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GLOBAL AIDS PARTNERSHIP

HIV/AIDS

Managing HIV & Antiretroviral Meds

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CHAPTER 1

Introduction and Teaching Helps

Key Points

- This unit can be used by individuals or groups to learn how to successfully live with HIV and manage HIV medications.
- Christians have a biblical responsibility to show compassion toward those affected by HIV.
- Adults learn differently than children and special focus should be given to interactive activities and group discussion.

Using This Manual

This manual was designed as a guide for those with HIV or who are working with those who are HIV positive. This manual is a tool with suggestions based on research and recommendations from groups such as the World Health Organization (WHO), United Nations AIDS Council (UNAIDS), and the Centers for Disease Control (CDC). These are just guidelines and will have to be adjusted to individual situations or regions.

Not all foods, medications, and tests mentioned in this resource are available in all regions of the world. Some investigating may be needed to identify local resources.

HIV/AIDS, ART, and the Church

Questions for Discussion

- What is the church's role in responding to HIV?
- What are some actions that the church or community can take to help those with HIV/AIDS get treatment?
- What could your church or community do to help those with HIV manage the daily task of living with HIV?

Activity

Read Matthew 25:34–40 as a group. Ask:

- According to this passage, what is the correct response when a Christian sees someone hungry or thirsty?
- What does this passage tell us about how God views physical needs in people's lives?

Jesus told His disciples a story about those who served God and those who served themselves. In Matthew 25:34–40 (NIV), Jesus told His followers,

Then the King will say to those on his right, "Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me."

Then the righteous will answer him, "Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?"

The King will reply, "Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me."

Jesus highlights the importance of serving others in both spiritual and physical ways.

Jesus highlights the importance of serving others in both spiritual and physical ways. Jesus did not say, "I was hungry and thirsty, and you preached to Me." In those times, the need was physical, and as Jesus' representatives, He expected His followers to respond to these physical needs with physical help. Ultimately, the lostness of persons will always be forefront in the minds of those who follow Christ, and somewhere in the process, telling of the good news of Jesus must happen.

Today, Christians around the world have the same opportunity to respond to physical and spiritual needs around them as the disciples with whom Jesus was talking. Every church is different and the resources and needs around them are different.

There are many ways that a church can reach out to people living with HIV and help them manage their disease:

- **Transportation to and from clinics**. Just because antiretroviral therapy (ART) is freely available in many parts of the world does not mean that a person has easy access to it. A person with HIV may need transportation to or from clinic appointments and/or to the pharmacy.
- **Watching children**. Persons may be able to get to and from the clinic, but may need someone to watch the children while away.

- **Accountability partner**. To help individuals stay on their medication regimen, it is sometimes helpful for a friend or family member to check in on a regular basis (once a week or so) to make sure medications are being taken and appointments being kept up with, etc.
- **Household help**. Someone weak from HIV infection may be unable to perform daily activities like food preparation or clean up. Members of the church could stop by families' homes to help with these chores.
- **Teach classes on ART, opportunistic infections, or side effects**. Short classes in the evening or weekends are great ways to pass on information about ART and other related subjects. These classes also can be a way to introduce people who would not normally come to a service to a church and its members.

People learn through different methodologies.

Questions for Discussions

- How do adults learn new information?
- How are adults different from children?
- How do adults learn differently than children?

Adult Learners

There is a Chinese saying that states, "Tell me, and I'll forget. Show me, and I may remember. Involve me, and I'll learn." This means that for most people, simply telling them information does not mean they will remember it or do anything with it.

People learn through different ways. Often, being a part of an activity or project or seeing a demonstration helps people remember things better than just listening to someone talk about a subject. This is especially true of adults.

Teaching adults requires creativity. Adults need to be included in the teaching process by discussion questions, activities, and role plays. Adults already may have knowledge about the topic from life experience. This knowledge must be respected.

Teaching Strategies

Role plays

Role plays are spread throughout the unit to help demonstrate concepts and spark discussion among participants. If using this unit to teach a group, have members of the group come to the front and act out the role plays. Then take

time to ask questions of the group following the role play to help them understand the topic.

Questions for discussions

These questions are to prompt critical thinking about the topic. Take time to discuss these questions with the group. If you are working through this unit alone, stop and think about the questions and what your answer would be. There are no right or wrong answers to these questions; they are there to start you thinking.

Activities

Activities are simple exercises that can be done in a small group to help make the concepts discussed in the book clearer. They take few supplies. Doing, rather than just reading about something, makes it much easier to understand and remember the concepts.

Goals of the book

Readers will:

- Interact with their health care professionals and be informed and involved with making decisions concerning their health.
- Understand what ART is and the criteria for starting ART.
- Understand what antiretroviral medications (ARVs) are, their different types, how they work, and the possible side effects of ARVs.
- Know the most common opportunistic infections, their symptoms, and when to seek medical attention.

CHAPTER 2

About HIV/AIDS

Key Points

- HIV is a virus that causes the AIDS disease. There is no cure for AIDS, but people with HIV can take actions to live longer, healthier lives.
- HIV is spread through blood, sexual fluids, and breast milk. It cannot be spread through casual contact like hugging or shaking hands.
- HIV attacks the part of the body responsible for fighting disease—the immune system.
- There are many things that determine how healthy or weak a person's immune system is.

Questions for Discussion

- What comes to mind when you think of AIDS?
- What do you think of when you think of a person who has AIDS?

Background of HIV/AIDS

The HIV/AIDS epidemic was first identified in the early 1980s in the United States. Since then, it has affected every region of the world. Millions of people have died from the disease; millions more are currently living with it. Africa is the most affected region, with some African nations having infections rates greater than 25 percent: 1 out of 4 adults in those countries is infected (UNAIDS, *Fast Facts About HIV Treatment*).

