

PEER EDUCATION Trainer's Manual

**Increasing the Knowledge and
Skills of HIV-Positive Adolescents
and Young Adults to Live
Emotionally, Physically, and
Sexually Healthy Lives**

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Description of the Training Program

The purpose of this training program is to increase the knowledge and skills of HIV-positive adolescents and young people to live physically and emotionally healthy lives and to be able to express their sexuality in a manner that is both safe and satisfying and without shame about their HIV status, sexual orientation, and gender identity.

The training is designed ideally to be conducted by peers (adolescents and young adults living with HI) or near-peers (older HIV-positive individuals who were infected at a young age).

Peers are already engaged in the education and delivery of supportive services to people living with HIV/AIDS (PLWHA) around the globe. Peers are essential educators and service providers, because:

- people tend to trust those who share similar experiences, especially the experience of people living with HIV;
- peer education programs have been proven to improve HIV treatment outcomes for PLWHA;
- community empowerment and advocacy work may be furthered and enhanced; and
- individuals who have been trained by peers frequently report feeling more empowered to take charge or effect positive changes in their lives.

The training includes both didactic presentations and interactive exercises meant to elaborate on and deepen understanding of the didactic portions.

This training program is made possible thanks to a collaborative effort between the International Association of Providers of AIDS Care (IAPAC) and the Pan American Health Organization (PAHO).

Notes for the Trainer

This Peer Education Training Manual is designed to assist HIV-positive adolescent and young adult peer educators and near-peer educators to increase the ability of HIV-positive adolescents and young adults to live well with HIV. While each module is deemed as important, it is up to the trainer to decide how and when to present each module.

The training was designed so that modules could be presented separately, over a series of weeks, or all together over the course of a weekend. The best method will be one that responds to the needs of the training participants. The curriculum is designed to build upon the peer educators' existing knowledge and experiences. The interactive portions, in particular, draw heavily on both the facilitation skills and the lived experience of peers and near-peers.

Manual Design

The manual's format consists of 11 modules covering key topics designed to increase participant's comfort with their HIV status and their ability to navigate their sexuality, their healthcare, and their mental healthcare. Each section is allotted a suggested duration, and in addition to suggestions for didactic presentation, instructions for interactive exercises are included. Interactive exercises are designed to build upon and deepen participants' understanding and comfort with each topic.

Duration

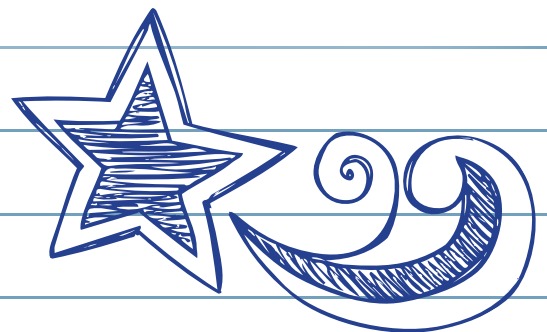
Each section includes the approximate time it will take to cover the information and to conclude each interactive exercise. The entire set of 11 modules can be completed in approximately 11 hours, excluding time for breaks if the training is held over the course of a weekend. You may choose to allow participants to ask questions at any time during didactic presentations or save them for the end of each section.

Learning Objectives

Learning objectives are listed so that trainers know what knowledge and skills participants should gain after completing each section.

Materials Needed

In addition to this manual, trainers will need a flip chart, markers, paper, pens/pencils, and photocopies of relevant sections. PowerPoint slide decks are also available. In order to get participants to come back for each portion of the training, you may wish to use small incentives.



Work for the Trainer to do in Advance

In addition to gathering the materials listed above, trainers should review each section thoroughly. The didactic portion of each module is written as though the author is presenting the training aloud. Trainers may wish to make notes and put each section into their own words, provided that the same key information is covered, but adapted for each audience. Trainers should familiarize themselves not only with World Health Organization (WHO) treatment guidelines, but also with treatment guidelines specific to the country where the training will take place. Trainers will need to prepare relevant sections in *Module 5: Magnetic Love–Mixed-Status Partnerships* and *Module 7: Care and Treatment* so that they are harmonized with local treatment guidelines.

Step-by-Step Instructions

This training should be as participant-focused as possible, with trainers utilizing their wealth of experience, both as peers or near-peers, and as educators to bring life and meaning to each module. In addition, trainers should strive to create a safe space for participants to share their thoughts, feelings, and experiences and to encourage the exchange of information and ideas. There is a recommendation for trainers to close each section with a summary of what transpired over the course of the module and to highlight examples that were elicited during the interactive portions.

Additional Considerations

When you reach the end of the entire set of modules that you plan to use, you may wish to celebrate in some way. This could include certificates of completion, special refreshments, and small gifts.

MODULE 1

Nice to Meet You

(30–40 minutes)



Module Objectives

1. Help participants feel comfortable with this program.
2. Encourage participants' contribution in subsequent modules.
3. Help participants begin setting goals for health and wellness.

Instructions

- This module is designed to help participants get to know one another and to help them feel more comfortable sharing personal feelings and experiences. (This ice-breaker part of the module may be skipped if most participants already know one another well, and the last two exercises in this module incorporated into the beginning of Module 2. Alternatively, the beginning can be used just as an "ice-breaker" using only questions 4, 5 and 6 or variations on them, such as "favorite movies, books, TV shows, etc.")
- Participants will pair up and interview one another. Then using the information they gather, they will introduce their partner to the larger group.
- Pair individuals into groups of two. Ask participants to choose someone they don't know well.
- Give participants about 5 minutes to interview each other using the following questions:
 1. What is your name?
 2. How old are you?
 3. Where were you born?
 4. What is your favorite food, and why?
 5. What is your favorite animal, and why?
 6. Who is one of your favorite musical performers, and why?
- After 5 minutes have elapsed, have participants go around the room and introduce their partners to the rest of the group.

Agreements

Let participants know that you want to create a safe space for learning and personal growth. In order to do that, however, the participants must come to some agreements about the ground rules they will follow to ensure the confidentiality and well-being of all of the participants. Go through these suggested ground rules and any others you think would be helpful and then ask if people want to add others. At the end, ask if people all feel they can agree to follow them.

