

CAREGIVER EDUCATION: GROUP SESSION 1

Introduction of Health Team

Training facilitators should introduce themselves, as well as other key staff (doctors/nurses) who are not present.

Overview of the Healthcare Setting

Services available at and around the healthcare setting should be introduced. The overview should include an explanation of the treatment clinic as well as available psychosocial support networks connected with the treatment clinic. Caregivers should be told how to access emergency support when needed.

The Immune System

Use Visual Aid 1 to reinforce the concepts introduced in this section.

Each of us has an **immune system** that helps us to fight disease.

The immune system is like an army that protects us from invading enemies.

White blood cells are like soldiers in the immune system army. They patrol our body, protecting us by helping us to fight many different infections.

Just as there are many types of soldiers in an army, there are also many types of white blood cells. One type is called the **CD4 cell**.

CD4 cells are like the officers in the army. They fight diseases and they also help to ensure that the other parts of the immune system work correctly. Having many CD4 cells is important in fighting disease and keeping our bodies healthy. Without an organized army that can fight, illnesses attack the body and may win the war against a patient's good health.

What is HIV?

Use *Visual Aids 2-4* to reinforce the concepts introduced in this section.

When discussing *Visual Aid 3*, use the whiteboard to compose a list of adjectives that describe each of the stages of HIV/AIDS depicted in the drawing (energetic, strong...tired, weak, etc). Be sure to involve all caregiver participants in this activity.

When discussing *Visual Aid 4*, emphasize methods of prevention for each mode of transmission. (Emphasize the importance of wearing condoms for those who are sexually active; emphasize the importance of PMTCT antenatal care, and HIV testing during pregnancy; urge HIV-positive women to seek PMTCT care for their newborns within 48 hours post-delivery; encourage HIV-positive mothers to feed babies using exclusive breast feeding or exclusive formula feeding in accordance with national guidelines; and emphasize the importance of always using a clean razor when shaving someone's head/beard.)

HIV stands for **Human Immunodeficiency Virus**.

Although our white blood cells know how to fight and kill many viruses, HIV is different. HIV actually attacks the body's immune system and destroys CD4 cells. HIV looks for the CD4 cells, goes inside of them, and makes copies of itself. As it does this, it destroys the CD4 cells.

With less protection from CD4 cells, our immune system army becomes weak, and our body has more difficulty fighting off other diseases such as malaria, TB and diarrhea.

Even when HIV-positive, we start out feeling well and strong. Over time, as more CD4 cells are destroyed, this begins to change. We feel weaker as our body's army is defeated. Sickesses that were once easy for our bodies to fight start to become more troublesome and serious.

Learning to protect ourselves and others from HIV is extremely important. We know that HIV is transmitted:

- through unprotected sexual intercourse
- from an infected mother to her child during pregnancy, delivery, or breastfeeding
- through direct contact with the blood or bodily fluids of an infected person

We know that HIV is *not* transmitted by:

- sharing a cup/plate with an infected person
- mosquitoes
- spirits/witchcraft
- kissing an infected person
- immunizations with clean needles

- sitting on the same toilet seat as an infected person

Basics of ARV Therapy Initiation

Use Visual Aids 5-9 to reinforce the concepts introduced in this section.

When showing Visual Aid 8, stress that all three ARVs must be taken in order for the HIV to “stay sleeping” for long periods of time. For children, you can explain that just like the soldier needs at least 3 parts to his uniform (shirt, pants and hat), we to always take all 3 ARVs together. Taking only 2 ARVs is like sending a soldier to battle without pants or underwear.

When showing Visual Aid 9, have the participants discuss the differences between this timeline and that shown in Visual Aid 3. Stress that children with HIV who receive appropriate care and treatment can live long lives. Encourage caregivers to plan for their children’s futures.

It is important to remember that people who are HIV-positive do not have to feel sick. While there is not yet a cure for HIV, there are things we can do to strengthen our bodies. We can even produce more CD4 soldiers to help protect ourselves.

Over time, many people infected with HIV reach a point where they no longer have enough CD4 cells in their immune system army. When this happens, they need to begin taking **ARVs** to help their bodies become and stay stronger.

ARV stands for **anti-retroviral**. Anti-retroviral therapies are medications that fight HIV. ARV medications kill some of the HIV and help to keep the rest of it sleeping so that it cannot continue to kill CD4 cells. We need to give three ARVs together so that they can continue to work against the HIV for a long time.