In places like Africa, AIDS affects the whole population in some way. It is generally spread through sexual contact between men and women or from an infected mother to baby. In other parts of the world, the epidemic has mostly been contained within certain groups of people like homosexual males or intravenous drug users.

Governments and civil groups have made great efforts to stop the spread of HIV/AIDS. In many parts of the world these efforts, combined with personal choices to abstain from sex before marriage and be faithful within marriage, have reduced the numbers of new HIV cases. However, in other parts of the world, the numbers of new cases are still growing.

Questions for Discussion

- What is the most common way for people in your country or community to contract HIV?

- What factors in your local community or the culture of your country impact the spread of HIV?
- Are there practices in your culture that discourage the spread of HIV? (For example, is faithfulness in marriage important for both men and women? Are young people encouraged to wait until they are older to become sexually active?)
- Are there practices in your culture that facilitate the spread of HIV? (For example, do people have easy access to illegal drugs? Is it acceptable for men to have multiple sexual partners?)

The good news is HIV is not easily spread. There are only three ways it can get into a person's body: through breast milk, blood, and sexual fluids.

HIV Transmission

The good news is HIV is not easily spread. There are only three ways it can get into a person's body: through breast milk, blood, and sexual fluids.

The first mode of transmission is through breast milk from a mother to child. If a mother is HIV positive and breast feeds her baby, it is possible for the baby to get HIV from the milk. If a woman who is HIV-positive has a baby, there are several options she can take to keep her baby from getting HIV. She can give her baby a milk substitute such as formula (made with clean water), but this can be expensive. The World Health Organization (WHO) recommends that a mother nurse her baby exclusively for six months. Then she should gradually wean the baby off breast milk, so the baby is not taking breast milk at all by the time he is a year old. A mother can also transmit HIV to her baby during the pregnancy and birth. (See Chapter 6 for more information on mother-to-child transmission.)

The second mode of transmission of HIV is through blood. If HIV-infected blood enters another person's body, the second person is exposed to the virus and may become infected. The most common way for this to happen is through reusing or sharing needles, especially among people who inject drugs into their bodies. The needle that a person uses to inject drugs can trap a person's blood inside it, so that the next person who uses the needle is exposed to the first person's blood. Blood can also carry HIV to another person if a medical or dental facility reuses needles or other medical equipment without properly cleaning them or if a person uses some kind of sharp object (like a razor) that has another person's blood on it.

To prevent the spread of HIV through blood, people should not share needles. In most parts of the world, a person can buy his own needle and ask the doctor to use it if he does not think proper needle disposal is being followed. A person

should cover his hands with something like gloves or a plastic bag before touching someone else's blood.

In most of the world, people having sex with partners of the opposite sex (men having sex with women and women having sex with men) are the largest spreaders of HIV.

The third and most common way a person gets HIV is through unprotected sex with someone infected with HIV. Any kind of sexual activity outside of a monogamous (one man with one woman for life) relationship can spread HIV, but some kinds of sexual practices such as anal sex, rough sex, or dry sex can spread HIV more easily. The more partners a person has sex with and the more times they have sex, the greater the chance that they can become infected with HIV. A person can become infected after just one unprotected sexual encounter.

In most of the world, people having sex with partners of the opposite sex (men having sex with women and women having sex with men) are the largest spreaders of HIV. In some parts of the world, however, people who have sex with partners of the same sex (men with men, for example) account for a large percentage of HIV infections.

Using a latex condom when having sexual intercourse can reduce a person's chances of getting HIV, but it cannot eliminate the risk completely. The only way to eliminate the risk of getting HIV is to abstain from sex before marriage and for both partners within marriage to be completely faithful to each other. In many countries, HIV testing is required prior to marriage.

There are many ways that HIV is not spread. HIV is not spread from skin to skin, so a person cannot get it from hugging, kissing, or shaking hands with a person who has HIV. A person cannot get HIV from using utensils or toilets or beds or blankets of a person with HIV. People with HIV can live and work alongside other people without infecting them.

For someone who has HIV, it is essential to take measures to help maintain a healthy immune system. HIV is constantly attacking the immune system, slowly destroying it. This allows other diseases to infect the body. Eating healthy, nutritious foods strengthens the immune system of a person with HIV and helps him stay healthy longer.

HIV and the Immune System

Questions for Discussion

- What are some things that make people susceptible to disease?
- Are there steps people can take to lower their chances of getting sick?

Role Play

Outline an area on the ground and label it "the body." Have five volunteers each hold a sign—two are "T-cells," two are "germs," and one is "HIV." The two people playing the T-cells should stand inside the circle marked "body" and keep the two people playing "germs" out. Then the person playing the role of "HIV" should step in and defeat the T-cells. The germs should follow HIV into the body.

About the drama ask:

- What is protecting the body?
- How did the germs finally get inside the body?

HIV stands for Human Immunodeficiency Virus. This is a tiny germ that can invade a person's body and attack the white blood cells that fight off sickness and help the body heal from injuries.

HIV stands for Human Immunodeficiency Virus. This is a tiny germ that can invade a person's body and attack the white blood cells that fight off sickness and help the body heal from injuries.

Normally, when a person becomes sick, the immune system defends the person's body from the illness and the person gets better. One of the most important parts of the immune system are the T-cells (also called CD4 cells), which help protect the body from disease. The immune system acts somewhat like an army defending a country. As long as the army is stronger than the attackers, the country is safe. For a human, as long as the immune system is strong it can fight off the disease germs that are trying to make that person sick.

The HIV germ attacks these T-cells that are so important for the immune system. When a person's immune system is weak because HIV is attacking it, other diseases such as tuberculosis (TB) and pneumonia are able to enter a person's body and make the person sick. When a person's immune system is so weak that he is not able to fight off these other infections, the person is said to have AIDS (Acquired Immunodeficiency Syndrome). It can take many years after HIV enters the body for the person to develop AIDS.