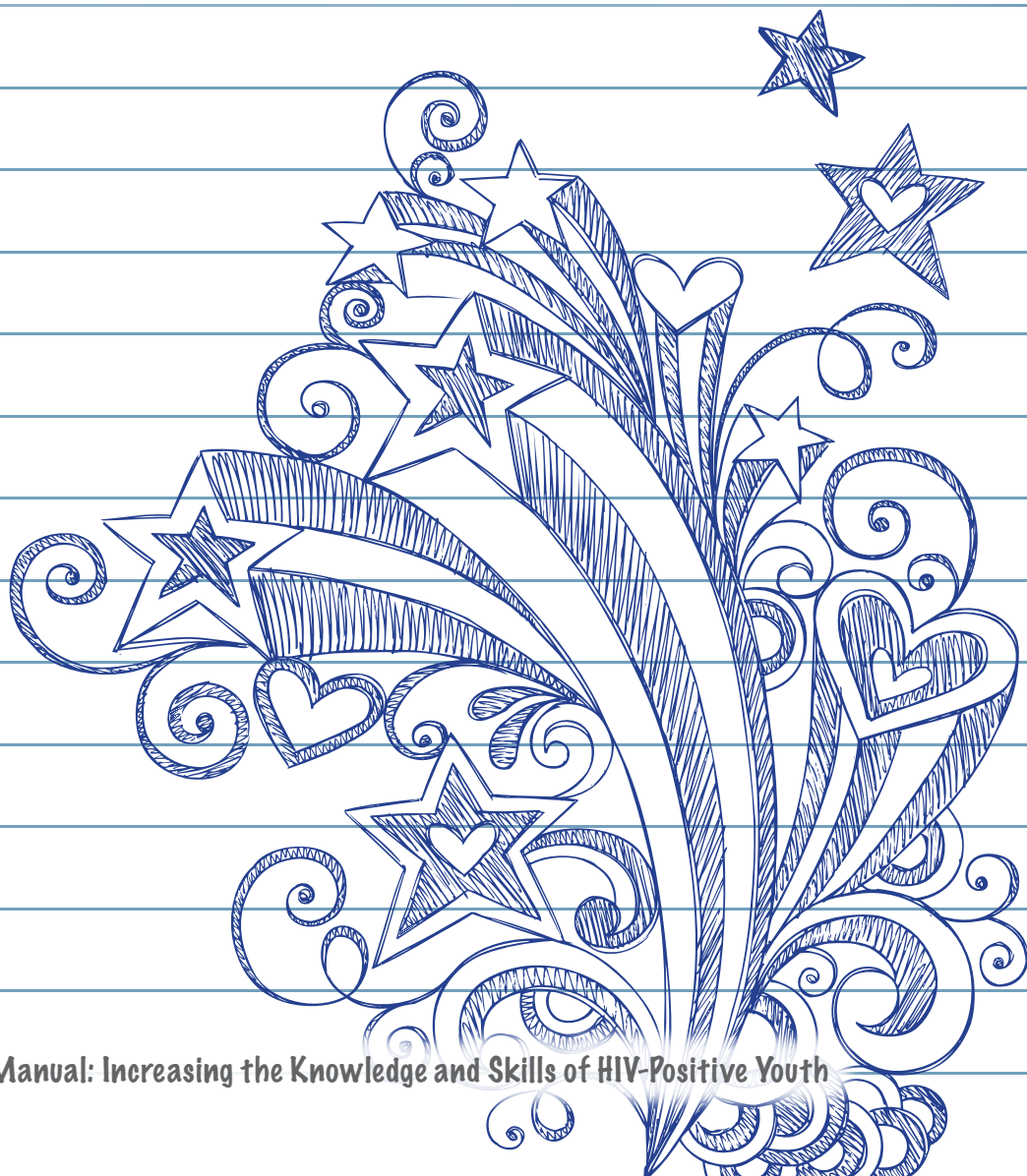
- Keep each other's confidence. What is said here stays here.
- Suggest, don't criticize.
- Try to use "I" statements (e.g. I felt bad when you....) when offering criticism or sharing your beliefs.
- Keep an open mind.
- Stick with it through the hard parts.
- Try to attend every module.
- No cell phones.

Goal Setting

Explain that personal goals are often best reached when we have a sense for what we want to get out of life and what we most want to do and achieve. For this reason, the group will be asked to fill out a goals sheet at both the beginning and the end of the training and to share those goals with the group. Sometimes sharing your goals with others can help you achieve them.

Pass out the following work sheet to participants along with pens or pencils and ask them to take about 5 to 10 minutes to fill them out and turn them into you for safe keeping. Stress that you won't read them and will only keep them safe and hand them out later to compare how people's feelings and views have changed since the beginning of the workshops.

If the training will last over several weeks you may also wish to set up a private Facebook group for the group to communicate with you and others during the course of the training. Instructions may be found here: <https://www.facebook.com/about/groups>. If you set up this group, explain that it is voluntary. Also ask people to keep a journal and make time at the beginning or end of each of the following modules to discuss what they've written in their journals.



MODULE 1

Worksheet

Name _____

What are three things you would like to achieve in the next five years in your school, personal, or professional life?

What do you feel are the biggest obstacles in the way of you achieving your goals?

What would the ideal romantic and sexual life look like to you?

What positive steps can you take now that can lead to a more healthy and fulfilling romantic and sexual life?

Are there any people who don't know about your HIV status that you would like to, or feel you should, tell?

What are your biggest fears of disclosing your HIV status to others?

MODULE 2

We Are All Sexual Beings

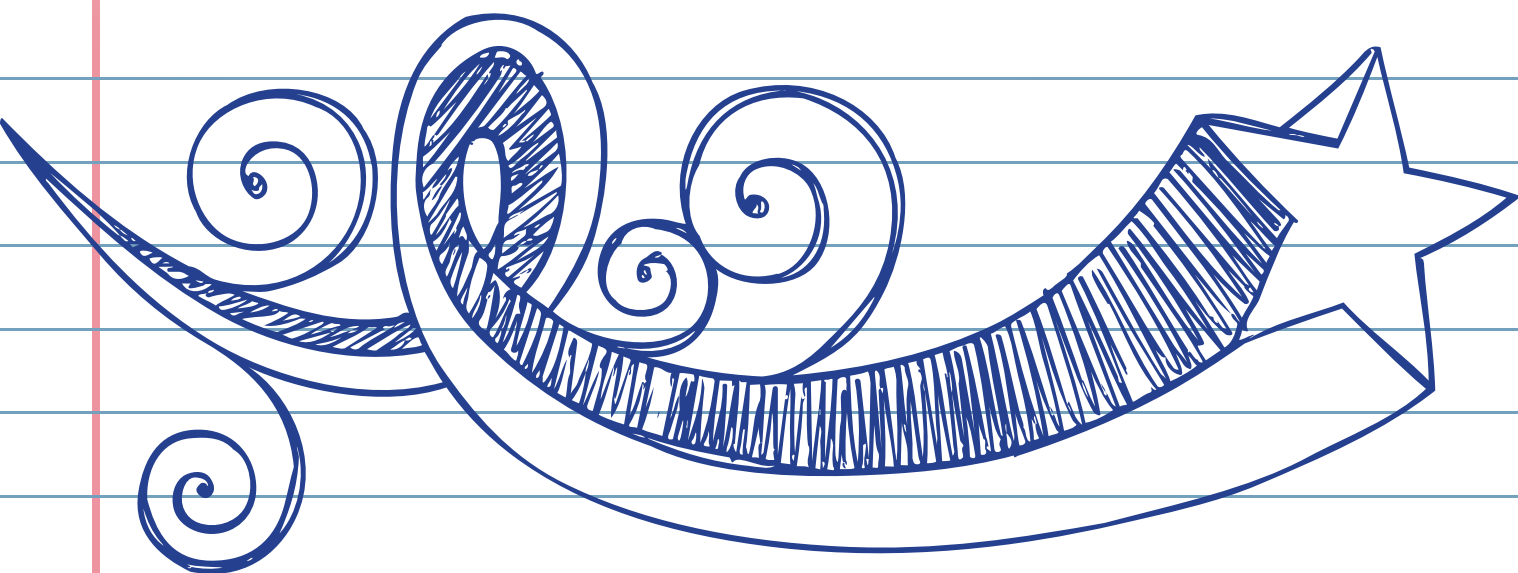
(60 minutes)

Module Objectives

1. Enable participants to describe a variety of healthy and positive ways to process and express their sexual and romantic values.
2. Increase the participants' skill and comfort discussing sex and sexuality with their peers.
3. Help participants feel a sense of support and solidarity with fellow participants.
4. Help participants gain an understanding of methods for becoming comfortable with sexual and romantic choices, even if society, friends, or family disapprove.

