Ask what the caregiver/adolescent will do in case of side-effects.
- Recommend caregivers/adolescent **not to stop the (child's) treatment and to come to the clinic immediately**. Side effects can be treated. The clinician must first assess the child and then advise what to do.

6) Communicating with the child about his health and medication (for caregiver only).

- Remind the caregiver that it is important to communicate regularly with the child about the visits to the clinic, taking medication, etc. It will help the child to take medication correctly.
- Explain that if the child feels safe to ask questions about the medication to the caregiver, they won't ask other people. He can encourage the child to ask questions.
- Check if the caregiver has any further questions.

### 10.2.2 Non fully disclosed child/adolescent

Review of the motivations to start treatment:

- Involve the child in the discussion **but DON'T mention HIV**.
- Ask the child what he would like to do in the future (e.g. goals hobbies, talents, work).
- Mention the caregiver's goals for the child's future (from previous session without naming HIV).
- Remind the caregiver and the child of the importance of taking treatment in order to reach these goals.

Based on the need, continue or start the disclosure process with the child (refer to the section on disclosure).

Make an appointment for the next session. Congratulate caregiver about starting treatment for the child and direct the caregiver and child to the clinician.

### 10.3 Adherence follow-up session at month 1 on ART

**Focus on** Assessing how the patients managed to implement the adherence strategies, assess other obstacles that interfered with the treatment and discuss what to do in case of travel and/or substance use.

**Duration** 20-30 minutes.

**Tools** Patient file / Adherence plan (Annex 4).  
Pill pathway (Annex 11).

### 10.3.1 Caregiver and fully disclosed child/adolescent (individual)

Make sure that undisclosed children are taken care of by someone outside of the consultation room.

Ask how the caregiver is feeling and how the child is doing since starting treatment. Acknowledge that it can be difficult to create new habits and ask caregiver how she is coping. Congratulate the caregiver for continuing to give his child's treatment (and the child for taking treatment if present, thus fully disclosed).

Ask the caregiver/adolescent to describe the way he gives/takes ARV treatment: name, dosage, and timing.

For caregiver of non-disclosed child, find out what questions the child has asked and how the caregiver managed to answer the child's questions.

Ask the caregiver/adolescent to explain how the ARV treatment works (what it does to HIV) and complete/correct information where necessary.

Ask if the caregiver/adolescent has faced obstacles giving/taking medication (side effects, forgetfulness, etc.). For each obstacle, ask the caregiver/adolescent what he has done to overcome the obstacle. Based on the caregiver's feedback, see if the original adherence strategies need to be revised or adapted.

Assess the number of missed doses and the reasons for missing them. Ask what helps remember to take/give the drugs at the right time.

Verify whether the caregiver/adolescent has understood instructions given by the prescriber regarding any changes in medication dosage (e.g. If the regimen contains Nevirapine, inform about the change of drugs after 2 weeks on treatment).

Continue to identify adherence strategies and educate the caregiver/adolescent regarding the following common barriers to adherence:

#### 1) Planning for trips.

- Explain that if the caregiver/adolescent has to travel or move elsewhere, he should inform the clinic staff before leaving. The staff could then give enough medication to cover the travel period or until he gets to a new clinic.
- The caregiver should make sure he takes all the important information regarding the treatment (e.g. patient card with name of the medication or a referral letter).
- Assess if they have any trips planned in the coming months and what could prevent them from coming to the clinic before going on a trip.
- Help the caregiver to identify a clinic in the area where they usually travel.
- Ask the caregiver who is the adult who can take care of the child and give the correct treatment to the child in case he travels without the child.

#### 2) Dealing with substance use.

- Explain that taking alcohol or drugs makes it difficult to remember to give/take treatment. It is best to limit the use but if he is planning to drink alcohol or use drugs, it is important to make sure to give/take medication first.
- Assess what the caregiver/adolescent could do to make sure he remembers to give/take treatment in case of using alcohol or drug. E.g. Give/take the treatment before starting drinking.
- Let the caregiver/adolescent know that if they feel alcohol/drug use is affecting their life and adherence, they can discuss with the health care provider and be referred to services that may help to work on that problem (in case specialized counselling or a rehab service exists in the area).

In case the caregiver is not able to care for the child (due to travel, substance use, being sick, etc.) a secondary caregiver should be identified to give treatment to the child.

### 10.3.2 Caregiver and non-disclosed child

If the child wasn't in the session, thus has not yet been disclosed, invite him to join the session to provide information according to his age, understanding and what has been agreed with the caregiver (refer to the chapter on disclosure for the session content).

## 10.4 Adherence follow-up session at month 3 months on ART

**Focus on** Prevent future adherence problems, educate on the viral load test, plan full disclosure for the child (if not yet done).

**Duration** 20-30 minutes.

**Tools** Child and adolescent flipchart (Annex 13).  
Patient file / Adherence plan (Annex 4).

### 10.4.1 Caregiver and fully disclosed child/adolescent

Continue to identify adherence strategies and educate the caregiver/adolescent regarding the following common barriers to adherence:

1) Preventing any future problems in taking the treatment.

- Remind the caregiver that making a change in daily life such as giving/taking medication every day takes time and practice. Forgetting a dose or missing an appointment might happen. If it does, it is important to get back to the adherence routine as soon as possible instead of giving up.
- Assess how the caregiver/adolescent would feel if he forgot to give/take medication and what he can do to pick himself up and start to give/take treatment again.
- Assess the number of missed doses and the reasons for missing them. Ask what reminders help to take/give drugs at the right time.

2) Educate on viral load.

- Ask the caregiver/adolescent if he remembers what ARVs are supposed to do to HIV in the body.
- Remind the caregiver/adolescent that the ARVs decrease the amount of HIV in the body, keeping it strong and healthy. – Flipchart page 10.
- Ask if they know how to check if the ARVs are working. Explain that: “A viral load test measures the amount of HIV in the blood and is done by drawing blood”.
- Explain when the first viral load test will be done (4 or 6 months after starting ARVs and then after 1 year on ARV treatment).
- Explain that after that, the viral load will be done every 6 months or every year (depending on the child's age, and the setting). If there is a problem, the viral load will be done after 3-months.
- Explain the meaning of undetectable/low viral load: *there is so little HIV in the blood; it cannot be seen with this test. HIV is still there, but it is very small in the body. An undetectable viral load is very good as it means you are healthy and the treatment works well.*
- Explain the detectable/high viral load: *there is too much HIV in the body as it can be seen in the blood. The HIV is still making more of itself in the body and will make the body sick. You (and your child) will need to come more regularly to the clinic until the viral load is under control.*
- Tell the caregiver/adolescent that the most common cause of high viral load is when people are facing problems in giving/taking medication every day. Communicating problems with the clinic staff early can help you to solve the problems and get your child's/your VL undetectable.
- Assess the caregiver's understanding by asking what viral load result he would like to achieve.

- 3) Agree on a goal with the caregiver/adolescent regarding the result they would like to achieve (e.g. viral load undetectable).
- 4) Thinking about progressive disclosure to the child (for caregivers of non-fully disclosed children).
  - Assess the level of disclosure of the child and provide recommendations on partial and full disclosure according to the age and developmental level of the child.
  - Remind the caregiver that disclosure helps the child understand why he must take medication every day and increase adherence.
  - Tell the caregiver that at some point he will need to fully disclose the HIV status to the child and that it is best to do this when the child starts to ask question about his illness and treatment. For many people this is not an easy thing to do, but it is important that the child hears it from the caregiver (in collaboration with the counsellor) rather than someone else.
  - Assess when the caregiver thinks he and the child will be ready for full disclosure.
  - Reassure that the counsellor can provide support if the caregiver struggles with disclosure.
  - Explain to the caregiver that the child should also understand the importance of the viral load test and results.
  - Propose to explain to the child why the blood tests are important without talking about HIV.
  - Assess if caregiver is willing to bring child into session for the child friendly version of the viral load explanation. If caregiver agrees, invite child to the session.

#### 10.4.2 Non-disclosed child

Provide information according to the child's age and understanding and agreement with caregiver. See above section for counselling caregiver of non-disclosed child.

Education on viral load for the child:

- Review information from partial/full disclosure on ARVs that help to keep the red germ asleep – Flipchart page 10.
- Explain that sometimes it is necessary to do a blood test to make sure the sleeping germ is still asleep / controlled.
- Ask if the child has any questions and make sure he understands the reason for the blood test.

### 10.5 Adherence follow-up session at month 6 on ART

<b>Focus on</b>	Review the education on the viral load test, inform that the test will take place on that day and provide information about differentiated models of care.
<b>Duration</b>	20-30 minutes.
<b>Tools</b>	Child and adolescent flipchart (Annex 13). Patient file / Adherence plan (Annex 4).