Right now, there is no cure for HIV. Once a person tests positive for having the virus in his body, he will have it his entire life. Without certain medications called antiretrovirals (ARVs), the HIV will weaken the person's immune system and he will develop AIDS and die. This process can take many years, but normally takes between two to ten years.

The immune system protects a person from diseases. A person's overall health affects the way the immune system protects the body. The immune system is complex with many different elements that make it stronger or weaker. For example, food plays an important role in the strength of the immune system. Some people are born with stronger immune systems than others. Additional factors that affect how healthy a person's immune system is are the presence of other infections, how healthy a person was growing up, exercise, and availability of clean water.

For someone who has HIV, it is essential to take measures to help maintain a healthy immune system. HIV is constantly attacking the immune system, slowly destroying it. Keeping the immune system of a person with HIV strong helps him stay healthy longer.

Some things a person can do to keep his immune system healthy include:

- Eating a healthy, balanced diet.
- Identifying and treating infections quickly.
- Using only clean water for drinking, cooking, and washing dishes.
- Getting plenty of exercise, without overworking oneself.
- Getting plenty of sleep.
- Protecting oneself from environment hazards like inhaling smoke.
- Wearing clothes appropriate for the weather (warm clothes with layers for colder climates and light clothing for warmer climates).

Note: Nutrition is a vital part of building a strong immune system and successful management of HIV. Because of this, GAP has an entire unit dedicated to *Introduction to Nutrition*. For more information on the connection between nutrition and HIV see that unit. It is available free of charge in the Resources section of our website: www.globalaidspartnership.org.

CHAPTER 3

Health-Care Setting

Key Points

- People with HIV should be informed about their health, options for care, and medications.
- There are many different tests people with HIV might undergo.
- Knowing what questions to ask will better prepare a person to meet with his health-care provider.

Questions for Discussion

- In your community, where do people get tested for HIV?
- Where do people receive treatment for HIV? Is there more than one place a person with HIV could go?
- Is there a strong stigma—or negative feelings—toward people who seek treatment for HIV? What causes people to reactive negatively toward people with HIV?

Common HIV/AIDS-Related Tests

HIV/AIDS test

Testing for HIV is indicated if there is a possibility that an individual has been exposed to the virus. This may happen through higher-risk behaviors, such as unprotected sex, sharing drug injection equipment, or other means, as in exposure during a medical procedure or having come in contact with infected bodily fluids. For some, getting tested may be very frightening because of the potential of testing positive. Yet, getting tested can relieve unnecessary worry and stress of uncertainty. By detecting HIV early, there is the possibility to improve the quality of life for the individual and others affected by the result with proactive strategies for holistic care. Whether the results are positive or negative, in almost all cases it is better to know.

HIV is most commonly diagnosed by testing blood, saliva, or urine for the presence of antibodies to the virus. It takes time for the body to develop these antibodies, so these tests are not accurate immediately after infection. It can take from 12 weeks to six months (in rare cases) from the time of infection for an antibody test to show positive. Therefore, one or more of these tests could give a false negative if the testing falls in the window period—from the time the virus is contracted to when the antibodies are detectable. During this window period, an infected person can transmit the virus to others. It is, therefore, necessary to test twice at least three months apart for a more accurate diagnosis.

PCR test

Another newer test checks for the HIV antigen, a protein produced by the virus immediately after infection. This test is accurate within days of infection, but may not be available in all areas. It is often used to test babies born to women who are HIV positive.

After receiving a positive diagnosis of contracting the HIV virus, there are other types of tests that can help your doctor determine what stage of the disease is present.

CD4 count

CD4 cells are a type of white blood cell that the HIV virus specifically targets and destroys. These are "helper" cells that initiate the body's response to infection. A healthy person's CD4 count can vary from 500 to more than 1000 cells/mm3. Even if a person has no symptoms, HIV infection is termed AIDS when the CD4 count becomes less than 200 cells/mm3 (less than 350 cells/mm3 in some countries).

Viral load

This test measures the amount of the virus in your body fluid. It determines the severity of the infection. If the viral load is high, it is an indication that the virus is reproducing and the disease will likely progress faster than if the viral load is low. This test is used to monitor the effectiveness of treatment for patients on ARVs.

Drug resistance

This type of test determines if your strain of the HIV virus is resistant to any anti-HIV medications. It is not available in most parts of the world.

After receiving a positive diagnosis of contracting the HIV virus, there are other types of tests that can help your doctor determine what stage of the disease is present.

Questions for Discussion

- In your community, who typically makes health-care decisions for people? Themselves? Their doctors? Community leaders?
- Are there any barriers that make it difficult for people to talk with their doctor or health-care professional about questions or concerns?
- Who handles health care in your community—a doctor, a clinic, a midwife, or other local practitioner?

Patients' Rights and Responsibilities

Adults have the right to make decisions for themselves. Making decisions for one's own health is necessary for overall well-being and is related to quality of care. The more you know about the HIV virus, the better you can control the impact of living with the virus.

The first step in making those decisions is to gather information. People who learn as much as they can about their choices will tend to feel better about the decisions they make.

Talking to a health-care provider is not always easy, but if there is a concern regarding a health-related issue or treatment, make the effort to talk to your doctor. People who work with their doctors in making health decisions are generally happier with their care. Only the individual knows how his choices are best suited to his needs, values, beliefs, fears, experiences, and lifestyle.

People who work with their doctors in making health decisions are generally happier with their care.

Activity

As a whole group or in small groups, come up with a list of questions a person with HIV might ask his health-care provider. Include questions about diagnosis, medications, treatment options, and anything else that a patient would need to know.