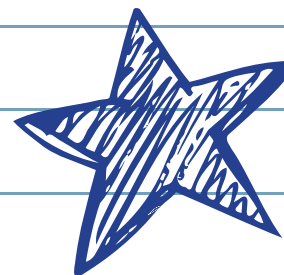
Introduction

- The goal of this session is to make you feel comfortable with, and confident about, the sexual and romantic choices you make.
- Sexual and sensual activities can be among the most pleasurable physical and emotional experiences available to human beings.
- Positive sexual experiences can flood the body with hormones that make a person feel good, both physically and mentally.
- Having sexual feelings is a normal part of becoming an adolescent, and later an adult.
- Unfortunately, our families, friends, and society sometimes have negative judgments about adolescent sexuality—particularly among HIV-positive adolescents.
- It is not uncommon for HIV-positive people to have negative emotions (such as fear, shame or guilt) about their HIV status and about being sexual with others, particularly partners who are HIV negative.
- For HIV-positive people to have fulfilling and gratifying experiences associated with their sexual and romantic choices, they have to transform any negative emotions into positive ones.



Exercise #1—Reframing (30 minutes)

- If there are eight or more people, break the group into two or more smaller subgroups. Provide each with a pad of paper and pens (or more ideally a flip chart and markers). Ask for a volunteer who has neat handwriting to be a scribe. Ask for a volunteer from each group to facilitate asking the questions.
- If the group is fewer than eight people, a single group is fine. Serve as the scribe as people contribute.
- Give the groups 10 minutes to answer the questions. Give them a warning about 8 minutes into the exercise that their time is nearly over so that their scribe can ensure that they have captured and recorded their contributions.
- Ask the scribes to collect entire phrases. For example, if a participant says that her parents think she shouldn't have sex until she's married, the scribe should write that out rather than simply writing, "no sex."
- Ask each group to answer the following three questions:
 - *What negative messages have you heard from friends, family members, or society about sex among adolescents, whether boy-with-girl, boy-with-boy, or girl-with-girl?*
 - *What negative messages have you heard from friends, family members, or society about people living with HIV?*
 - *What negative thoughts and feelings do you think many HIV-positive people have about themselves when it comes to sex and dating?*
- Have each group swap their answers with the group to their right.
- Now ask each group to write out one or more positive rebuttals to the negative statements that were given to them.
- Give the groups 10 minutes to record their ideas with a 2-minute warning before time is up.
- Have each subgroup share their positive rebuttals with the whole group. (This should take about 5 minutes for two small groups and up to 10 minutes when there are multiple groups.)
- After reviewing the positive rebuttals, praise the participants for their work and ideas. Then, ask the group how it feels to hear positive answers to these negative statements. Are these positive statements something they can apply in their own lives? Discuss this for 5 to 10 minutes depending on the size of the group, and their level of participation.



Positive Perspectives on Sexuality

It is Possible to Have Good Experiences with Dating and Sex

Regardless of when and how a person was infected with HIV, a diagnosis can often feel like it will have a dramatically negative effect on your sexual and romantic future. HIV-positive adolescents—both those born with HIV and those infected later—frequently report fear that no one will ever want to be with them in a sexual or romantic way. It's very common to feel this way. Although discrimination is a painful reality, it's not a given. And when discrimination is present, there are useful strategies to apply to the situation.

There is a Lot to Think about When it Comes to Dating and Sex

There are many things to consider with respect to sex and romance, including disclosure, safer sex practices and minimizing alcohol and drugs whenever possible. We will cover these topics in greater detail in subsequent training modules.

It is Possible to Overcome Stigma about your HIV Status, Dating, and Sex

In this training, we will be dealing with overcoming stigma associated with being HIV positive and the relationship between stigma and the natural expression of our sexuality.

What is stigma? Stigma is defined as a mark of disgrace, usually associated with some quality that a person possesses. Some people feel that HIV can have the same effect unless you keep your HIV status a secret. Even when it is a secret many people still walk around with negative feelings about themselves and their HIV status.

The big question is: how do we understand and potentially act on our sexual and romantic desires in a way that is fulfilling and emotionally as safe as possible and that doesn't increase feelings of stigma?

Sex is More than Just the Physical Act

It's important to remember that sex is as much something that happens with your brain as it is something that happens with your body. Though the primary focus is usually on physical activities, some of the most pleasurable parts of sex and romance involve flirting, fantasy, and talking with prospective partners.

One of the benefits of the initial "getting to know you" process with a new partner is that it can give you more time to decide how you want to handle disclosing your HIV status if the person doesn't already know. Flirtation can also actually enhance emotional and sexual pleasure if you do decide to become intimate with a new person.

Sex Can be Safe and Satisfying—If You Decide for it to Be

If you choose to have sex—and that is a big choice to make—it can be loving, safe and satisfying, but above all, it must be consensual. (If you feel forced into having sex with anyone you should reach out to a trusted friend or family member who can help you.) If you do make the decision to have sex, there are some important questions to consider first:

Are You Attracted to and Interested in being Sexual with Your Partner?

It's usually a good idea to express your sexuality only with a partner who you like and to whom you are attracted. Having sex with people you don't like, or to whome you aren't attracted, can result in poor self-esteem and even depression.

Sometimes, though, we may choose partners for different reasons; this is especially true if you are struggling financially and your way of supporting yourself is through sex work. If this is true for you, one of the most important things you can do is make sure you're physically and emotionally safe, and that you choose partners who treat you with as much kindness as possible.

Have You Disclosed Your HIV Status to Your Partner, or Do You Feel that You Need To Do So?

We'll be talking more about HIV disclosure in a later module, but this can be an important consideration before you have sex with someone new.

Have You Discussed Your Limits with Your Partner—The Things You Do and Don't Feel Comfortable Doing?

Talking about sex before you actually have sex is generally a good idea. It might seem more romantic and spontaneous to "just let things happen," but this can be a recipe for misunderstandings and bad experiences. Besides, if you decide to have sex, talking about it first can actually enhance the experience.

Do You Feel Comfortable Slowing Things Down if You Change Your Mind?

Being able to say, "No," or, "Slow down," is especially important if the person you are sexual with has some level of power over you. Maybe they are older, or have more money. Perhaps they have a temper, or they're intimidating in some other way. Whatever the details, sometimes we enter into relationships with people who have a lot of emotional or physical power over us and this can make it difficult to set limits.

If your partner doesn't respect your limits, or constantly puts you down, or is physically abusive in some way, it's probably a good idea to find someone you trust to talk it over. Remember, there are professionals and groups that you can turn to if you need help.



There are Risks and Rewards to Meeting Someone New

Some of the most basic questions that most people have when getting to know someone on a romantic or sexual level include:

- Are they physically attracted to me?
- Do they like my personality?
- Do they share my values, interests, and sexual desires?

With HIV there's inevitably a fourth question:

- If my prospective partner knows that I'm HIV positive, will they still be interested?

That's a tough question to ask because some people will lose interest, or may initially have a negative reaction before coming around.

What's very important to keep in mind about such people is that their prejudice is based on ignorance and stereotypes and not on an accurate depiction of your worth and desirability. It literally has nothing to do with you personally.

Let's face it though. Rejection is hard no matter the reason, but it can be particularly painful if it's just because you happen to be HIV positive.

Fortunately, most people with HIV, including HIV-positive adolescents, ultimately find partners who love them and desire them no matter what a blood test says.