#### 10.5.1 Caregiver and fully disclosed child/adolescent

- 1) Review education on viral load (from previous session).
  - Ask the caregiver/adolescent what does the viral load test measures and what can be the different results.
  - Explain that the first viral load test will be done today.
  - Assess the caregiver's understanding by asking what viral load result he would like to achieve (revising the goal from previous session).

2) Provide information about differentiated models of care:

If the project has implemented differentiated models of care to facilitate access to ART (such as Community ART groups, Youth Clubs, Family Clubs, etc.), the children/adolescent and caregivers who meet the criteria should receive information about these models and how to join them. More information on the differentiated models of care can be found on the SAMU web site: <http://samumsf.org/>

**10.5.2 Non-disclosed child**

Provide information according to the child's age and understanding and agreement with caregiver. See above section for counselling caregiver of non-disclosed child.

Education on viral load for the child:

- Review information from partial/full disclosure on ARVs that help to keep the red germ asleep – Flipchart page 10.
- Explain that sometimes it is necessary to do a blood test to make sure the sleeping germ is still asleep / controlled.
- Ask if the child has any questions and make sure he understands the reason for the blood test.

Congratulate the caregiver and the child for continuing to give/take the treatment and refer for the blood test.

## 11. Patient support, education and counselling for long term follow up of patients on ART

After a first undetectable viral load test result, routine patient support, education and counselling can cease. Children/adolescents and their caregivers will be offered PSEC at their own request, or when recommended by the healthcare provider. Ongoing peer support can be offered through support groups and group-models of differentiated ART delivery, whereby health education and peer support are part of the package.

Adherence patterns can change over time and children/adolescents will need different levels of support as their life circumstances change. It is therefore expected that all patients will need extra support at certain stages within their life-long treatment paths. Children or adolescents may also present with other needs requiring support such as a need to progress in disclosure, support around sexual and reproductive health for adolescents, a new caregiver who is unfamiliar with HIV & ART, a change in dose for ART.

Referral criteria to be used by the healthcare provider need to be clearly identified within the project which will trigger additional support to children/adolescents and their caregivers.

### 11.1 Identifying adherence and retention problems

Following methods should be used in a project with HIV-infected children and adolescents to evaluate adherence and retention:

- Patient self-report to be done routinely at every clinic visit.
- Identification of patients who missed an appointment to be done routinely.
- Viral load to be done at month 6 and then yearly (some national ART guidelines may propose an adapted schedule).

Please refer to the *MSF PSEC Guideline for Adults Living with HIV and/or TB* on general information regarding identifying adherence and retention problems. The *MSF-OCG Stepped-up Counselling Guideline for Children and Adolescents* (Annex 17, 18) provides practical examples of how to get children/adolescent to report on their adherence and tips on how to go about adherence problems.

As patients are not routinely seen by dedicated PSEC staff at every visit, other healthcare providers will need to be involved to routinely evaluate patient's adherence, like the nurse or doctor consulting the patient or the drug dispenser. It is crucial that everybody approaches the patient in a non-judgmental way.

Patients with adherence issues should be referred to the PSEC staff for additional support. We recommend the use of the following referral criteria:

- A child/adolescent with an adherence issue as identified through self-reporting by the clinician.
- A child/adolescent coming late for appointment (number of days exceeding number of days of buffer stock, generally more than 2 weeks).
- A child/adolescent with a high viral load (generally VL>1000 copies/ml).

A flagging system can be implemented in the clinic to make sure these patients are referred in a timely manner for support (e.g. sticker on the file, unhappy face on the document with the viral load result in the file, etc.).



## 11.2 PSEC for patients with an adherence issue or who missed an appointment

<b>Who</b>	Patients with an adherence issue as identified through self-reporting / being late for an appointment.
<b>When</b>	At day of consultation when issue is identified.
<b>Duration</b>	20 minutes.
<b>Mode</b>	Consider seeing the child/adolescent and caregiver together as well as separately to get a good view of the issues at stake.
<b>Tools</b>	Child and adolescent flipchart (Annex 13). Patient file / Adherence plan (Annex 4).
<b>Objective</b>	Identify the adherence issue and help patient identify appropriate solutions.
<b>Topics</b>	It is important to remain patient-centred. A good understanding of the child/caregivers' issues can only be obtained by listening.

- Evaluate the child/adolescent adherence and get specific information about missed doses (see Annex 17):
  - In what situation(s) were doses missed?
  - Explore the reason for missed doses (forgot, misunderstanding on how to take medication, fell asleep, ran out of pills, difficulty with medication schedule, ...).
- Review the adherence plan (behavioural aspects):
  - How does the current medication schedule fit the daily routines of the child/adolescent? In which situations does he find it most difficult to take his medication?
  - What are the reminder strategies put in place? (calendar, reminders, assistance from family members,...).
  - Who gives the medication to the child?
  - How does the caregiver plan for trips? (Asking a longer ART refill, getting medication at nearest ARV treatment clinic at travel destination, need for a transfer to another clinic...).
  - Where are extra doses of medication kept, to take when the child/adolescent is away from home?
  - How does the caregiver/adolescent deal with side effects the child/adolescent may be experiencing?
  - How does the caregiver/child/adolescent manage missed doses?
- Explore other factors that may affect missing doses and try to help identify adapted strategies:
  - Explore cognitive component: motivation to take ARV medication, expectations about benefit of ARV medication, degree of knowledge on HIV and ART.
  - Assess emotion/mental status of child/caregiver/adolescent: level of stress related to medication and related to life events, feelings of loneliness, self-blame, poor self-esteem, depressed mood, hopelessness, addiction to alcohol/drugs, etc. Provide counselling support with regards to emotional concerns. For screening of depression of children/adolescents, refer to Annex 5.
  - Assess socio-economic status: support system, transportation problems, social stigma, financial concerns, HIV status disclosure, social support, occupational/educational challenges.
- Assess any need for referral back to the doctor (usually related to side effects).
- Decide with child/adolescent/caregiver if a follow-up session needs to be planned.



### 11.3 Enhanced adherence counselling (EAC)

Caregivers and children with a high viral load should receive support to ensure viral load suppression. In the period between the first and the second viral load test (usually around 3 months), patient's adherence must be reinforced to ensure the viral load suppression. In the absence of viral load monitoring, suspicion of immunologic failure (based on CD4) or clinical failure should be used as a criteria for referral for EAC.

We recommend at least 2 EAC sessions with the patient upon receiving a viral load result above 1000 copies/ml. The first session needs to be offered the same day the viral load result is received. The second session is offered one month later and before the 2<sup>nd</sup> viral load is taken. Alternatively, the second session can be conducted the same day the second viral load is taken, to avoid delays. More sessions may be offered, according to the patient's needs.

An example of a session guide for EAC for children & adolescents can be found in Annex 18.

<b>Focus on</b>	Educate on viral load and common reasons for a high VL, assess adherence barriers and identify strategies to overcome barriers to adherence, revise the adherence strategies from the ART initiation counselling (adherence plan in) based on the needs identified.
<b>Duration</b>	30-60 minutes.
<b>Tools</b>	Child and adolescent flipchart (Annex 13). Patient file / Adherence plan (Annex 4).

#### 11.3.1 Caregiver alone and fully disclosed child/adolescent (individual)

It is important to keep a patient centered approach to find out the reasons why the patient has adherence issues. The counsellors should be able to adapt the list of topics to be addressed based on the patient needs.

For adolescents, it is important to separate the caregiver and the adolescent to facilitate the points 4 to 7 of this session, so that caregiver and adolescent can each experience a safe space in order to speak about barriers to adherence. The adolescent might not be comfortable to talk about some topics in front of the caregiver.

Provide education and counselling on the following:

- 1) Inform about the result of the viral load test and assess the patient's understanding.
- 2) Assess caregiver/adolescent's knowledge about HIV and ART and complete information as needed.
  - Explain that the result raises questions about the child/adolescent's adherence.
  - Provide information on the meaning of the high VL. E.g. a high viral load means that there is a large amount of HIV in the body and a low CD4 count means that there are not enough soldiers in the body to defend it against diseases.
  - Inform that the most common reason for a high viral load result is that people have faced problems in giving/taking medication every day.
  - Inform that in few cases, there might have been a problem with adherence in the past and then ART does not work anymore because the virus has changed (has become resistant). In these cases, it means that the treatment might need to be changed for a treatment that works well on resistant HIV: the 2<sup>nd</sup>/3<sup>rd</sup> line ARV treatment.

From this point, see adolescent separately and emphasize confidentiality regarding what the adolescent will share.

- 3) Review messages on the risk of non-adherence and resistance- Flipchart page 12 - and explain that there is another treatment that works to keep the purple germ asleep – Flipchart page 13.