When meeting with your doctor or health provider, asking questions is important to clarify any instructions or new information. Make a list of what to ask the doctor before you go, if possible. If you forget a question or think of one later, write it down to ask the next time you visit the clinic.

Questions to Ask Health-Care Providers

What are your choices?

Ask the doctor to clearly explain the decisions that need to be made (and when) and to outline options and related effects.

Communicate your fears.

Consider your own needs and values and what you hope for the best possible outcome. Be open and honest with your doctor. Ask for clarification for anything not understood. Weigh the good and the bad of each option. Ask the doctor if the expectations are reasonable.

What are the side effects and long-term outcomes?

Will that option be satisfactory?

Make a plan of action.

After the decision is made, find out what can be done in order to have the best possible outcome. Be honest about what you are willing and able to do. Stick to the plan. Take the medications if indicated, return for the next appointment, eat and drink things that will make you healthy, etc. Think positively about the decision made. People are made up of more than just the physical body. Make sure to take care of yourself physically, spiritually, emotionally, mentally, and socially. When one area is out of balance, it affects the whole body.

Evaluate progress.

If the plan is working, that's great! If it's not, it is time to discuss this with the healthcare provider. Are there still concerns? Gather more information. Reassess your options.

The disease is stressful for the individual and the caregiver. Caring for someone with HIV/AIDS is an emotional responsibility.

Activity

As a group, make a list of all the people who might be involved in caring for a person with HIV in any way. Think about people other than health professionals, such as family and friends. Beside each person's name, write what their role in caring might be.

An individual's closest circle usually includes family, good friends, and neighbors. They may be the ones who help the individuals with their care and will be affected by the choices made. Individuals should consider telling these people their HIV status and talking to them about the health-care decisions. Ask their opinion of the options and listen to their input.

One of the best places for people with HIV/AIDS to be cared for is at home. Being at home is less expensive, more comfortable, and gives more control of personal preferences. Every person with HIV/AIDS-related issues is unique and is affected by the virus differently. Many times what is needed is not medical care but help with activities of daily living.

The disease is stressful for the individual and the caregiver. Caring for someone with HIV/AIDS is an emotional responsibility. Caregivers must remember to care for themselves.

CHAPTER 4

Antiretroviral Medications

Key Points

- Medications called antiretroviral medications (ARVs) treat but do not cure HIV.
- There are many different types of ARVs used in combination to treat HIV.
- The most common types of ARVs are classified as first-line medications; less common ARVs are called second- or third-line ART.
- How closely a person follows the health-care provider's recommendations is called drug adherence. People with good drug adherence have more success with ART.

Questions for Discussions

- Who provides antiretroviral medications in your community?
- What are some of the costs associated with ART? If ART medication is provided free, what are other costs (transportation to the clinic, missed work, payment for other medications, etc.)?

Medications to treat HIV are called antiretroviral medications (ARVs). The medication regimen is called antiretroviral therapy (ART or in some places, HAART—highly active antiretroviral therapy). ART does not cure HIV, but it does prevent the symptoms of AIDS (opportunistic infections, weight loss, etc.) from developing in most people. Most people with HIV can live healthily for many years because of ART.

Over 30 types of medications are ART medications. Each of them is slightly different from the other, but they are divided into six main types based on how they block the virus copying itself.

Remember, HIV is a virus that reproduces in the body, destroying immune cells (T-cells) to make copies of the virus. Each ART medication tries to block the virus's ability to copy itself. Each of the six types of ART blocks this reproduction in different ways.

The six major types of ART are:

- *Non-nucleoside reverse transcriptase inhibitors* (NNRTIs): NNRTIs bind to and alter reverse transcriptase, an enzyme HIV needs to make copies of itself.

- *Nucleoside reverse transcriptase inhibitors* (NRTIs): NRTIs also block reverse transcriptase, an enzyme HIV needs to make copies of itself, but in a different way than NNRTIs.
- *Protease inhibitors* (PIs): PIs block HIV protease and another enzyme HIV needs to make copies of itself.
- *Fusion inhibitors*: Fusion inhibitors block HIV from entering the CD4 cells of the immune system.
- *CCR5 antagonists*: CCR5 entry inhibitors block CCR5, a protein on the CD4 cells that HIV needs to enter the cells.
- *Integrase inhibitors*: Integrase inhibitors block HIV integrase, an enzyme HIV needs to make copies of itself.

Most people on ART take medications from at least three of these categories at the same time so the virus is less likely to become resistant. Combining medications from these groups is the most effective way of preventing HIV from multiplying in the body.

Each ART medication is slightly different than the others, so each has special instructions about when and how to take them. Some of the medications cannot be taken soon after eating and some have to be taken at mealtime. Some ART medications are always taken in the morning or some always at night. Because of this, ask the doctor or clinic about the specific instructions for each medication prescribed.

At times, more than one type of medication is combined into the same pill. This way people who take these medications do not have to take as many pills to get the medication they need.

Not all medications are available in all regions of the world and different medications have different names in various places.

First-Line, Second-Line, and Third-Line Treatment

HIV medications are divided into first-, second-, and third-line drug treatments. First-line treatments are the ARVs that are most common, effective for most people, and the least expensive. First-line medications control most HIV symptoms with the lowest number of side effects for most people. When a person is started on ART, they are almost always started on first-line medications. Only if combinations of first-line medications do not work will a person with HIV be advanced to second-line medications.

Second-line ART is available in many parts of the world, but they are far more expensive and often have more side effects than first-line medication. They are only used if HIV cannot be controlled by the first-line medications.

Third-line medications are the least available of ART medication and are often extremely expensive. They are new medications and are not always as tested as second- and first-line medications. They can have many more side effects than other ART medications.