When it Comes to Romance and Sex it's Important to Know Your Own Values, Wants, and Needs

A value is something that has worth; that means something to you. In the context of sex, you might value an open relationship, or monogamy.

There are many legitimate ways to approach your own sexuality. You may only want to have sex if you've progressed to a very serious point in a relationship, perhaps even marriage. Or you might be comfortable acting on your sexual desires with more casual partners. Whatever your approach, what's most important is to stick to your values.

Sometimes it can be tempting to settle for less than what we want, particularly when we don't feel very good about ourselves. The unfortunate consequence of this is that while we might feel good in the moment, it often makes us feel worse in the long run.

When it comes to dating and sex most of us want to be honest and want to be treated honestly; most of us wish to be kind and want to be treated kindly. The following exercise will help you identify and explore your own values.

Exercise #2—Understanding and Asserting Your Values (20 minutes)

Introduction to the Exercise *(Share the following as an introduction)*

Each of us has the right to be treated well and in a way that is consistent with our values. Likewise, each of us has a responsibility to act in a way that is consistent with our values and to explicitly share our values with the people we care about.

Next we're going to identify our values and the things that sometimes get in the way of acting consistently with our values, or from being treated well.

- First, ask the group to share examples of values that people may have (e.g. honesty, faithfulness, hard work, kindness, etc.), both in terms of how they want to behave and how they want to be treated. Provide an example if people need it to get started. Continue for approximately 5 minutes.
- Then write (or have prepared) the following three questions on a flip chart, white board or something similar:
 1. What strongly held values guide how you want to behave toward other people?
 2. What strongly held values are important to you in a relationship or sexual partnership?
 3. What things get in the way of either behaving the way you want to or from asking to be treated the way you'd like to be treated?
- Pass out pens and paper and ask people to take about 10 minutes to write down their answers. Walk around and help people if they struggle to identify their values.
- Next, ask people to share their values, to explain why they're important to them, as well as the obstacles that can get in the way of either acting in their own interest, or demanding that other people treat them well. Continue for approximately 5 minutes. If a particularly rich discussion begins to take place, and you have the time, you can go longer than 5 minutes.
- Finally, ask the group to explain why it's important to understand their own values and to be assertive about those values with romantic and sex partners. Continue for about 5 minutes, and then complete the module by summarizing the conversation that just took place.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 3

Who, When, and How to Tell

(90 minutes)

Learning Objectives

1. Help participants list which friends, family, and sexual partners they'd like to disclose their HIV status to, and provide methods for having that conversation.
2. Help participants identify ways to talk about sex and sexual activities with family and friends.
3. Help participants gain more confidence about disclosure and learn how to deal with negative disclosure experiences.

Topics to Cover

- The benefits and disadvantages of disclosure in non-romantic/sexual relationships
- The benefits and disadvantages of disclosure in romantic/sexual relationships
- Techniques of disclosure
- The legalities of disclosure

Introduction: To Tell or Not To Tell

You may have just learned that you are HIV positive, or you may have known for some time. Either way, there are going to be situations in your life where you're going to have to decide whether or not to share your HIV status. This isn't always an easy decision to make. In fact, disclosing your HIV status can be one of the most frightening things you can do. But the collected wisdom of other people living with HIV can be very helpful. You'll also be able to share your own wisdom and experience with each other.

Disclosure - What it is and Why is it Important?

What is disclosure? It simply means telling someone something about yourself that they don't already know. In this case, we're talking about HIV, so HIV disclosure is telling someone else that you're HIV positive.

Disclosure Basics - Some Benefits

Disclosure is important for a number of reasons. First, in the best case, it can ensure that friends and family members can provide the kind of emotional and practical support that is helpful when living with HIV. Living with a secret, especially one as big as HIV, can eat away at your self-confidence and lead to serious depression and anxiety. Finding a loving and supportive person to talk to about your experience living with HIV can be useful.

Disclosure to romantic and sexual partners is also important. With romantic partners, HIV can be such a big thing for those living with the virus that telling partners can ultimately be a relief when people respond well to the news. With sexual partners there may also be laws about disclosing your HIV status that you should be aware of, and disclosing can help to ensure that you don't put your partners at risk.

Disclosure Basics - Your Healthcare Providers

Disclosing your HIV status to your healthcare and dental providers will allow them to give you the best possible treatment. They should already be using something called “universal precautions.” This means that providers should be practicing medicine and dentistry as though every patient could be infected with HIV or other infectious diseases—not just you. This might mean they wear gloves and masks as a precautionary measure. For this reason, telling your healthcare or dental provider is not so much about protecting them or other patients as it is to ensure that you get the best health and dental care that you can.

There are certain diseases and conditions that are more common for people living with HIV, particularly people with weakened immune systems, and it can be very helpful for providers to know your status when treating you.

Disclosure Basics - Work and School

Most of the time, there is no need to inform employers, teachers, or school administrators about your HIV status, but in some cases it might be helpful if you need to explain why you have to go to appointments with doctors or other providers to help you live well with HIV.

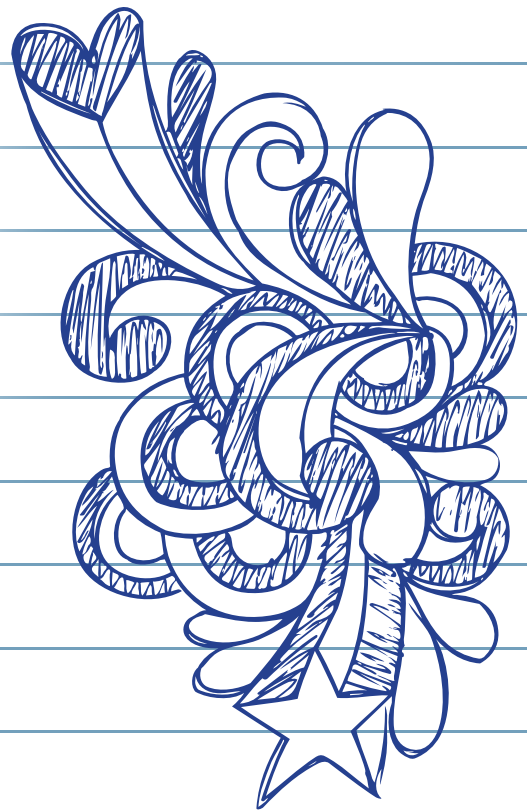
You should be cautious about telling employers and school officials, however, unless your particular city, province, or country has legal protections in place to guard against unfair treatment due to medical conditions such as HIV.

Interactive Exercise #1 - Personal History

(10–15 minutes)

In this section, participants should be encouraged to share some of their personal experiences with disclosure. Ask for several volunteers to share their experiences, whether they are good or bad. It can be helpful, however, if at least one person shares a gratifying experience. (You may need to encourage sharing.)

Allow time for at least three or four people to share their experiences. Next, ask people to share their thoughts on both the benefits and disadvantages of disclosing their HIV status.



Disclosing to Family, Friends, and Sex Partners

Disclosing isn't necessarily easy, regardless of how or when you were infected with HIV. For those who got infected as adolescents, there are often feelings of shame about the way that they became infected. For those infected as babies, there can also be shame about HIV, and about how their parents were infected.

In fact, a study published by the Pediatric HIV/AIDS Cohort Study found that adolescents infected at birth were somewhat less likely to disclose their HIV status to sex partners, even those with whom they had unprotected sex. In this study about one out of three did not disclose their status with their first sexual partners, and this was largely due to fears about how people would react to the fact that they are HIV positive.