- 4) Explain that it is common that the lack of support, family problems, the wish to fit with peers and many other reasons impact on adherence. Invite the caregiver/adolescent to express freely the barriers he has faced to give/take the treatment.
  - Ask what situations make it difficult to give/take the treatment or to come to appointments.
  - Ask what could be the reason for adherence issues or treatment failure according to the caregiver/adolescent.
  - Assess the family and social situations.
  - Discuss if there are several caregivers who are responsible for giving the treatment.
- 5) Identify and support strategies to overcome adherence barriers.
  - Review the motivations to give/take treatment (goals for the child's future).
  - Support the caregiver/adolescent to come-up with solutions regarding the identified adherence barriers.
  - Support the caregiver to identify strategies to ensure good adherence and ways to implement them.
- 6) Show some flexibility on the time to take ART and clear misconceptions about ART.
  - Assess how the caregiver/adolescent has been told to give/take the treatment.
  - Recognize that it can be difficult to respect all these "rules" and show flexibility (e.g. regarding the time to give/take the treatment, if they are with friends at the time of taking the treatment, it is ok if they don't take it exactly the same time every day as long as they take it every day around the same time, etc.).
  - For adolescent, clear potential misconceptions around alcohol or drug use. Even if they are using alcohol or drugs, it is still important to make sure they take treatment.
  - Explain that patients do not need food to take treatment. It is okay to take ART on an empty stomach.

Review and update as needed the different adherence strategies previously identified by updating or creating the adherence plan in Annex 4.

For adolescents, propose that the caregiver comes back after agreeing what information can be shared.

- 7) Inform about follow-up visits and the possible change of treatment (based on clinical advice).
  - If there is a psychosocial issue that is interfering with adherence and will require several counselling sessions to resolve, establish a plan for follow-up sessions with the caregiver/adolescent (adapting the schedule to clinical follow up and drug refills) and link through the appropriate referral channel if needed.
  - Inform about the next monitoring test to evaluate adherence (e.g. in case of a first high VL, the next VL test should be done after 3 months).
  - Inform about the implication of the result of the next test (e.g. if the result is back to normal, the patient will stay on current treatment and if otherwise, will possibly switch to 2<sup>nd</sup> /3<sup>rd</sup> line ART).
- 8) If possible, and if agreement is obtained, families should be visited at home by a community health worker or a counsellor to enhance family support.

### **11.3.2 Non-disclosed child (with or without caregiver)**

Provide information on HIV, ART, HIV resistant and 2<sup>nd</sup> /3<sup>rd</sup> line ART according to the age, the understanding and what has been agreed with the caregiver – Flipchart pages 7 to 13.

A second EAC session should be planned to evaluate the strategies put in place to overcome the adherence barriers. More sessions may be needed, depending on the child/adolescent/caregivers needs.

## 11.4 Patients changing treatment within the same treatment line

Refer to the *MSF PSEC Guideline for Adults Living with HIV and/or TB* for detailed contents of this session.

## 11.5 Counselling and education for patients with confirmed treatment failure

Specific education and counselling session should be provided to caregiver of children and to children/adolescents who will be switched to 2<sup>nd</sup> or 3<sup>rd</sup> line ART.

**Focus on** Explaining the functioning of the 2<sup>nd</sup> /3<sup>rd</sup> line treatment, revise and adapt adherence strategies to the new treatment (dose, schedule, etc.).

**Duration** 30 minutes.

**Tools** Child and adolescent flipchart (Annex 13).  
Patient file / Adherence plan (Annex 4).

### 11.5.1 Caregiver and fully disclosed child

- Review of the EAC sessions (assessment of barriers to adherence).
- Review of education on HIV resistant and on 2<sup>nd</sup> /3<sup>rd</sup> line ART – Flipchart pages 12 and 13.
- Re-assure the patient about the fact that the new treatment usually works well against the resistant HIV.
- Emphasize on the importance of being adherent to the new treatment and the risk of resistance.
- Reinforce how to take the new treatment (based on clinician advice).
- Inform about the (non-)availability of a 3<sup>rd</sup> /4<sup>th</sup> line treatment (depending on the project and the national policy of the country).
- Revise adherence strategies from the initiation and adherence counselling and adapt them to the new treatment (motivations to start the new treatment, attendance to appointments, support system, treatment schedule, reminders, etc.).
- If possible, and if agreement is obtained, families should be assessed through home visits.

### 11.5.2 Non-disclosed child (with or without caregiver)

Provide information on the change to 2<sup>nd</sup> /3<sup>rd</sup> line ART according to the age, the understanding and what has been agreed with the caregiver - Flipchart pages 12 and 13.

Second line follow-up counselling sessions should be planned until a first viral load at month 6 is taken, at the same intervals as for 1<sup>st</sup> line ART (month 1, 3 and 6) addressing following topics:

- Identify any barriers to his adherence.
- Identify strategies to ensure good adherence to his treatment.

After month 6 another VL test will help assess whether the patient needs further enhanced adherence counselling.



# Annexes

Most of these annexes can be downloaded from : <https://tukul.msf.org/psec>

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## Annex 1. List of competencies for children/ adolescents living with HIV

Source: Adapted from ESTHER – <http://vih.org/reseau/gip-esther> “dossier individuel d’éducation enfant/adolescent”

This list of competencies is used as a basis for the development of a patient education and counselling program for children/adolescents living with HIV. This tool identifies the objectives to be reached during a patient education and counselling session, according to the developmental stage of the child. According to the personal characteristics of the child or adolescent, some will acquire certain competencies earlier or later than others.

Age	3 to 6	6 to 10	10 to 12	> 12
Identify the family members or people who live with the child/ caregiver.	x	x	x	x
Share what he likes and dislikes.	x	x	x	x
Explain what happens when coming to the clinic (seeing the doctor/ nurse, collecting treatment, being weighted, taking blood, etc.).	x	x		
Tell his caregiver if he’s hungry, if he feels pain, if he vomited or injured himself and is bleeding.	x	x		
Identify dangerous objects or hygiene items that shouldn’t be shared with others (razorblades, toothbrush).	x	x		
Show its treatment and say how it tastes.	x	x		
Link taking treatment with a specific moment of the day or daily habit (morning, breakfast, brushing teeth, etc.).	x	x	x	x
<b>Express how he lives with his illness and treatment</b>				
Express his feeling about his health.	x	x	x	x
Express how he feels and potential difficulty regarding his treatment.		x	x	x
Express his emotions following full disclosure of his HIV status (if disclosed).		x	x	x
<b>Understand his illness</b>				
Explain his illness using analogies (red germ attacking green soldiers).		x		
Give the name of the virus (if disclosed).		x	x	
Explain the reason for not necessarily feeling sick (if disclosed).		x	x	
Explain the risk of getting infections if not taking treatment (if disclosed).		x	x	
Explain the ways of transmission and prevention of HIV (if disclosed).		x	x	

**List of competencies for children/adolescents living with HIV (continued)**

Age	3 to 6	6 to 10	10 to 12	> 12
<b>Understand and explain the treatment and the follow-up</b>				
Explain the importance of taking the treatment and coming to appointments.		x	x	
Show the treatment he takes.		x	x	
Name his treatment (if disclosed).		x	x	
Describe the time he takes the treatment		x	x	
Explain the importance of taking the treatment daily using analogies (to keep the red germ asleep)		x	x	
Explain where the treatment is kept		x	x	
Explain what to do in case of vomiting or forgetting the treatment		x	x	
Express himself about the constrains linked to his treatment and follow-up				x
<b>Express concerns and prevent HIV/STIs transmission</b>				
Identify dangerous objects or hygiene items that shouldn't be shared.		x	x	
Express his questions and doubts about sexuality and feelings (desire, seduction, etc.).				x
Explain the changes in his body.			x	x
Identify the risk of transmission of HIV, STIs and unwanted pregnancies.				x
Apply preventive measures and explain the advantages of using condoms.				x
Insert a condom.				x
Identify social support (if possible person in the family or the household).		x	x	
Discuss about relations with the family and social network.				x
Identify a trustful person with whom he can share his HIV status.			x	x



## Annex 2. Training manual on support to children living with HIV

Developed in conjunction with MSF-OCB patient support for HIV-Infected Children (2008)

Available on: <https://tukul.msf.org/psec>



« Support to children living  
with HIV/Aids »

**Training manual**

September 2008

**Médecins Sans Frontières**  
Operational Centre of Brussels

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« Support to HIV+ children » Training manual – September 2008 – MSF OCB

## Annex 3. Initial needs assessment for children/ adolescents

Adapted from “Patient initial assessment, MSF-OCA Tashkent project”, “Disclosure assessment, MSF-OCB Khayelitsha project” and “Patient file, ESTHER”. MSF internal documents.