When to Start on ART

Not everyone diagnosed with HIV needs to start on ART right away. The need for ART is determine by many personal factors and the availability of medication in different parts of the world. A person who has HIV but whose immune system is strong and who is otherwise healthy often does not need medication immediately. His medical provider will continue to monitor him through blood tests and checkups and determine the right time for the person to start on medication.

It is always best to avoid starting on ART if it is not needed. ART medications have many side effects that can affect a person's life. Furthermore, the sooner someone is started on ART, the more likely the virus inside of them will become resistant.

It is always best to avoid starting on ART if it is not needed. ART medications have many side effects that can affect a person's life.

Each person with HIV is different and the health-care provider will evaluate each person's need for ART individually. However, generally a person needs to start ART if:

- His or her CD4 count falls below 350 (or 200 in some countries).
- He or she starts showing symptoms of AIDS such as opportunistic infections or significant weight loss.
- She is pregnant or trying to become pregnant.
- She is breastfeeding.
- He or she is a young child.
- He or she is also infected with hepatitis C or tuberculosis.

Questions for Discussion

- What are some reasons people do not take their ART medications as directed?
- What are some practical ways people can improve their adherence to ART?

Drug Adherence and Resistance

Once someone is started on ART, how closely he follows his health-care provider's instructions to take his medication as directed is called *drug adherence*. A person who takes his ART on a regular schedule, keeps his clinic appointments,

and follows his doctor's instructions has good drug adherence. A person who misses doses of medication or does not keep follow-up appointments is said to have bad drug adherence.

There are many reasons people do not adhere to their medication regimen. Sometimes patients do not understand the importance of their ART medication, it is too difficult or expensive to get to the clinic or pharmacy, or the clinic has long waits (Kip, Ehlers, and van der Wal 2008). People with HIV who also abuse drugs or alcohol often have very poor drug adherence.

Drug adherence (taking drugs regularly and as prescribed) is a significant issue for several reasons:

- Medication is not as effective; it may not prevent HIV from developing into AIDS.
- It is harder to assess if a person's ART regimen is working.
- Side effects are more severe because a person's body does not adjust to the medication.
- HIV can become resistant to the medication.

Drug resistance is a concern related to adherence to medication. HIV is a virus that mutates (adapts to changes) easily. Poor drug adherence gives HIV more opportunity to mutate. If HIV mutates, ART might become ineffective, side effects might become more severe, and opportunistic infections may develop, leading to AIDS and even death.

Ways to reduce risk for drug resistance:

- Keep appointments with health-care providers.
- Take medications as directed.
- Find someone (family, friend, or spouse), whom you can trust to support you and keep you accountable to take mediation as directed.
- Monitor side effects and symptoms and report them to your health-care provider.

CHAPTER 5

Opportunistic Infections

Key Points

- Opportunistic infections are diseases that take advantage of the body's weakened immune system and cause illness in people with HIV.
- Common opportunistic infections include tuberculosis, bacterial infections such as pneumonia, and fungal infections.
- Hepatitis C and B are blood-borne liver diseases that affect many people who contact HIV through blood transmission.

Questions for Discussion

- What are common illnesses or infections that affect people with HIV in your community?
- Are any of these common causes of death?
- Do these illnesses also affect people who do not have HIV?

Opportunistic infections are illnesses that take advantage of a person with HIV's weakened immune system. There are many types of opportunistic infections and all require specific treatment.

Depending on the medications available and a person's need, someone taking ART may also be started on other regimens, such as medications for TB or supplements. These medications do not replace ART, but treat symptoms or side effects of HIV or ARV medications.

Tuberculosis

Tuberculosis (TB) is the primary cause of death for people with HIV in the world. People who do not have HIV can be infected with and die from TB. People with HIV should be screened for TB, and people with TB should be tested for HIV, if possible.

TB symptoms are a cough (sometimes bloody), weakness, night sweats, and fever. It is diagnosed by taking a sputum (fluid coughed up) sample and examining it under a microscope by a healthcare professional. It can also be diagnosed by taking an X-ray of the lungs.

TB medications are available in many parts of the world where ART is available and provided at the same clinics. Most people who take TB medications take them for a period of time (usually six months) to treat active TB infections. A person's symptoms will typically decrease before the treatment regimen is done,

but he or she should complete the entire treatment. However, once someone has had TB, they will always test positive.

Pneumonia and Other Bacterial Infections

Many opportunistic infections are caused by types of germs called bacteria. Bacteria cause sickness in people with and without HIV, but people with HIV are most susceptible to infection. Pneumonia, intestinal infections, skin infections, ear and nasal congestions, and more can all be caused by bacteria.

Most bacterial infections such as pneumonia and intestinal infections can be treated using antibiotics taken as pills, liquids, or intravenously. These medications are normally taken for a set period of time, usually ten days or two weeks. This can be repeated if the first round of medication was not effective. Often the healthcare provider decides if a person needs antibiotics to clear up an infection.

Fungal Infections

Fungi are another cause of opportunistic infections, causing mouth sores, vaginal infections, yeast, and rashes. In some cases, fungal infections can cause more serious infections like pneumonias or brain infections.

Oral fungal infections—sometimes called thrush—are the most common type of fungal infection in people with HIV.

Oral fungal infections—sometimes called thrush—are the most common type of fungal infection in people with HIV. The fungi that cause mouth sores spread fastest when sugars are present, so a person with mouth sores should avoid eating sweet things such as sodas and honey. Keeping the mouth clean helps prevent mouth sores and helps them heal faster. If the mouth sores are too painful for a person to brush his teeth, rinse the mouth with soda water several times a day. It can also help to rinse the mouth with clean water before eating a meal.