Other studies, however, have found that the vast majority of people who become infected do take steps to protect their partners. Either way, disclosure remains a significant issue.

If you do disclose your status to anyone, there are important things to consider first. This includes whom you should or shouldn't tell, why you feel you want or need to disclose, and what you hope to get out of disclosing. Deciding when to make the disclosure, and how you want to say it, is also key. Before you disclose your status, consider some of the following points:

Who to Tell

Some people decide at a certain point in their lives that they will be very open about their HIV status, even with strangers and employers. Some even go on television, appear in news stories, or openly blog about their experiences. Others operate on a "need to know," basis, only telling a few people about their HIV status and asking those they do tell to keep that information secret from others. Neither way is right or wrong, and there are benefits and disadvantages to each.

Being open about one's status can be an extremely potent way of taking the shame and stigma out of living with HIV. It can be a way of saying to the world, "Hey, HIV isn't such a big deal, and if you can't accept me, then that's your problem, not mine."

However, being so open about your HIV status can have disadvantages. It can take away your ability to control who knows about your status, how they find out, and how much they know about your personal story. Gossip is an unfortunate reality in life, and if it will cause you stress to not be certain who does and does not know about your HIV status, then being open and public about your status may not be a good idea.

In fact, limiting whom you tell, and how people find out, can be a source of personal empowerment and help you feel in control of your life. Disclosing places you at risk of rejection and discrimination, and it could also jeopardize your social life, your work or school life, or even your personal safety in some cases.

For those who find out they are infected while in primary relationships with another person there are different considerations. First, it is possible that their partners are HIV positive and don't know their status. Second, if their partners are not HIV positive, then steps must be taken to reduce the risk of HIV transmission.

If you become infected and have sex partners other than your primary partner, this can be a very difficult conversation to have, but it's an important conversation nonetheless. None of us wants to be responsible for passing on the virus to others, but people certainly have a right know that they have been exposed to HIV. We will talk about how to have this conversation, but it's a conversation that's probably necessary to have unless it would put you at physical risk. (Bear in mind, some partners might grow violent when these disclosures take place, and it's important to minimize that risk.)

If, like many people with HIV, you prefer to disclose your status to some people and not to others, there are some things you should consider before having the conversation.

Why Tell?

Ask yourself, why does this particular friend, family member, or sex partner need to know your HIV status? Do you need their emotional or practical support? Are there physical or mental health issues you're dealing with that require the support of someone else? Does keeping HIV a secret feel like it will harm the closeness you currently share with your friend, family member, or partner? Do you need to change your normal sex practices in order to protect your partner if they are not infected?

What do you hope to get out of making this disclosure? Are you hoping for emotional support? Unconditional love? Concern? Are you hoping that they will be able to offer you practical support, such as giving you money or a place to live, or help with things like getting to the doctor or paying for medication? What do you expect their reaction might be?

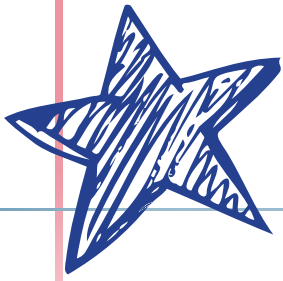
Understanding your hopes and expectations before making a disclosure about your HIV status is very important as it can affect what you say, and when you say it.

What to Tell?

As important as it is to determine whom you want to tell, it's equally important to determine what you want to tell them. Are there details you want to keep to yourself, even if they ask? Have you thought about how much they might want to hear from you?

Remember that you've possibly had at least a little bit of time to get used to the fact that you are HIV positive. The person you tell might also need some time to come to terms with it. This can affect how much you tell them at first.

Do you want to get into how you became infected? Are you prepared to discuss this? In some cases, especially for gay men and transgender women, coming out about their HIV status may mean coming out about their sexuality or gender identity. For those who've injected drugs, coming out about HIV may mean coming out for the first time about drug use. How much does the person you are telling already know about these things? How might knowledge of these things affect how they treat you or feel about you?



Telling a primary partner may result in disclosing that you have had sex with other partners, or used injection drugs. Sometimes you might have had unprotected sex with a new partner before telling them your HIV status. Disclosing this information can ultimately risk not only your emotional well-being, but also your physical well-being. For this reason, it is important to think carefully about when, where, and what to discuss.

One of the most challenging things about disclosure is that it isn't always possible to predict how people are going to react to you. People with HIV who have disclosed to friends, family, or sex partners can share how they have sometimes been surprised by people's reactions. Those they expected to have negative judgments have sometimes been incredibly loving and supportive. Unfortunately, the opposite sometimes happens and people we think will be supportive can react negatively, at least at first. Thus, disclosure always carries at least some risk, and it's best to remember this when considering what to tell.

Here is some advice that the HIV-positive staff members at AIDSmeds.com, among others, have provided:

- Easy does it. In most situations you can take time to consider who to tell and how to tell them.
- Keep it simple. You don't have to tell the person every detail.
- You have a virus. That doesn't mean you've done anything wrong. You don't have anything to apologize for simply because you are HIV positive.
- Consider whether there is a real purpose for you to tell this person or if you are simply feeling anxious and want to "dump" your feelings.
- People, especially those we may have placed at risk of infection, have a right to have their own reactions and may need time to respond in a more positive and supportive manner.
- Telling people indiscriminately may affect your life in ways you haven't considered, especially legal considerations.
- Having feelings of uncertainty is normal. Take deep breaths before, during, and after disclosing your status.
- Your friend, family member, or sex partner may have strong feelings when learning about your HIV status and might want support as well. This can be particularly true for parents and best friends and those with whom you've had sexual relations. Think ahead of time whether you feel comfortable turning to them for support.
- There's no perfect roadmap for disclosure. Trust your instincts, not your fears.
- Whatever the response you receive in a specific situation, and even if it doesn't go the way you'd hoped—at least at first—you are going to survive this situation, and your life will go on.
- Millions of others have had to deal with this experience and they've gotten through it. You will too.

When and Where to Tell?

Let's walk through a situation that is common, but probably not the best way to inform a friend, family member, or sex partner:

You've both taken the bus home from somewhere and you are walking through your neighborhood. You both have things you have to do very soon and you blurt it out. While it might seem "safer" to have an excuse to not have much time to get too deeply into things, this really only defers a potentially heavy conversation for another time and almost ensures that things will be a bit awkward and strained until you actually get the time to talk in the future.

Instead, you may want to wait until you know you'll both have free time and can talk uninterrupted for at least 20 or 30 minutes, or even longer. Trust your gut, both about what you need and how you think the conversation will proceed in the most positive manner.

How much privacy do you want? You may not want to have this conversation face-to-face, and be forced to deal with their reaction in person. If so, have the conversation on the phone.

If you feel a strong sense that things will likely go well, then have the conversation in person, but make sure that you will have privacy. If at all possible, make sure that other people won't interrupt you while you're talking.

Generally, you will have time to make the decision about when to tell a friend, family member, or a new romantic partner. But one type of person you will likely want to tell as soon as possible after finding out your status are current or very recent sex partners, or injection drug using partners. (This disclosure is less urgent if you've not had unprotected sex or shared equipment with them.) But even with current and former sex or drug using partners you'll want to ensure that you can speak to them without interruption.

Dealing with Negative Responses

First of all, breathe! Our brains and bodies are equipped with something we call the "flight or fight" response to stress. What this means is that every part of our bodies, when faced with danger, is prepared to either run away very quickly, or to fight to protect ourselves. The thing about stress is that we can actually override that fight or flight response with just our breathing.