**The first part of the assessment should be compiled by the counsellor with the caregiver. It is best to obtain background history from caregiver without the child present and then to see the child or adolescent separately.**

Date: \_\_\_/\_\_\_/\_\_\_ Filled by \_\_\_\_\_

MSF ID _____
Name of Child: _____ DOB: _____ Age: _____ Sex M <input type="checkbox"/> F <input type="checkbox"/>
Caregiver accompanying child: _____ Parent <input type="checkbox"/> Relative <input type="checkbox"/> Non relative <input type="checkbox"/>
Address: _____ Phone number: _____
Other caregiver of the child: _____
Address: _____ Phone number: _____
Date of diagnosis of HIV/AIDS: ___/___/___
How was the child’s HIV status discovered? _____ Mode of transmission _____
CD4 Count: _____, date: ___/___/___ HIV VL: _____, date: ___/___/___
ARVs yes <input type="checkbox"/> no <input type="checkbox"/> If yes, when started, date ___/___/___

### I. PSYCHOSOCIAL HISTORY (with the caregiver)

#### 1. Family structure

a) Structure and functioning of family: (family members, strengths and challenges of family):

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b) Who is the child closest to? (e.g. who does the child experience as emotionally supportive?):

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c) What is the family’s response to the child’s diagnosis of HIV/AIDS?

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d) Have other family members been tested or diagnosed with HIV/AIDS?

Family member	Status	On ARVs
	Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>

e) What other issues or concerns would you like our help with as the caregiver for this child?

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## 2. History of child

a) Have you observed any delays when you compare the child to other children of the same age in the following areas? If yes, describe.

*(To compile with caregivers to evaluate if the development of the child is the norm for age or if there are developmental delays that require intervention.)*

Learning to speak or communicate: \_\_\_\_\_

Ability to move and physical development: \_\_\_\_\_

Ability in learning or thinking: \_\_\_\_\_

How the child behaves: \_\_\_\_\_

Child's emotional reactions: \_\_\_\_\_

Child's relation with others (friends, siblings, etc.): \_\_\_\_\_

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Psychiatric history (feeling down, worried, agitated or reaction to traumatic event in the past):

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b) What is the child's level of education (school performance, ability to memorise, etc.)?

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c) Child's strengths, interests and challenges:

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d) Is the child showing any symptoms of depression (feels sad, irritated mood, diminished interest or pleasure in all activities, insomnia, physically agitated or slowed down, etc.)?

yes  no  If yes, what have you noted? \_\_\_\_\_

e) Has the child been informed of his/her HIV+ status? yes  no

**If yes:**

Level of disclosure partial  full

Who did the disclosure? \_\_\_\_\_ When, date: \_\_\_\_/\_\_\_\_/\_\_\_\_

What was the child's reaction to knowing he/she has an illness?

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How is the child coping since then?

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**If no:**

What has the child been told about HIV/AIDS? Or health condition, in general?

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How does the child name his disease, treatment, etc.:

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Do you agree it is important for your child to know his/her HIV status at this time? Should he know the reasons about coming to the clinic or taking medication? Who do you feel is the best person to disclose?

A family member? Who: \_\_\_\_\_

The caregiver with the counsellor? Who: \_\_\_\_\_

A non-relative, e.g. counsellor, family friend? Who: \_\_\_\_\_

**3. Caregiver's knowledge about HIV**

What do you know about:

- HIV transmission and prevention:

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- HIV action on the immune system:

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- Anti-retroviral treatment (ART):

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#### 4. Barriers to start treatment

a) Economic (problems with adequate housing, food, transportation to clinic):

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b) Mental or emotional distress (*in caregiver or child*):

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c) Social (conflict in family, lack of support for family or child, non-parental or non-relative caregivers, stigmatization):

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d) Medical (opportunistic infections, other medical problems):

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e) Other barriers:

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## II. INTERVIEW WITH THE CHILD

*After seeing the caregiver, the counsellor will interview the child with or without caregiver according to the situation and with consent of caregiver. Children younger than 4 years of age should be seen with the caregiver.*

**Counsellor name:** \_\_\_\_\_ **Child name:** \_\_\_\_\_

a) Ask the child his name/ how he feels/ what he likes (games, food, sports, etc.).

Observation on child's attitude and speech abilities:

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Observation if the child seems appropriate (speech, behavior, interpersonal skills) for his age.

b) Ask the following questions to evaluate the child's understanding of own HIV status:

- What happens when you go to the clinic? \_\_\_\_\_
- What do you feel like when you visit the clinic? \_\_\_\_\_
- Do you take any medicines regularly? \_\_\_\_\_
- What medicines do you take? \_\_\_\_\_
- Why do you take these medicines? Have you been told why you take these medicines?  
\_\_\_\_\_
- Is there anything you are worried about relating to your medicines or why you come to the clinic? \_\_\_\_\_
- Who do you live with? Does \_\_\_\_\_ help you to remember to take your pills? \_\_\_\_\_
- Do you have any questions for us? \_\_\_\_\_

**Only if the child talks openly about HIV, then you can ask the following questions:**

- Do you know how to take care of yourself so that you can keep well with your HIV?
- Do you know how people can get HIV?

**Once these questions have been asked, it may be possible to determine how much the child knows about his status. One of the following outcomes can be decided (circle the appropriate one):**

- 1) **Need to start partial disclosure.** The child knows nothing about HIV, germs, why he goes to the clinic etc.
- 2) **The child is adequately Partially Disclosed.** He seems to have a good understanding of why he takes his medicines and why he goes to the clinic. He understands about a germ and that the body needs protection (immune system). He does not speak about HIV but this is ok as he is not old enough for Full Disclosure.
- 3) **Need to start full disclosure.** The child is properly Partially Disclosed but based on his age or maturity, Full Disclosure would be more suitable for him.
- 4) **Need follow-up on partial disclosure.** The child knows some info about why he goes to the clinic and why he takes medicines but either he does not know enough or much of the info he has is incorrect. Further work is needed to ensure that the child is properly Partially Disclosed.
- 5) **The child is properly fully disclosed.** He has a good understanding of the fact that he has HIV and what this means for him in terms of taking medicines, attending the clinic. He also has a good understanding about how to take care of himself and others. He understands how HIV is transmitted etc.
- 6) **Need follow-up on full disclosure.** The child knows that he has HIV but he is not properly Fully Disclosed – e.g. Lots of the info he has is incorrect or there are big gaps in his knowledge. For example, maybe he knows he has HIV but he doesn't know how people get HIV or he doesn't understand what HIV means in terms of taking medicines for life. Further work is needed.

## Annex 4. Adherence plan

MSF-OCB Khayelitsha project

**Patient file number:** \_\_\_\_\_

**Step 1: Motivation:** The goals for my child's future: \_\_\_\_\_

HIV/ART patient education session		Date ...../...../.....
HIV/ART patient education done: <input type="checkbox"/> yes <input type="checkbox"/> no		
<b>Step 2: Support system</b>		
Possible barriers to disclosure: _____		
I will disclose my child's status to: _____		
<b>Step 3: Planning for appointments</b>		Agrees to home visit: <input type="checkbox"/> Yes <input type="checkbox"/> No
How I will get to my child's appointments: _____		
Back-up plan to get to appointments _____		
How I will remember appointments: _____		
<b>Step 4: Readiness to start child's treatment</b>		
<input type="checkbox"/> I feel ready to start my child on treatment today _____		
<input type="checkbox"/> I will feel ready to start my child on treatment when I come back on _____		
<input type="checkbox"/> I don't feel ready for my child to start treatment and will come back on _____ to discuss it again		
<b>Step 5: Medication schedule and administering drugs</b>		
Possible difficult moments to give/take treatment: _____		
The best times for me to give my child/take treatment is: _____		
Possible difficulties in giving/taking treatment: _____		
Things I can do to make it easier: _____		
ART initiation session		Date ...../...../.....
<b>Step 6: Reminder strategies</b>		
My reminder tools are: _____		
I will put my reminder tools on: _____		
<b>Step 7: Managing missed doses</b>		
If I miss giving/taking a dose, my plan is _____		
<b>Step 8: Storing drugs at home and keeping extra doses</b>		
I will store my child's/my medication in _____		
I will keep extra doses in _____		
<b>Step 9: Managing side effects</b>		
My plan for minor side effects is _____		
My plan for side effects that worry me is _____		
Adherence follow-up session at month 1 on ART		Date ...../...../.....
<b>Step 10: Planning for trips</b>		Contact number of clinic: _____
Regular travel location: _____		Closest clinic at regular travel location: _____
<b>Step 11: Dealing with substance use</b>		
My plan to make sure my child is given treatment (or to take treatment) if I use alcohol or drugs: _____		
		Secondary caregiver: _____
<b>Step 12: Preventing any future problems in giving my child's treatment</b>		
What will I do if I make a mistake while learning to give/take treatment : _____		
Adherence follow-up session at month 3 on ART (education on viral load)		Date...../...../.....
Adherence follow-up session at month 6 on ART (education on differentiated models of care)		Date...../...../.....
GOAL 1: Undetectable viral load GOAL 2: Fully disclosing my child by the age of .....		