Antifungal medications are not available in all parts of the world. Treatment depends on the type of infections. Rashes and vaginal infections are often treated with an antifungal cream; pneumonia or other internal infections may require antifungal medication orally or intravenously. Antifungal medications through the mouth or intravenously often have side effects and cannot be taken over a long period of time.

Hepatitis B and C

People who contract HIV through injection drug use are also at a high risk of contracting hepatitis B and C, two liver diseases that can be spread through contaminated needles. If it is possible for a person to have contracted HIV through

contaminated blood or sharp objects, it may be wise to also test for hepatitis B and/or C.

In some regions of the world, there is a vaccine available to prevent infection with hepatitis B, but there is none for hepatitis C. Some people with hepatitis C have a chronic condition—the virus lives in the body, but produces few to no symptoms. Other types of hepatitis C are acute, causing sickness and death if untreated. Treatment for hepatitis C is a series of medications given over six months to a year, depending on the situation.

In some regions of the world, there is a vaccine available to prevent infection with hepatitis B, but there is none for hepatitis C.

Parasites

Parasites and worms are small organisms that infect the intestines of people who eat contaminated food or water. Many are spread through contact with animal or human feces, food that has not been washed properly, dirty hands, and contaminated water. Drinking from streams where animals or humans have relieved themselves, eating food that has not been rinsed off, or allowing animals to wander around cooking and living areas are some of the major means of spreading parasites.

Worms are much easier to prevent than to treat. Eating only clean food and water, washing hands after using the toilet and before preparing food or eating, and keeping animals away from food and food preparation areas are important to prevent parasite infection.

Medical professionals can prescribe medicines for parasite infections. These must be taken exactly as the provider ordered. In some countries, these medications can be bought without a prescription at a pharmacy. These medications will kill the worms, but the person can be reinfected if he continues to be exposed to what caused the infection.

CHAPTER 6

HIV/AIDS and Relationships

Key Points

- Humans are relational beings who live life in community.
- Discussing someone's HIV status can be difficult, but there are steps that can make the process easier.
- Mother to child transmission of HIV is almost completely preventable through exclusive breastfeeding and ART.
- People who are HIV positive can be sexually intimate with their spouses, but they have to protect themselves and their partners.

Telling Someone Your Status

We are created as relational beings. It may be beneficial for an HIV-positive individual to share his status, especially to family and close friends. It is recommended to tell those who have a sincere interest in the welfare of the individual and who may be affected by the decisions made. It is each person's choice when and who to tell. In many situations, friends and family will be the strongest and most helpful support system if the person is struggling. They may give wise counsel regarding health decisions. They will also be there for encouragement and to celebrate successes. The burden of carrying the secret of one's status alone may be harder than sharing with someone.

Here are some thoughts that may help the individual process sharing his HIV status:

Who are you likely to tell?

- Who will be most affected by my status and my health-care decisions?
- Who will give me the most support physically? Spiritually? Emotionally?
- Whom do I trust with this information?
- Who will give wise counsel?

Know why you are telling someone. What are your expectations of that person?

- Do I expect them to be my caregiver?
- Do I expect emotional or spiritual support from that person?
- Can that person afford to support me through the daily process? (Can they spare their time, money, resources, etc.?)
- Do I just want them to know because they will be affected by my decisions?

What might the reaction be? How will I deal with that reaction?

- Disappointment
- Anger (How would this be displayed—hurtful words, breaking things, acting out abusively or physically hurtful?)
- Feelings of betrayal
- Confusion
- Fear
- Worry/anxiety
- Concern
- Empathy
- Hope and helpfulness

How to Share HIV Status

- Prepare by informing yourself, then have information that you can pass on to the person you are telling.
- Try to control the setting of the interaction. A safe and neutral place will not add stressors to the conversation. If the situation becomes unsafe, make sure you can get to a safe place. It may be helpful to have someone you've already told and trust be with you when telling someone you expect to react badly to your news.
- Informing your spouse or sexual partner that you are HIV positive may be one of the hardest things to do, and this may not be possible if you fear your partner may react with violence. Your partner may not be in a position to offer any support. If your partner is not already HIV positive, then he or she should be tested right away.
- Accept the reaction. You cannot control how the other person will deal with the news. Give that person time to process.
- Draw encouragement and strength from those who are supportive of you. Thank those who are standing by you during this difficult time.

Mother-to-Child Transmission

Mother-to-child transmission is the most common way children become infected with HIV. Not all women who are HIV positive will pass the virus to their babies. Transmission from mother to child can occur during pregnancy, childbirth, or through breast milk.

An antiretroviral regimen is recommended for pregnant women for maternal health and to reduce the risk of passing the virus to their babies. You should see your doctor if you are pregnant or plan to become pregnant. The action for managing HIV during pregnancy is determined on an individual basis. HIV

medications transfer through the placenta and will help protect your baby from the virus, especially during childbirth.

Breast-feeding is by far the best way for most babies to be fed. It provides the nutrients your baby needs during the first few months of life. It also contains elements that protect against childhood illnesses such as diarrhea and respiratory infections. Unfortunately, breast milk carries the HIV virus and can transmit it to your baby. In countries where there is limited access to clean water, sanitation, and health services, it is necessary to continue to breast-feed your infant in order to reduce the risks of other related diseases. So, if you are unable to formula-feed your baby, breast-feeding is the best option available.

Through the breast-feeding period, however, it is advised that the mother and the infant take the course of antiretroviral drugs in order to reduce the risk of HIV infection. A mother is also advised to continue to exclusively breast-feed her baby for up to six months. After that time, introduce other foods while continuing to breast-feed for up to a year. Strict adherence of mother and baby to the antiretroviral medications will considerably reduce the risk of transmission from mother to child (WHO Infant Feeding Guidelines 2012).