So, if you're about to walk into a stressful conversation, such as a disclosure conversation, or if the person doesn't act the way you wanted, we can literally change our emotional and physical responses simply by changing the way we breathe.

Here's how it works:

Interactive Exercise #2 - The Power of the Breath (2–5 minutes)

Instruct participants to stand up or sit upright. Tell them to close their eyes and then take a deep, slow breath, concentrating on taking the air into their lungs. Tell participants to hold the breath for at least three seconds, and then to very slowly let the breath out through their mouths as though they are whistling.

Have the group repeat this three times. Then ask participants if their bodies feel different. Ask them if their minds feel calmer, if they feel both more alert, but also more relaxed. Ask people to share how it made them feel and whether they think this could be a helpful process both before disclosing their status to someone, and also if the person doesn't react well.



Telling a Current (or Former) Sex or Drug Using Partner

One of the most difficult people to tell about our HIV status is a person we've had sex with, or shared injection equipment with. This is especially true if we knew our status before we had sex or used drugs with them.

One of the most important things to remember walking into these conversations is that the person deserves the right to have a reaction. This may be shocking news to them. We don't have to allow ourselves to be mistreated, but expecting the other person to have either no emotional reaction, or only a positive and supportive reaction, is asking quite a lot.

For this reason, it can be very helpful to reach out first to a very trusted friend or counselor to talk through what we want to say and how we want to say it, as well as to prepare for a potentially emotional and negative reaction.

Another useful tool is to write out what you want to say in the form of a letter. In some cases, it can actually be good to give your partner that letter in person and ask them to read it before you talk. This can allow you to get out the most important information before the person begins reacting.

Because of HIV criminalization laws in some provinces, states, and countries, where you can get in trouble for not disclosing your HIV status if you knew it before the act, you will want to be very careful about what you say in this regard.

(Note to facilitator, explain HIV disclosure and transmission laws for your province, state, or country).

Honesty is important in any relationship, but your own well-being is also important. Think ahead about what you suppose your current or former partner might do, and act accordingly.

Telling a Friend or Family Member

Very close friends and family members may also have their own emotional reaction, though often for different reasons than a current or former sex partner. For some, it might be a shock that you have engaged in behaviors that put you at risk for HIV. If you were infected as a baby, it could simply be a shock that you've known for so long and that you've kept something so important a secret. Some may have ignorant notions about HIV and about people who are infected. In some cases, the negative reaction may be simply based on the grief your friend or family member might feel about the news.

As with current and former sex partners, it can be important to be prepared to let your friend or family member have space for their own reaction. Once again, you don't have to let someone mistreat you, but you may need to give him or her time. As much as you might want and need support, it could prove difficult for some people to give you that support right away.

Telling a Prospective Sex Partner

Let's say you're chatting with someone online, or that a new person wants to go out with you, when do you disclose and what do you say?

Some people take the approach that it is better to be out about their HIV status right away and that anyone who isn't interested isn't worth spending time on.

With sex partners, there is the complication both about the sexual acts you engage in, and also the legalities involved.

In terms of sexual behavior, from one perspective there really is no need to disclose if you don't place your partner at risk. We'll talk later about the most and least risky behaviors that might result in HIV transmission. But if you're engaged in very low-risk behaviors, is it your responsibility to disclose your HIV status, especially if disclosing might place you at risk of rejection?

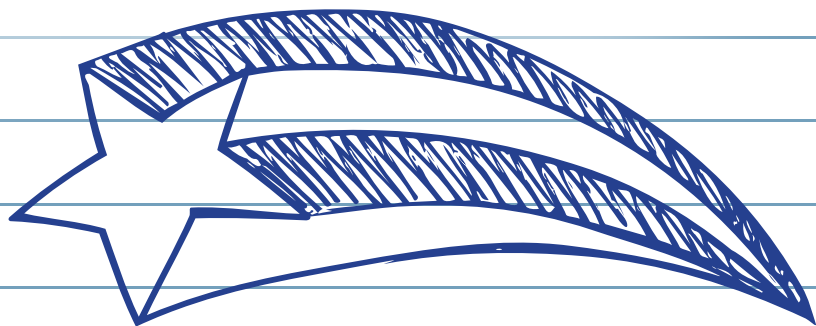
Different people have varying opinions about this. Some people feel that it's up to your sex partners to protect themselves, and that as long as you take all reasonable precautions, you don't owe it to them to disclose. Other people feel it's always the HIV-positive partner's responsibility, and many HIV disclosure laws are based on this belief. In those laws, no matter what you actually do, if you have any kind of sex with someone it's your responsibility to disclose your HIV status before you engage in any sexual behaviors. Failure to do so can result sometimes in severe legal penalties.

The focus of this module, though, is on negative reactions to your disclosure. In some cases, especially when it comes to online dating and hook ups, people sometimes explicitly state that they don't want to connect with people who are HIV positive. They may use terms like "clean only" or "disease-free, you be too." This rejection can cause you to feel discriminated against and stigmatized, which can result in depression and anxiety.

When you've met someone who hasn't explicitly stated that they don't want to hook up with or date someone who is HIV positive there are still the risks of negative reactions. In fact, it's far too common that the person discloses only to have their prospective partner tell them that they no longer feel comfortable with continuing the sexual or romantic relationship.

When this happens it's important to keep a few things in mind. First, how much does it bother you that this was the person's first response to you telling them of your HIV status? If they come around and later decide that they want to continue the relationship, would you still want to be with them?

If the person doesn't come around, how prepared are you to accept that news? Have you reached out for support ahead of time? Do you have a group of HIV-positive peers, or a trusted friend or counselor who can help you deal with this kind of rejection? Some people are fortunate, and never have to deal with this kind of rejection, yet others deal with it many times. Unfortunately, it's not always easy to predict. Being prepared for any outcome, and having support is always helpful.



Interactive Exercise #2 - Role-Play (20 minutes)

- Prepare slips of paper with one of two scenarios written down:
 1. You've disclosed your status and received a negative reaction from a friend or family member.
 2. You've disclosed your status and received a negative reaction from a prospective romantic or sexual partner.
- Put these slips into a hat or bowl and distribute them to all of the participants.
- Next, pair participants into duos. If there is an uneven number, pair up with the odd person out. Ask the participants to take turns using the role-play scenario they received.
- In order to get the subgroups going, and to increase the comfort of the participants, ask one of the most outgoing participants to do a first role-play in front of the whole group as an example.
- Give participants about 8 to 10 minutes to conduct their role-play. When this is complete, ask the group as a whole to discuss their experiences with the role-play, how it relates to their own fears or personal experiences, and how they feel they have learned to respond to negative reactions to disclosure.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 4

Sexual and Gender Identity

(60 minutes)

Learning Objectives

1. Participants will be able to describe the range of sexual and gender identities.
2. Participants will be able to describe the personal and societal oppression that often comes along with sexual and gender identities that are outside of what is considered to be the norm.
3. Participants will understand how stigma and social oppression around HIV status is very similar to that of sexual and gender identity.
4. Participants will be able to describe positive attributes of sexual minorities.

Facilitator's Note

This is important information to be shared about the range of sexual expression and sexual and gender identities regardless of who your audience happens to be. That said, there is a depth of discussion that may be easier to attain when the majority of the group members are similar in terms of sexual orientation and gender identity. This is especially true when participants don't know one another well. For this reason, we suggest two different ways to conduct this section. The first is where the majority of the group members identify as heterosexual and not as a transgender person. The second is where the majority are men who have sex with men and/or are transgender people. The primary difference is in the exercises, thus, the educational portion will be the same for both.