## Annex 5. Center for Epidemiological Studies Depression Scale for Children (CES-DC)

The Center for Epidemiological Studies Depression Scale for Children (CES-DC) is a 20-item self-report depression inventory with possible scores ranging from 0 to 60. It is to be used with children/adolescents aged 8 to 18.

INSTRUCTIONS: Below is a list of the ways you might have felt or acted. Please check how much you have felt this way during the past week. Circle the score from 0 to 3 for each answer to the following questions:

During the past week	Not at all	A little	Some	A lot
1) I was bothered by things that usually don't bother me.	0	1	2	3
2) I did not feel like eating, I wasn't very hungry.	0	1	2	3
3) I wasn't able to feel happy, even when my family or friends tried to help me feel better.	0	1	2	3
4) I felt like I was just as good as other kids	3	2	1	0
5) I felt like I couldn't pay attention to what I was doing.	0	1	2	3
6) I felt down and unhappy.	0	1	2	3
7) I felt like I was too tired to do things.	0	1	2	3
8) I felt like something good was going to happen.	3	2	1	0
9) I felt like things I did before didn't work out right.	0	1	2	3
10) I felt scared.	0	1	2	3
11) I didn't sleep as well as I usually sleep.	0	1	2	3
12) I was happy.	3	2	1	0
13) I was more quiet than usual.	0	1	2	3
14) I felt lonely, like I didn't have any friends.	0	1	2	3
15) I felt like kids I know were not friendly or that they didn't want to be with me.	0	1	2	3
16) I had a good time.	3	2	1	0
17) I felt like crying.	0	1	2	3
18) I felt sad.	0	1	2	3
19) I felt people didn't like me.	0	1	2	3
20) It was hard to get started doing things.	0	1	2	3

Score \_\_\_\_\_



Higher CES-DC scores indicate increasing levels of depression. The developers of the CES-DC have used the cutoff score of 15 as being suggestive of depressive symptoms in children and adolescents. Scores over 15 can be indicative of significant levels of depressive symptoms.

Screening for depression can be complex and is only an initial step. Further evaluation is required for children and adolescents identified through a screening process or who exhibit depressive symptoms.

**For further information:**

Faulstich ME, Carey MP, Ruggiero L, et al. Assessment of depression in childhood and adolescence: An evaluation of the Center for Epidemiological Studies Depression Scale for Children (CES-DC). *American Journal of Psychiatry*. 143(8):1024–1027; 1986.

## Annex 6. Examples of a child-friendly environment

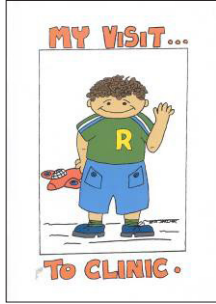
(Source: MSF Belgium & Switzerland Maputo, Mozambique project – Artist Zacarias Chemane)

More pictures can be found on: <https://tukul.msf.org/psec>




## Annex 7. My visit to clinic (children's book)

The booklet can found on: <https://tukul.msf.org/psec>

Title:	My visit to clinic
Picture:	
Thematic:	Primary thematic: Sleeping bug, hospital visit Secondary thematic: consultation, nutrition, examination (including stethoscope), testing of blood
Description / content:	Jacob has a "sleeping bug" in his blood, so he has sometimes to visit the hospital where they check his weight and height, where the nurse give nutritional advices, where the doctor makes an examination (with the stethoscope), where his blood is checked
Target audience:	Children : between ages of 5 to 9 years
Type of media:	Booklet: short story
Instructions:	Very little story to read as an introduction of a counselling To explain who is doing what at the clinic
Facilitator notes:	This book is not mentioning the name of the disease, must be used with non -disclosed children
Tips for adaptation:	/
Individual / group session:	Both
Language:	English
Author:	Written by Tina Clegg
Country of origin:	Uk

## Annex 8. Bekhi (children's book)

The book can be found on: <https://tukul.msf.org/psec>

Title:	Bekhi
Picture:	
Thematic:	<p>Primary thematic : Adherence to general drugs, Family support &amp; friends, Partial disclosure</p> <p>Secondary thematic : Stigma, Secret, Emotions (towards death)</p>
Description / content:	Very nice fairy-tale about a little lion who has a skin disease. He needs to complete 3 activities daily to recover his beautiful coat.
Target audience:	Children : between ages of 5 to 12 years
Type of media:	Book : fairy-tale. Audio version in French
Instructions:	Prepare some questions to discuss about after reading the book : questions about the story itself (e.g. Why has Bekhi to go to the Land of the Tree of Smiles, what is your favourite animal in the story, ...) and about the topics suggested above (taking drugs, family support, secret, ...) or distribute some roles for the children to play the story afterwards.
Facilitator notes:	As the book is small, it can be interesting to print the picture on separate sheets and to plastify them for making A4 images.
Tips for adaptation:	The story is long. Feel free to shorten and adapt the text to your public when reading.
Individual / group session:	Individual or group sessions
Language:	French (written & oral version), English , Portuguese, Linguala, Kinyarwanda
Author:	CHU St-Pierre Bruxelles © AIDS and children /Enfance et sida - Média Animation asbl <a href="http://www.aidsandchildren.org">www.aidsandchildren.org</a>
Country of origin:	Belgium

## Annex 9. The story of Thandi and Musa (children's educational flipchart)

This book can be found on: <https://tukul.msf.org/psec>

### The story of Thandi and Musa



#### How to use this book:

This book is a tool for the counselling of children living with the immunodeficiency virus.

It is meant for children between the ages of 5 and 14, who are undisclosed, partially or totally disclosed about their diagnostic, and who have already started, or are about to start antiretroviral therapy.

It touches on issues of infection, treatment and the importance of check-ups at a health centre. The book should not be given to the children and they should not read it by themselves. It should be read by a trained counsellor in group or one-to-one sessions, in the light of the child's level of disclosure. When reading, the counsellor should show the illustrations but not the text to the child. While reading, and afterwards, the counsellor should ask questions and talk with the children to make sure they have fully understood the story.

CONCEPTION AND TEXTS: Elaine TEIXEIRA, Clarice SAMO GUDO, Mildred LUIS and Wânia CORREIA  
DRAWINGS: Zacarias CHEMANE (Mozambique)

ADAPTATION IN ENGLISH: Philip MURPHY and David GOETGHEBUER  
March 2010

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# Annex 10. The story of Bobo (children’s educational video)

The video can be downloaded in different languages from: <https://tukul.msf.org/psec>



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## Animations 'The Story of Bobo'

The Story of Bobo consists of two animated short films Be HIV free and Be AWARE, take CARE. Be HIV free tells in a simple way how the hiv-virus works inside the human body. Be AWARE, take CARE shows how medicines (antiretrovirals or ARV's) work inside the body and what happens if you do not take your medicines on time or stop taking them.

The many questions about the hiv-virus raised by children, adolescents and adults who played the game LOVE check inspired the idea for the animated films. Originally, the animations were made for children in South Africa, but they proved suitable to a much wider audience. By now, there are versions in over 20 different languages.

Every culture, population or family has different views on sexual relations. What is said in the animations about, for instance, ABC is just one of many ideas that are out there. At the time these films were made, ABC (abstinence, be faithful and use a condom) was the most common form of prevention. It goes without saying that your norms and values regarding a healthy sexual relationship are yours to determine, as long as the opinions, health and rights of adults and children are respected.