If a child is born to an HIV-positive mother, he must be tested for HIV. He may be started on ART before it is known if he is positive or negative. Young children who are HIV positive have much better outcomes if they are started on ART early (Fetzer et al. 2007).

Sexual Activity When HIV Positive

People who are HIV positive may feel guilty or embarrassed discussing sexual relationships. However, the topic of sexual activity is important for their partners. The majority of HIV infections are transmitted through unprotected sexual relations. Disregard for safe sex practices plays a major role in increasing risk.

Not having sex (abstinence) before marriage is the most effective way of avoiding the transmission of the HIV virus and is the biblical standard for Christians to follow. If you are having sex, take precautions and stay away from risky behaviors (such as unprotected vaginal or anal sex). This is important for married couples if one or even both are HIV positive.

For married couples, latex condoms are very effective if used correctly and consistently. Use a condom every time you have anal or vaginal sex. Consider using a condom during oral sex. Never use a condom that has expired. Never reuse a condom. Do not double up on condoms (two condoms at one time). Avoid breakage by sharp objects or spillage when the male has ejaculated. Be sure the condom is not too tight at the tip to allow room for ejaculation fluid at the end. Do not use oil-based spermicides or lubricants as these will cause the condom to burst.

Male circumcision significantly reduces the risk of HIV transmission during sex. However, circumcision is much less effective than proper condom use. Male circumcision benefits over time with a lower prevalence of HIV in the male population.

If you or your spouse is uncomfortable with sex after learning that you have HIV, remember that you can still enjoy kissing, hugging, and touching. These actions carry no risk for infection.

If you and your spouse would like to have a child and one or both of you are HIV positive, there are strategies that may be available for you with limited risk of passing the infection to your spouse and baby. Talk to your health-care provider.

When both spouses are HIV positive, they should not engage in frequent unprotected sex, because there is a risk of one reinfecting one another with a different strain of HIV.

Proactive strategies for reducing risky behaviors include:

- Abstinence.
- Male circumcision.
- Regular, proper condom use during sexual contact within marriage.
- Limit alcohol (Alcohol heightens the risk for sexual behavior and impairs judgment.)
- Avoid illegal drug usage, especially injections.
- Do not share needles.
- Schedule invasive procedures with reputable doctors/health-care providers.
- Wear personal protective equipment and use precautions when you know you'll be likely to come in contact with bodily fluids.

CHAPTER 7

Common Side Effects of ART

Key Points

- Side effects are unwanted negative effects of medications. ARVs can have many side effects.
- ART medications should never be discontinued without consulting a health-care provider, but all side effects should be reported.
- There are many things that can be done at home to help control side effects.

ART medications are each different, but they all carry the potential for side effects. Side effects are negative reactions that some medications cause. Every person reacts to medication differently. Some people are able to take ART with few or only minor side effects. Other people have many and severe side effects.

Most side effects of ART are manageable. Many are worse when someone first starts taking medication and then decrease after several weeks or months as his body adjusts to the medicine. Some side effects can be serious or life-threatening. Other side effects are not immediately noticeable, but as a person with HIV gets older, ART can cause medical problems (such as heart disease or liver problems).

Without ART, people with HIV will die of AIDS sooner. An HIV-positive person with ART available should take his ART medication regardless of side effects. However, sometimes it is possible to switch to a different medication or make other changes that lessen side effects. Any side effect should be reported to the healthcare provider so he and the patient can make a decision about what is best. A person should never quit taking his medication without talking to his health-care provider first.

Some side effects are so severe they interfere with a person's ability to live a normal life. In extreme cases, side effects are so serious they can lead to sicknesses that cause death. Because of this, all side effects should be reported to the health-care provider.

Lactose Intolerance

A common problem for people with HIV is sensitivity to milk and milk products such as yogurt and cheese. This is called being lactose intolerant. Some people are severely lactose intolerant and cannot tolerate anything made from milk or foods with milk in them. Other people are mildly intolerant and can eat things like cheese or small amounts of yogurt, but not pure milk.

Lactose intolerance is often diagnosed by symptoms. If a person is regularly nauseated or has abdominal pain after eating milk products, then he should try to avoid milk products and see if the feelings go away. If they do not, then he should consult with his healthcare provider about other possible causes of the discomfort.

Nausea and Diarrhea

Diarrhea is when a person passes watery stool more than three times a day. Continuing to pass watery stools for longer than a few hours can become a serious health concern, especially for someone with HIV. They lose water and nutrients and can become dehydrated. In some cases, this dehydration can become so serious that a person can die.

A person with diarrhea should continue to eat and drink as long as he does not start vomiting. Since diarrhea causes someone to lose water and nutrients, it is important for people with diarrhea to eat and drink as much as possible. Drinking oral rehydration fluid, fruit juices, and broths can help replace lost nutrients and water quickly.

A person with diarrhea should continue to eat and drink as long as he does not start vomiting.

Tips for eating when nauseated or having diarrhea:

- Soft foods such as mashed potatoes and yams, porridge, and soft fruits (such as bananas, mangoes, pumpkins, and carrots) are easier to eat and digest.
- Peel and cook all foods. This makes it easier to digest and reduces gas in the intestines.
- Avoid high amounts of fats and coffee, caffeinated teas, and sodas.
- Avoid extremely spicy, hot, or cold foods.
- Drink juices, broths, herbal teas, and rehydration fluids to replace fluid.
- Eat small amounts of food often.
- Eat dry and salty foods such as crackers.
- Avoid smells that worsen nausea.

Loss of Appetite and Loss of Weight

ART may cause a person to not feel hungry even though he has not eaten in a while. This and other side effects such as nausea can lead to weight loss. Unwanted weight loss of more than 6–7 kg for adults is a serious condition called *wasting syndrome*.