Sexual and Gender Identities is Complex

Sexual and gender identities are both complex, and they're determined not only based on our sexual and romantic desires, or how we view our own gender, but also on how our culture shapes us. In some cultures, most men who have sex with men identify themselves as "gay" and only rarely have sexual or romantic relationships with women. In other cultures, very few men who have sex with men would identify as gay and most would ultimately end up in primary relationships with women. While some of this has to do with desire, a great deal of it also has to do with the way the culture at large feels about sex between men.

It's similarly complex when it comes to gender. Our "cis-gender," which is the biological sex we were assigned at birth, may be totally consistent with the gender we feel we are. If you were assigned a male gender at birth and you feel like a male, that's one form of gender identity. There are some people assigned as male at birth, however, who feel from their earliest days like they are female or who don't feel completely male or female. It is usually only as adolescents or adults that they can begin to express themselves and define themselves as something other than male. Some people don't choose a specific gender or have identities that are much more fluid when it comes to gender.

When it comes to sexuality and gender, the binary we are used to (e.g. boy is born a boy and loves a girl who is born a girl) doesn't work for everybody. The various combinations on this story are both rich and important, and they are a valuable and legitimate ways to be in the world.

Also when we talk about gender we will be using two words with similar, but different meanings. Your gender relates to how you view yourself as either male or female (or neither!), while sex refers to the biological sex you're assigned at birth.

Let's start by unpacking some of the basic meanings around sexuality.

Heterosexual

In this case, the person identifies himself or herself as predominantly attracted to a different sex or gender for sex and relationships. Studies have shown, however, that at least some percentage of people who identify as heterosexual do sometimes have sex with people of the same sex. In some cultures, this appears more likely among women and in others it is more likely among men. Because sexual surveys can be very difficult to do, and because homosexual sex is still so stigmatized, particularly in very traditional or religious cultures, there's a lot we still don't know about the variety of sexual experiences around the world.

Bisexual

In the case where people identify as bisexual, they usually say that they are attracted to both sexes and genders. Some people may have sexual relationships with one sex and romantic relationships solely with another. For instance, a bisexual male may often have sexual experiences with men, but predominantly have romantic relationships with women. The opposite can be true, however, for both sexes. Some people who identify as bisexual may never act on their attractions with both sexes, and will only have sexual and romantic relationships with a single sex.

Gay, Lesbian, Homosexual, or "Same Gender Loving"

In this case, people say they are predominantly attracted to the same sex or gender and tend to only have romantic and sexual relationships with those who are of the same sex or gender. In many cultures this is as much of a cultural identity as it is a sexual orientation. What that means is that people develop an entire cultural way of being in the world that is defined by the fact that they typically are only attracted to or have sex with people of the same sex or gender. Interestingly, heterosexual people have exactly the same kind of cultural identity, but because it is the "normal" way to be, straight people don't typically see themselves as having a "culture."

Undefined and Gender Queer

Some people reject sexual orientation labels and don't like to be called one thing or another. Their actual sexual behavior may range on the spectrum from homosexual to heterosexual and the presentation of their gender may be very stereotypical or contrary to usual expectations.



More about Sexuality

It's this last point that is very important to grasp when we try to understand the practice and definition of sexuality in human beings. Some people identify themselves based on the kind of people they have sex with, while others don't. Though it can be confusing, neither way of living your life is inherently better than another, though for just about anyone it is helpful when your behavior matches your beliefs and values. Conflicts between beliefs and behavior can have negative consequences. Those negative consequences can include depression and anxiety and difficulty achieving satisfying romantic relationships.

It should also be stated that sexual identity may be fluid and may change over the course of a lifetime. Some people know at a very young age that they are primarily attracted to members of their same sex. Others don't realize this until they become adolescents or even older adults. Also, some people may identify as gay or lesbian for some period of their lives and then later as bisexual or straight or vice versa.

How Common is and How Do Societies Deal with Homosexuality?

Though experts suggest that the overall number of people who exclusively have sex and relationships with people of their own sex is small, perhaps three percent or less in most cultures, how the issue gets dealt with has changed a great deal over the past several decades, especially in higher-income countries in Europe, North and South America, and Australia.

Whereas people who had homosexual relationships once worked diligently to keep those relationships a secret, it is now quite common in some cultures for gays, lesbians, and bisexuals to be socially open about their desires and relationships. This is called being "out" or "coming out." People who are homosexual, but don't share that information with family members, friends or school or workmates are often referred to as "being in the closet" or "closeted."

In those cultures where people can safely come out about their status and gain the social support of their peers, this has been linked to fewer problems with depression and serious mental illness than people who keep that part of their lives a secret from most people.

Some Notes about Gender Identity

Transgender (or just "Trans") is an umbrella term that refers to people who identify themselves and express themselves as a gender different from the sex they were assigned at birth. As modern transgender culture has developed, and as transgender persons have become more empowered and organized, these individuals have begun to more formally express their preferences in how they are spoken of and described. Following are some basic principles outlined by the Lesbian, Gay, Bisexual and Transgender Community Center in New York City:

Some people who express themselves and appear to have a gender identity different than the sex they were assigned at birth don't necessarily identify as transgender. That's important to remember and we shouldn't make assumptions.

Transgender persons may choose to never use hormones or surgery to cause their bodies to conform to the gender they believe is more genuine.

Some trans persons prefer to identify as “genderqueer” and see themselves as either between genders or as neither a man nor a woman. Genderqueer individuals may not even identify as a transgender person.

Interestingly, many traditional cultures once accepted, at least to some degree, people who didn’t conform to the sex they were born with. People with gender expression considered different than the norm had a place in society and could live in many cultures without a fear of violence and discrimination. In fact, some indigenous cultures sometimes revered people with non-traditional gender expression as religiously and culturally powerful.

In more recent decades, non-traditional gender expression has become much more stigmatized and transgender persons often find themselves the victims of violence, employment and housing discrimination, and societal rejection.

How Common are Transgender Persons and How Do Societies Deal with Differences in How People Express their Gender?

There has been less research on gender identity than sexual orientation, so it is difficult to determine how many people have a gender identity different than the one they were assigned at birth. This is especially true because of the stigma associated with not conforming to your assigned gender, and the fact that not all transgender persons are able to change their gender expression in a more public or formal manner.

As with sexual orientation, however, in higher-income countries transgender persons are now able to live more openly and are beginning to gain social and legal protections from discrimination.

Legal and Human Rights Issues around Sexual Orientation

(NOTE: Because legal issues can vary a great deal from country to country and province to province, it may be useful for your workshops to contact a local advocacy or legal group that deals with gay, lesbian, bisexual, and transgender issues so that you may provide information that is most relevant for your participants.)

Because homosexual acts are so stigmatized in many cultures and locations, there are often laws in place that forbid and punish those acts. These are usually called sodomy laws. In some countries, violating sodomy laws brings only minimal punishments, or the laws aren’t regularly followed. In other countries the punishments can be as severe as the death penalty. No matter the severity of the punishment, however, legal sanctions against homosexuality have resulted in significant oppression for many gay, lesbian, bisexual, and transgender people around the globe.