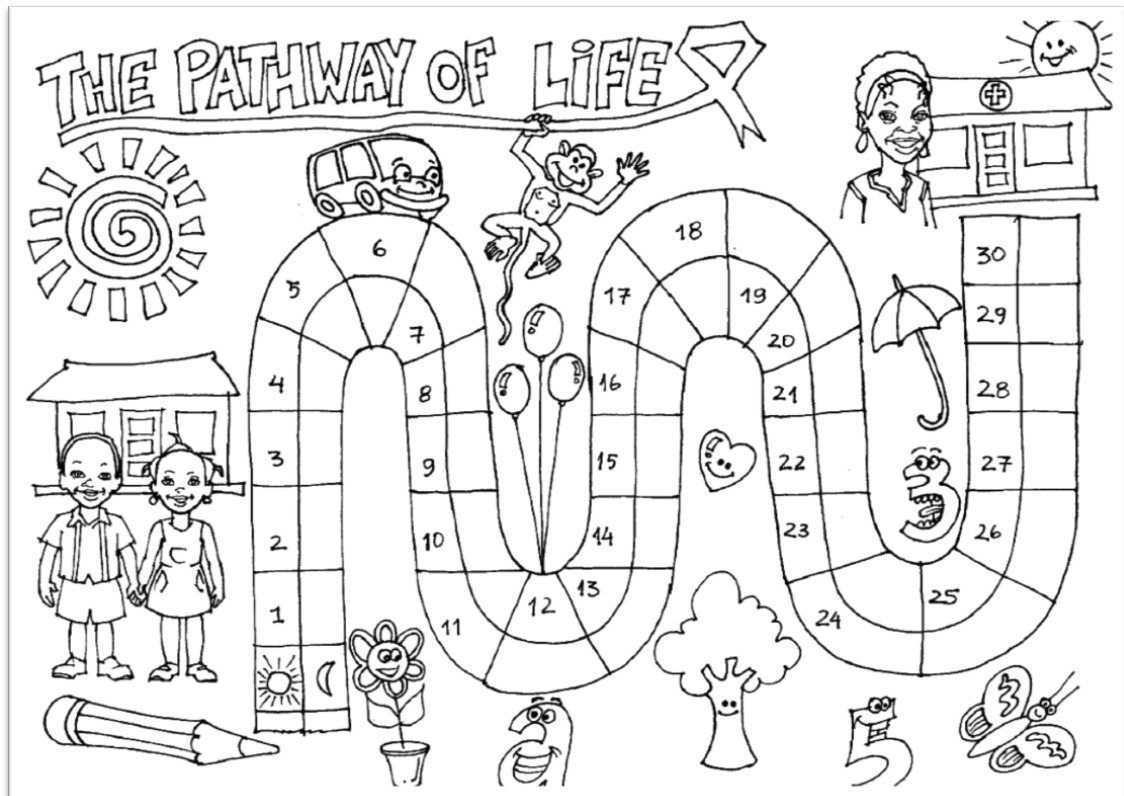
Be AWARE, take CARE (2005) was made by: Aljen Hoekstra, Joost Lieuwma, Bento Kassies, and Bastiaan Swager  
 Be HIV Free (2007) was made by: Aljen Hoekstra, Joost Lieuwma, Bento Kassies, and Bastiaan Swager with the support of Gerrit Elbrink, Wip Vernooij and Marcel Smetsers

Expert advice & support: Linda van der Knaap, hiv nurse in Sophia Children's Hospital of the Rotterdam Erasmus Medical Centre, Christien Broecheler, Gosia Grubba, Cynthia Jordan, Hugo Tempelman, a Dutch doctor working in South Africa, and WEB.foundation  
 Singer: the nationally and internationally



## Annex 11. Pill pathway (children's self-management of adherence tool)

Full version available on: <https://tukul.msfi.org/psec>



## **Annex 12. Group sessions for children and caregivers**

### **1) When to do group sessions?**

- For Pre-Test counselling.
- For education on HIV and ART.
- For disclosure (PD1, PD2, FD2) or adherence sessions.
- For support groups.

### **2) Why do group sessions?**

- To provide peer support, to reduce a sense of isolation.
- For education, provision of emotional and social support.
- To avoid long waiting times (when ART provided in sessions) or use the waiting time to provide education and support.

### **3) What to discuss in group sessions?**

- HIV-related topics: the visit to the clinic (clinical follow-up, blood test, etc.), the human body (immune system), modes of transmission, opportunistic infections.
- ART-related topics: adherence, side effects, viral resistance.
- Living with HIV: disclosure, emotions, secret, family, future, healthy sexuality, etc.

### **4) How to conduct group sessions?**

- General Organisation
  - Book children/caregivers on the same days.
  - Disclosed and non-disclosed children should not be mixed.
  - Sessions should offer separate time for children and caregivers, so they can feel free to express the issues they are facing in the family (or dealing with the child/adolescent).
- Principles:
  - Keep the session short (30 min maximum if it's for educational purpose), support groups could be 1-2 hours.
  - A maximum of 20 participants per group is recommended.
  - Use different methods, adapted to the ways children communicate, their developmental level and their disclosure status.
  - Make it fun, we are not at school.
  - Get all children involved, not one by one.



- 
- Structure of a session:
    - 1) Welcoming energizer and introduction song/greeting game
      - Get to know each other, feel at ease.
      - Use techniques for introduction (e.g. everyone says his name and something he likes).
    - 2) Activity of the day
      - Share information related to the session of the day (e.g. pre-test education, visit to hospital, partial disclosure, etc.) using appropriate material on the topic (counselling cards, games, storybooks, etc.).
      - Assess understanding using games, drama, drawing, story writing, etc.
      - Invite participants to express and exchange on own experiences, elicit their knowledge and provide peer support.
    - 3) Summary
      - Recap of main messages
      - Review the main messages and link with own life goals.
      - Check understanding by asking open-ended questions.
    - 4) Closing message
      - End with a positive or pro-active message (e.g., ask them to share a wish/dream they have for the future, or how they will incorporate something they have learned during the group into their daily life).
      - Praise children/caregivers for attending.

## Annex 13. MSF child and adolescent flipchart for HIV testing, disclosure & adherence counselling (2016)

Full version is available on: <https://tukul.msf.org/psec>

### Child & Adolescent flipchart for HIV Testing, Disclosure & Adherence Counselling

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**Target group**

Children & adolescents in need of HIV testing, disclosure or adherence counselling, and their caregivers.

**Use of the flipchart**


The flipchart is a tool to use during counselling sessions on HIV testing, disclosure and adherence. It is a collection of different images that can be selected according to the goals of the counselling session and the understanding of the child. The child counselling guideline accompanies this tool and can guide the counsellor in the selection of images.

Every image is accompanied by some ideas of questions and main messages to discuss. Where needed, messages have been adapted for partial and full disclosure.

**Content**

<p><b>INTRODUCTION</b></p> <ul style="list-style-type: none"> <li>Card 1: Progressive disclosure</li> <li>Card 2: Playground</li> <li>Card 3: Feelings</li> </ul> <p><b>GENERAL HEALTH</b></p> <ul style="list-style-type: none"> <li>Card 4: Visit to the hospital</li> <li>Card 5: The human body and the blood circulation</li> <li>Card 6: Blood and green soldiers</li> <li>Card 7: Protection by green soldiers</li> </ul> <p><b>HIV/AIDS</b></p> <ul style="list-style-type: none"> <li>Card 8: Infection with the red germ</li> <li>Card 9: Red germs destroying green soldiers and yellow germs entering the body</li> </ul>	<p><b>ADHERENCE</b></p> <ul style="list-style-type: none"> <li>Card 10: Taking treatment</li> <li>Card 11: Adherence to treatment</li> <li>Card 12: Treatment resistance</li> <li>Card 13: Second and third line treatments</li> <li>Card 14: Side effects</li> </ul> <p><b>TRANSMISSION</b></p> <ul style="list-style-type: none"> <li>Card 15: Ways of transmission</li> <li>Card 16: Sexual violence</li> </ul> <p><b>LIVING WITH HIV</b></p> <ul style="list-style-type: none"> <li>Card 17: Keeping a secret</li> <li>Card 18: Growing up as an adolescent</li> <li>Card 19: Sexual relationships</li> <li>Card 20: Female reproductive system</li> <li>Card 21: Male reproductive system</li> </ul>
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This flip chart has been validated by the PSEC representatives of OCA, OCBA, OCB, OCG and OCP (October 2016).  
Adapted from MSF-OCB Mozambique Counselling Cards, (September 2009).  
Conception : David GOETGHEBUER, Nazira NANGUY, Wânia CORREIA, Text : David GOETGHEBUER, Wânia CORREIA, Szaz BAERT. Drawing : Zacaria CHEMANE.


## Annex 14. Auntie Stella (participatory toolkit for youth)

This tool can be found on: <https://tukul.msf.org/psec>


# AUNTIE STELLA

## FACILITATOR'S AND ADAPTATION GUIDE

### (ENGLISH VERSION)



July 2006  
Training and Research  
Support Centre  
(TARSC)  
© Zimbabwe



Auntie Stella is a participatory toolkit for youth. An interactive web version is available in English at [www.tarsc.org](http://www.tarsc.org) and [www.auntiestella.org](http://www.auntiestella.org). Auntie Stella is also available in Shona, Ndebele and Kiswahili, with plans for translations into French and Portuguese in the coming year. These translations can be accessed at <http://www.tarsc.org/publications/> under the Children, women and youth section. To make it easier to access these materials, we have divided each translated version into 3 files:

- Auntie Stella question cards
- Auntie Stella answer cards
- Auntie Stella Facilitator's and Adaptation Guide


Please make sure you download all three documents for a complete set.

Auntie Stella is also available on CDROM and as a printed pack with the letters on cards. The toolkit contains 40 laminated question and answer cards, a 40-page Facilitator's and Adaptation Guide and two information cards — one listing the topics in the letters and the other explaining difficult words.