While ARVs do not cure HIV, taking them helps slow down the HIV virus so that the infected child can feel better, have less sickness, and can live a normal, healthy life.

Even if someone’s immune system is weak, he/she might not be ready to start treatment. The doctors and nurses will explain whether an individual child is ready to begin ARVs.

Why is Adherence So Important?

Use Visual Aids 10 and 11 to reinforce the concepts introduced in this section.

HIV is **a life-long infection that requires life-long treatment**. Remember that ARVs protect patients from illness by keeping HIV asleep. However, if the medicines are not taken properly, the virus can wake up and harm the body.

Caregivers must understand that HIV-positive children will need to take ARVs for the rest of their lives. This will require discipline, determination, and support from family and community.

Some types of ARVs must be taken every 24 hours, or once a day. However, most ARV medicines only work for 12 hours at a time. Therefore, they must be taken twice a day - in the morning and then again in the evening. This means that the child will have to **take the medications at the same time every day**. The dose schedule is designed so that the child always has a certain amount of medicine in his/her body.

If the child does not take his/her medicine at the correct time, does not take the proper dose, takes some of the medicines but not others, or stops and starts the medicines, the medicines will stop working and the HIV will wake up and attack the CD4 cells. When there is not enough medicine in the body to keep the virus asleep, the virus may become tricky and learn how to get away from the medicine. When this happens, the medicines that we use to force the virus to sleep will no longer work and will never work again. This is what is known as **resistance**.

Children need to understand why taking their medicine is so important. Remind them that it's not about not being sick; **it's about staying healthy**. Even when the child starts to look and feel stronger, they need to continue taking their medicines regularly so that the soldiers of the body remain strong.

Explain that: ***When you are good about remembering sometimes, but not all of the time, it allows the virus to become tricky. The virus learns to escape from the medicines. This is a permanent problem, not just a temporary one. This means that the medicines won't work anymore, even if you then begin taking them properly again. It is important to never share the child's medicines with someone else. If you share them, they won't work for the child or for the other person.***

Remember: in order to stay healthy and strong, most patients must take their medicines every day for the rest of their lives.

Barriers to Adherence

Caregivers and patients often say that it can be difficult to take the medicines every day and on time. Why might this be?

Raise the question written above with the group. Based on caregiver feedback, make a list of potential barriers to adherence.

If not articulated by any of the participants, be sure to emphasize that inconsistent/rotating caregivers and poor knowledge/understanding are two major barriers to adherence.

- Inconsistent or rotating caregivers
- Knowledge/ understanding
- Readiness/commitment
- Forgetfulness
- Lifestyle
- Traveling
- Medication burden
- Side effects
- Socioeconomic factors
- Stigma/cultural factors
- Disclosure
- Lack of support

Discuss ways in which caregivers and clinic staff can work together to address each of the barriers identified.

The most common cause of resistance is failure to have perfect adherence – that is failure to take the right dose at the right time every day. However, it is possible – but rare – that people develop resistance for other reasons.

ARV treatment may seem complicated at first, but with some practice, and with the support of family, friends, and health staff, HIV-positive children can do very well and live much happier, healthier lives. There are people who got this disease in the 1980s, when we first learned about it, who are still alive today. Over time, taking medicine can become just like eating and sleeping - a normal part of life that you always remember.

Roles, Responsibilities & Expectations

What do medical staff members expect of the patients and their caregivers?

- Honesty

- Regular, open communication
- Participation in adherence training sessions
- Attendance at all scheduled appointments
- A strong commitment to ARV therapy

What can patients and their caregivers expect of medical staff members?

- Excellent medical care
- Compassion
- A judgment-free environment
- Assistance with any problems that might arise

Communicating with the Health Team

We understand that children may have trouble taking the ARV medicines. It is ***normal to feel afraid or anxious***. Expressing these feelings to the health team can help.

If the caregiver or the child feel discouraged and want to stop treatment, they should talk to the doctor before doing so. The ***clinic team is here to help*** address any problems that the medicines might cause. If any of the medicines need to be changed or stopped for any reason, the clinic team can help make changes most safely.

Adults who care for a child with HIV should learn as much as they can about HIV, the medicines the child is taking, and how best to address any problems at home that can affect the care of the child. They should ask about resources and support that are available. The more information they have, the better equipped they will be to help the child stay healthy.

Be sure to leave ample time for discussion before ending the session. Ask each participant if he/she has questions about any of the topics addressed. Remind participants that they need to attend Session 2; provide them with the exact time and place.