Normally, the best thing for someone without an appetite to do is eat. There are ways to increase a person's appetite. Dealing with the cause of lack of appetite (if

it is feeling depressed or diarrhea for example) is important. It is also important that a person with HIV choose to eat, even if he does not feel like eating. The best way to stimulate an appetite is to eat.

How to increase appetite:

- Eat smaller meals more often and whenever you feel hungry.
- Add flavors to foods such as squeezing lemon juice over food or adding spices.
- Try many different foods, looking for something that tastes good to you.
- Eat with family or friends instead of by yourself.
- Do not eat large amounts of foods that are difficult to digest, such as broccoli, beans, and lettuce.
- Do not drink soda.
- Chew on dried fruit such as mangos or oranges to stimulate your appetite.

Fatigue

Fatigue is when a person feels tired and weak all the time. He might become tired after doing simple activities that do not make most other people tired, such as walking. A person might feel very sleepy or not have a desire to do any activity. A person can feel like he is too tired to even eat.

Most people feel better with HIV/AIDS medications, but at first ART might make others feel worse. It takes several weeks for the body to adjust to new medications. During this time, increased weakness is normal, but a person should start feeling better eventually.

A person who is tired should try to get enough sleep at night. Naps during the day are also alright if the person is very tired. A person should be active when he feels well, but if he is tired, he needs to rest.

Anemia

Anemia is a common cause of fatigue. Red blood cells carry oxygen from the lungs through the body. *Anemia* is when a person does not have enough red blood cells. Symptoms of low levels of red blood cells include fatigue, weakness, shortness of breath, and paleness. Anemia can be caused by ART medications, especially when they are first started.

A person can treat anemia by increasing the amount of the mineral iron he consumes. Iron pills are available, but the easiest way to treat anemia is often through eating more foods high in iron and vitamin C such as these:

- red meat (deer, beef, etc.)
- eggs
- dark, leafy greens (spinach, collards, etc.)
- dried fruit (such as prunes, raisins)

- mollusks (oysters, clams, scallops)
- turkey or chicken giblets
- beans, lentils, chick peas and soybeans
- animal liver
- artichokes

Bone Loss

Bones are the central support system of human bodies. Bones are porous—they have many tiny holes throughout them. The more holes in a person's bones, the easier the bones break. Bone loss happens naturally as people age and is more common in women than men. Severe bone loss is called osteoporosis. ART causes bones to lose mass faster and can lead to osteoporosis in younger people.

The best way to prevent bone loss is through consistent exercise and a diet of foods high in vitamin D and calcium. Food high in calcium and vitamin D include milk and milk products such as cheese and yogurt, almonds and some other nuts, eggs, broccoli, and some seafood like sardines and salmon.

Neuropathy (Leg Pain)

Nerves are the body's way of communicating with itself. If a person wants to move their hand, nerves take this message from a thought in the brain to the hand and the hand moves. This communication often happens almost instantly.

Neuropathy is nerve damage that results in tingling, numbness, burning, itching, and pain. It occurs most often in the hands and feet, but this damage can happen all over. Neuropathy can be caused by many different things, including certain ART medications. Once nerves are damaged, the damage is permanent, but the symptoms can be reduced. If neuropathy is generalized, it can affect nerves in important organs and cause organ failure and death.

Neuropathy is nerve damage that results in tingling, numbness, burning, itching, and pain, most often in the hands and feet, but this damage can happen all over.

Mild neuropathy can be controlled by exercise and medications such as ibuprofen and acetaminophen (paracetamol). If neuropathy is very severe, a health-care provider might switch a person's ART medication to prevent further damage.

Trouble Sleeping

People with HIV often have difficulty sleeping because of stress, depression, pain, or symptoms of opportunistic infections. ART can cause more problems sleeping, resulting in restlessness and nightmares. Most of the time, these symptoms are short-term and decrease after a person adjusts to his medication.

Liver Damage

The liver filters harmful substances out of the blood and stores important nutrients from foods. All medications pass through the liver. ART medications can damage the liver, especially if the person taking ART is also infected with hepatitis B or C or if a person abuses alcohol or drugs.

Liver damage cannot be reversed in most cases. However, there are things that people can do to prevent liver damage, such as:

- Eat orange and dark green vegetables.
- Drink plenty of clean water.
- Avoid high fat foods.
- Eat healthy fats such as avocados, fish, flaxseed, nuts, seeds, and beans.
- Eat plenty of protein such as meat, eggs, dairy, nuts, and beans.
- Avoid alcohol, smoking, and drugs.

Heart Disease

The heart is one of the most important organs. It pumps blood throughout the whole body to provide nutrients and oxygen. Heart disease such as heart attacks and strokes are a leading cause of death for both men and women worldwide. As people get older the heart grows weaker, leading to these problems. Lifestyle choices such as eating an unhealthy diet, smoking, and consuming large amounts of alcohol and taking medications such as ART can cause the heart to weaken faster, exhibited by heart disease in younger people.

Eating a healthy diet that is low in fat and high in vegetables, fruits, and proteins (such as beans and lean meats) can decrease a person's risk of heart disease. Being overweight is also a major risk factor for heart disease.

It is true that taking ART can cause side effects and may be difficult to adjust to; it is also true that it is life-saving for those affected by HIV. Being on these medications reduces the possibility of transmitting to another person as well. Though it is not a cure, it can extend life indefinitely.

As Christians, we are grateful that God uses medicine and medical science as a wonderful tool to assist His children. We also believe in divine healing and should always pray for complete healing. There have been documented healings of those who were HIV positive and even with full-blown AIDS being healed. It is right and biblical to pray for this. Wisdom would say however, not to abandon ART until such a time as medical tests indicate that healing has occurred.

It is hoped that the information provided in this manual will be of assistance to you as you or those you know journey through this season of living positively with HIV.

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