To find out more about the Auntie Stella programme, or to place an order for a CDROM or hard copy, please contact [admin@tarsc.org](mailto:admin@tarsc.org) or Box CY2720 Causeway, Harare, Zimbabwe


# Annex 15. Love Check Game (awareness game for youth)


This tool can be downloaded from: <https://tukul.msf.org/psec>




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## LOVE.check | the LOVE.check game

LOVE.check is an awareness game consisting of 70 cards. Each card shows a photograph and every photo appears twice in the game. During the playing of the game pairs are selected, just like in the memory game. After that the pictures are spoken about further, with the guidance of a group leader. In the game there are mostly four storylines. Like one story is about a family in which a number of members are hiv+ or have aids. Another story is about falling in love, friendship, sexuality and hiv/aids. Yet another story speaks of a girl that's in danger and a fourth story line shows the prejudice and stigma's that exist around getting infected. The storylines are developed for each country because they need to match the culture of the country. On top of that the game finds its shape with the cooperation of a sexologist, an education- and culture specialist and the WEB.foundation in cooperation with a local team. The game can be played by children who cannot read or write. Preferably an adult is present to guide and explain the rules printed on a flyer. In addition to these rules all photographs are described in ways how one is infected and how to avoid infection, about myths, etc.

The game is supplied in printed format and can be played on the website and downloaded from this website.



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## Annex 16. Practical tips for giving medication to young children

### For giving medication to infants

- › Use a syringe to give syrup, respecting the dosage recommended by the clinician (caregiver to practice with water during session).
- › Keep the infant close to you to avoid that he moves too much.
- › Put the medicine in the corner of his mouth along the side of the tongue. It will be more difficult for him to spit it out.
- › Keep the infant's mouth gently closed until he/she swallows, however be careful not to block his nose or breathing.
- › Be sure the infant swallowed the medicine well.
- › NEVER shout at the infant, rather comfort him and assure him with a warm physical presence.

### For giving medication to toddlers

- › Make drug-taking as a routine in life.
- › NEVER punish or threaten the child who doesn't want to take his medicines. Rather let him understand you know it is not fun and not easy but you know he can do it and you are there to support him.
- › Cover the taste with something the child likes (juice, rice, ...).
- › Do not mix medicine with essential food. The child could link the bad taste with it and refuse taking the essential food, even when there is no medicine in it.
- › Offer the child the possibility to choose how to take the medicine (with juice, with rice,.. ) This will give him some responsibility. Ask him how he wants to take them but never IF he wants to take them!
- › Some children prefer taking the medicine at once and then to quickly drink something else, others will prefer to take the medicine one step at a time with a drink in between. Again, here you can offer the choice to the child.
- › Be sure the child swallowed the medicines well.
- › Help the child feel proud of taking his medicines well. Praise his actions every time.
- › Connect the child's health improvement with the fact that the child takes his drugs well. **Praise his efforts as much as you can.**

## Annex 17. Evaluating and supporting the child/ adolescent's adherence

*Adapted from MSF-OCG Stepped-Up Adherence Counselling for Children & Adolescents - 2016*

Assessing the adherence of the patient is not a school exam or judgment of the person, it's an important step used to help the child and the caregiver to know how they are feeling about their treatment.

From initiation, the evaluation of the child's treatment adherence should be routinely done at any clinic visit through self-reporting.

### **Self-reporting methods for ART adherence:**

#### **1) Interview**

The counsellor should create an open and non-judgmental communication where parents and children feel at ease to tell the truth.

Example of open questions to ask:

- "Your mum told me you can take your drugs by yourself? That's great! Can you tell when you are taking them?" (positive reinforcement)
- "Some other children tell me taking drugs is not always easy. Can you give me an example of when it was difficult for you?" (allow disclosure of difficulties with adherence)
- "Tell me about the last three days. What have you done? Do you remember about when you took the drugs?" (3 days recall)
- "I know sometimes in the beginning these medicines can cause some nausea/other side effect: how has it been with you/him/her?" (identify side effects)
- "What do you do to remember that you have to take the medicine?" (Encourage positive reminder strategies)
- In the last 7 days, how many doses did you miss? \_\_\_\_\_ doses \_\_\_\_\_% (see table below)
- Could you describe further the situation when you missed your doses?

The counsellor should also ask how the child feels about taking his medicines in terms of how the medicines affect him physically, emotionally and socially. Giving the child the opportunity to express any frustrations or difficulties and helping him work through his issues may help offset future problems.

Sometimes the aging caregiver, such as a grandmother, thinks the child is taking his medicines because it disappears soon after she prepares it for him. However, it could be that the child merely takes the pills and throws them away when she is not looking.

Counsellors must stress the importance of accurately reporting the child's adherence. Child and caregiver must feel that they will not be scolded or judged for telling the truth or that they will disappoint the healthcare staff. The child should not consider it as passing a school exam! Counsellors can encourage and praise the child and caregiver when adherence is good

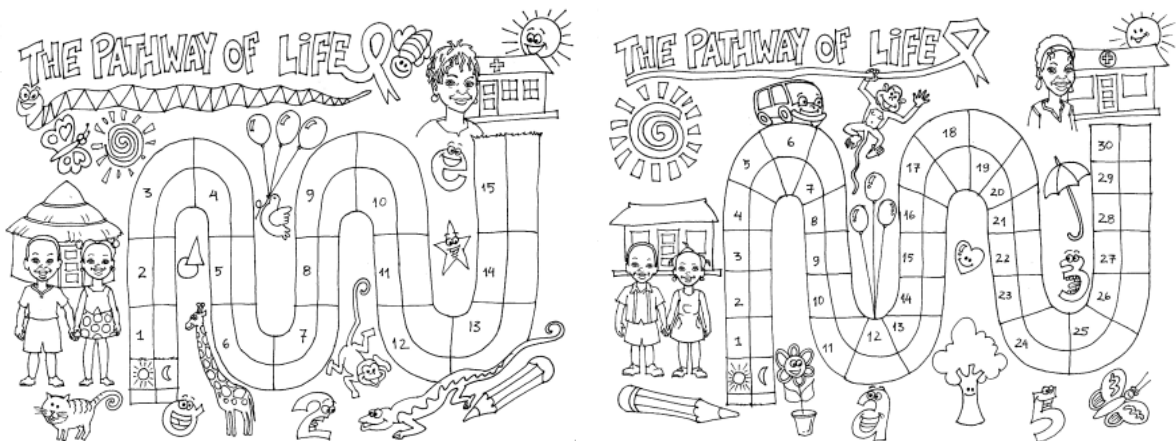


but should not scold them when it is bad as this will only cause them to be less truthful in the future. Instead, counsellors should help them identify and work through their adherence challenges.

## 2) Treatment reminder tools

Some tools can be used to measure adherence like the “Pathway of Life” completed by the child at home. The tool needs to be well explained to the child before handing it out. Following explanation can be give: “This is a game that shows how long it is until the day when you will come back to the hospital. Each time you take the tablet, you will colour one square of the pathway.” Show how the path goes from the client’s home to the facility and that at each square there is a number representing the number of days until the next visit.

This tool can then be used at the next clinic visit to discuss adherence. The most important is to involve the child through these tools. Make it a nice experience for them to present it and to explain the way they take their medicines. (Be aware: if the child feels it more as a control than a support it won’t give reliable and useful results!).

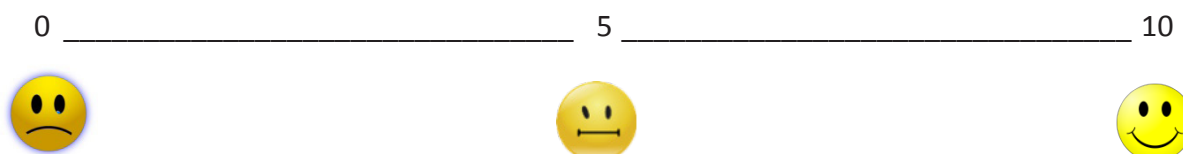


## 3) Visual analogue scales

These scales and other self-report tools help the child and the caregiver to evaluate the adherence of the child to the treatment. It avoids the patient to feel controlled and gives him an active place in his health care.

Proper explanation needs to be given when inviting the child or the caregiver to rate themselves on the visual scale.

For example, the counsellor should explain that if the child hasn’t taken any dose, they should mark 0/sad face and if the child has taken every dose, they should mark 10/smiley face. Half of the doses would be in the middle.



Another version uses glasses of water instead of smiley faces. The healthcare provider can explain its use as follows:

*“I have 3 glasses of water in this picture. Each glass has a different amount of water. Glass number one has least amount of water compared to the others. Glass number two is much better; it has a bit more water. Glass number 3 is very good because it is full. Imagine that one of these glasses shows how you follow your treatment and care. Good health follow up doesn’t only mean that you take the drugs at the right time, it also means you go to the consultations, counselling sessions and draw blood when asked by the doctor. Now if you were to choose one of the glasses to explain how well you follow your treatment which one would you choose? Why?”*



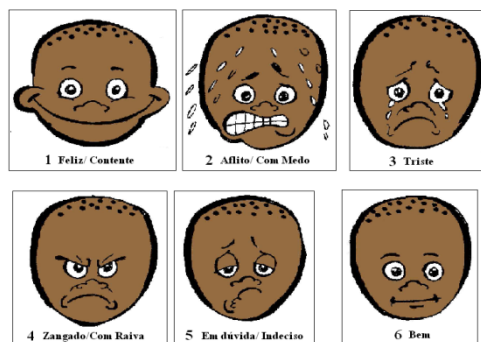
Visual analogues scales can also be used to evaluate the child/adolescent’s mood or pain level.

### MOOD ASSESSMENT

This material is intended to be used with children and adolescents of all ages, and that have shown difficulties to verbally express their feelings.

#### Health care provider’s guide:

- Ask the client to choose the image that best describes their feelings.
- You can refer to a specific moment in time (when child started getting sick, when child used to feel healthy, etc), referring to a past or present feeling, or even a possible future feeling s/he imagines will have if a specific thing happens (treatment completion, returning to school).
- After each image pointed, probe on the reasons for choosing it.



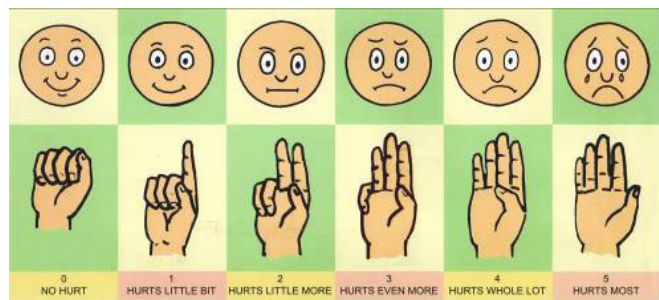
**Note:** This tool can also be used with children who are victims of violence.



## LEVELS OF PAIN ASSESSMENT

Health care provider's guide: Ask the client to point the image or numbers that can indicate if they are in pain and how much pain, from the least severe to the most severe.

- **3-7 years old: Faces Pain Scale:** Faces start with image that represents least amount of pain. Very happy > no hurt; Hurts just a little bit; Hurts a little more; Hurts even more; Hurts a whole lot; Hurts as much as you can imagine (don't have to be crying to feel this much pain).
- **8 years or greater - Numeric rating scale for pain:** "On a scale of zero to ten, where zero means no pain and ten equals the worst possible pain, what is your current pain level?" The numeric rating scale may be categorized into no pain (0), mild pain (1-2), moderate pain (3), and severe pain, (4-5).



## Finding solutions for adherence issues

Never blame or judge the child/caregiver as it will only create the danger that the patient will not recognize the truth or dare to speak about his difficulties anymore, and will not increase adherence. Rather try to understand the difficulties behind the non-adherence and involve the child and his caregivers to find solutions. This necessitates having a non-judgmental attitude, and creating an atmosphere where children and caregivers feel free to talk.

Do not suggest all kinds of solutions without clear assessment of the reason for adherence difficulties. You might introduce nice tools but not adapted to that specific problem. Tools need to be adapted to the encountered difficulty: understanding, technical problem, emotional difficulty, social problem, etc.

Some possible solutions will be:

### 1) Appropriate education

Health staff often thinks non-adherence is linked to poor or misunderstanding of the given information and just restarts the same education session as before. Lack of understanding can be the reason of the problem at the beginning, but should not last if the child gets regular adherence sessions. More often, the child and caregiver know the way to take ART but they don't perceive the importance of taking the treatment. The accent should be put more on "What happens in short and long term when you don't take ART", rather than just "You should take them like this and at this time". The objective is to reach awareness and not just remembering a message by heart.

### 2) Evolution of disclosure progress (partially – to fully disclosed regarding HIV + status):

Assess the impact of the secret in case of non-disclosure and possible need for disclosure. If you feel the child doesn't show enough concern, doesn't understand the reason for taking drugs, shows anger and refuses to take the drugs, it may be necessary to move ahead in the disclosure process.

**3) Review use of routines**

Help the caregiver and the child to find the easiest methods regarding their specific situation. What is the child doing or what happens every day around 7 or 8 in the morning and 7 or 8 in the evening (eating, brushing teeth, hearing the church bells ring, father leaves home, ...). Support them to link taking medication with daily activities.

**4) Suggest some tools to remind the child to adhere:**

Use pill-path, visual reminder tools, alarm clock, pill-boxes for both practical aspects and involvement of the child.

**5) Show how to take the drugs concretely (with placebo).**

Help parents to normalize the procedure of taking drugs. Give them advice on how to reinforce and praise the child positively when taking the drugs well.

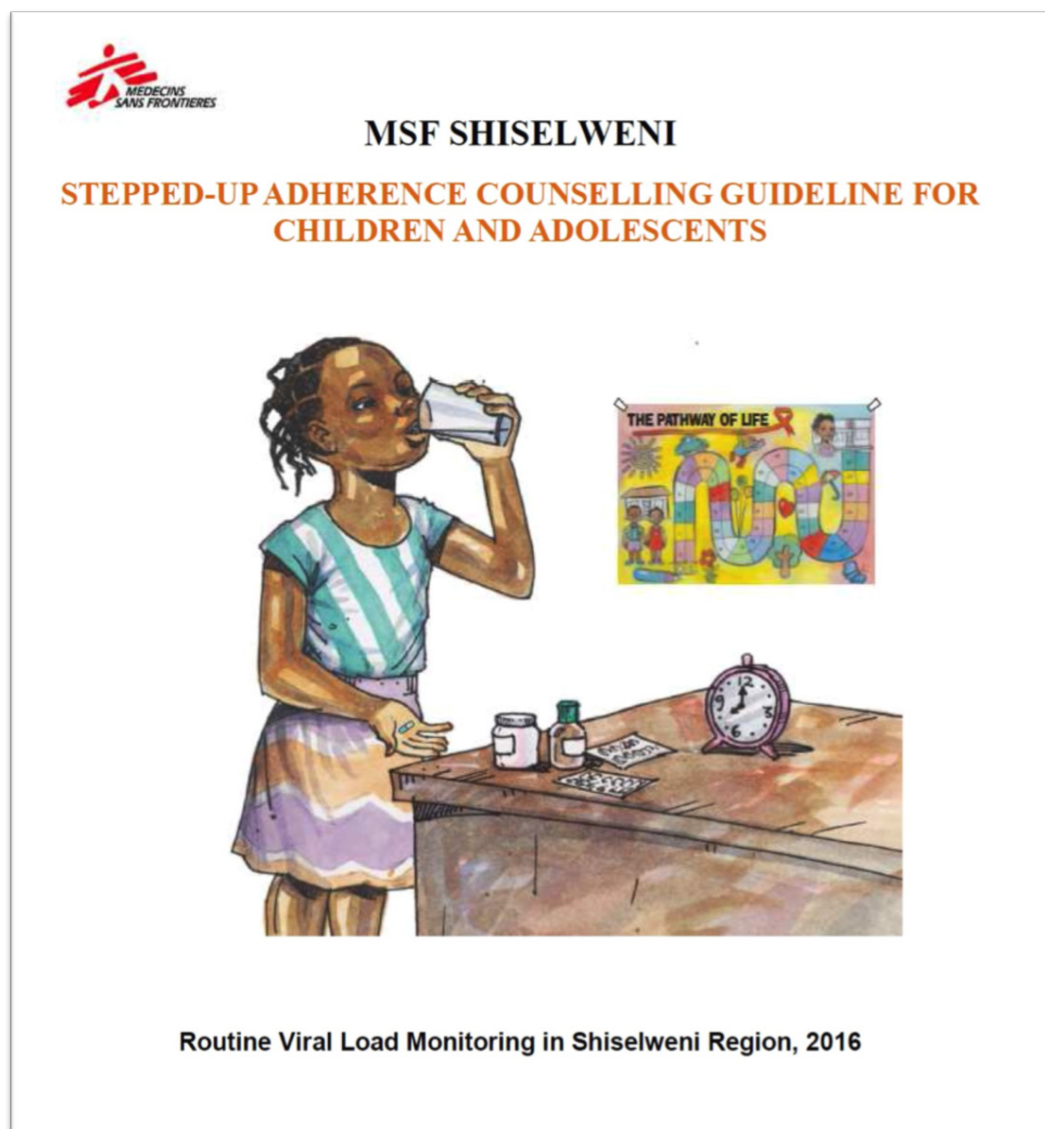
**6) Emotional support:**

Use non-judgmental encouraging language and body-language to communicate openly, and allow time to review the beliefs of the caregivers and/or child about HIV/AIDS and treatment, and help them cope with the disease and treatment.

Allow the child / caregivers time to talk about feelings and difficulties related to adherence.

## Annex 18. Enhanced adherence counselling guideline for children and adolescents (2016 from MSFCH Shiselweni project)

Full version available on: <https://tukul.msf.org/psec>



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