Similarly, there are often no legal protections in place to guard against discrimination against people who live openly as gay or lesbian. These can include the risk of being fired from your job or kicked out of your home simply for being gay, lesbian, bisexual, or transgender. In countries that do not legally recognize relationships between two men or two women, gays, lesbians and bisexuals may be forbidden from visiting a hospitalized partner, and they might be taxed more heavily if one of them dies and tries to leave money, a house, or other property to the other.

In recent years, a number of countries, including countries in Europe and Latin America, have removed discriminatory laws and some have even passed domestic partnership or marriage laws that honor relationships between two men or two women.

Interactive Exercise #1 - Stereotypes (15 minutes)

This exercise is designed for groups where most of the participants would likely identify as heterosexual and where few would identify as transgender persons. In groups where there are gay, lesbian, bisexual, transgender or queer (LGBTQ) participants and they are open and comfortable talking about their sexual orientation or transgender status, add a second half to the exercise (an additional 5 to 10 minutes) asking those members to discuss the kinds of oppression and discrimination they have faced in their lives.

Preparation

Cut up paper into small pieces

Exercise

- Pass out the small pieces of paper, giving each participant at least three or four slips of paper and a pen or pencil. Ask participants to take a few minutes to write down stereotypical beliefs of LGBTQ persons and to then fold the slips of paper up and put them in a bowl or hat.
- After everyone has completed filling out their strips of paper and has put them in the bowl or hat, select slips one by one, read them out loud, and then ask the group to comment on which groups might hold that particular belief about LGBTQ people, why they might, and how that belief is not often true. Go through the bowl, skipping over those that are redundant.

Interactive Exercise #2 (15-20 minutes)

This exercise is designed for groups where most, if not all, of the participants are openly LGBTQ.

- Break into groups of two or three at most. Distribute paper and pens or flip charts and markers.
- Ask participants to interview one another and ask them to document some of the most offensive things they've read or heard about LGBTQ persons. Give people about 5 to 10 minutes to complete this task.
- Next, ask participants to state the offensive things they've read or heard. With each one, stop the group and ask for examples of what a person could say or write in response to these offensive messages.
- Then ask the participants to interview one another, and ask them to write down the most affirmative and accepting things they've read or heard about LGBTQ persons in a public forum, whether directly, from a friend or family member, or on, say, a TV show. In particular, ask participants to identify public writers or other figures who've said affirming or accepting things about LGBTQ persons. Give people about 5 to 10 minutes to complete this task.
- Ask the participants to report back on these affirmative messages and stop at each point to survey the group about their feelings about these affirmative messages.

Interactive Exercise #3 (10-15 minutes)

This exercise is designed for groups where most, if not all, of the participants are openly LGBTQ, and is a companion piece for Exercise #2, but more specific to HIV.

- Provide paper and pens or pencils to all participants and ask them to write down negative messages they have heard about people living with HIV from other LGBTQ people, whether in person, online, or in the media. Give them approximately 5 minutes to write down these negative messages.
- After people have written down these negative messages, ask people to go around sharing them with the larger group and with each message, ask how the group would like someone – whether another HIV-positive person or a noted personality – to respond to those negative messages, either privately or publicly.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 5

Love and Latex: Safer Sex

(45-60 minutes)

Learning Objectives

1. Participants will be able to place the concept of safer sex in a self and life-affirming context, one that is not shame-based.
2. Participants will be able to describe multiple methods for reducing the risk of ongoing HIV transmission, super-infection, and other sexually transmitted infections (STIs).
3. Participants will be able to demonstrate improved safer sex negotiating skills and strategies.
4. Participants will be able to properly use both male and female condoms.

Introduction

Living with HIV can sometimes put you in an awkward position when it comes to sex and romance. On the one hand, we have no wish to cause harm to other people. For that reason, most of us would do anything we can to avoid transmitting HIV to our partners. If things were simple, we would simply let everyone know that we are HIV positive and always take every precaution to avoid transmission. Sex and relationships are complicated, however, and HIV can be very stigmatizing, so what should be simple is sometimes not so easy.

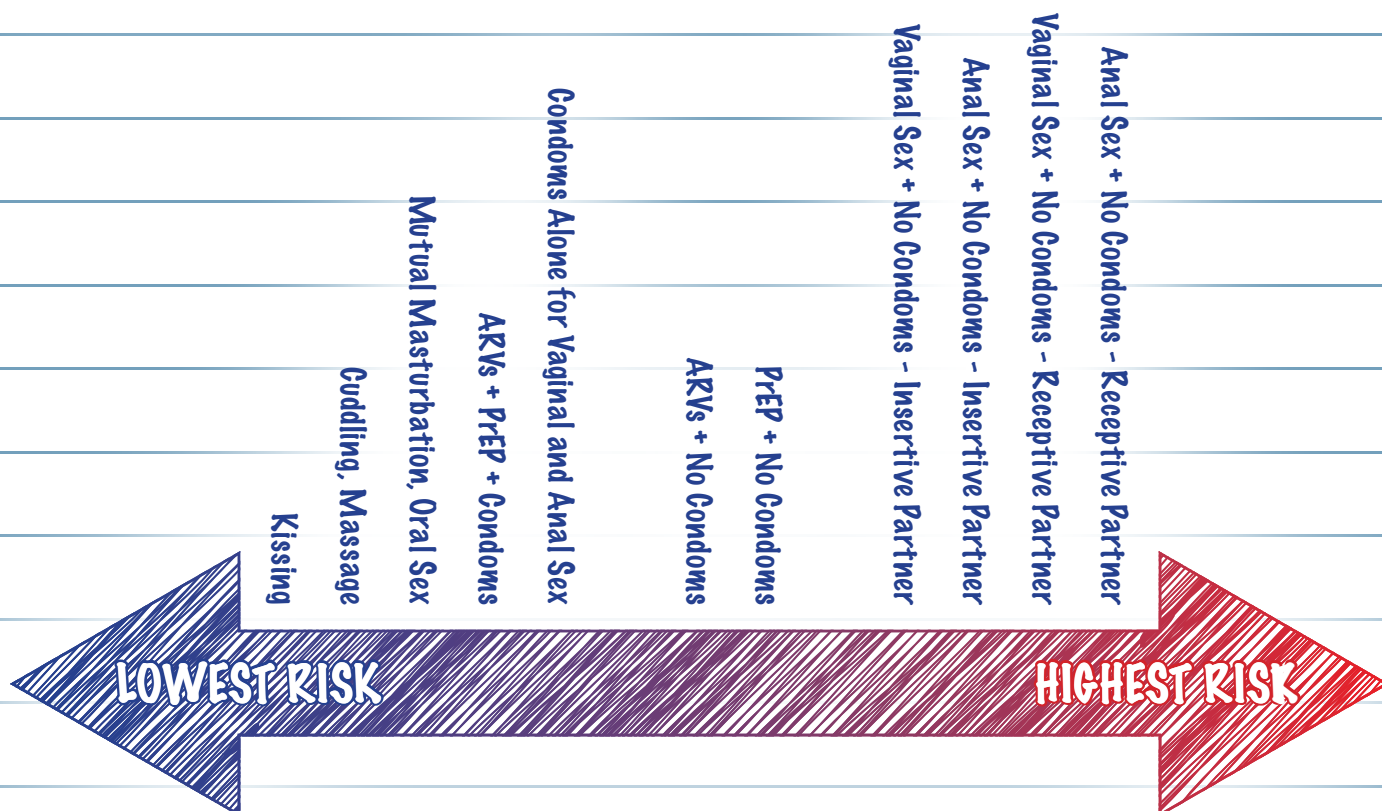
Some people think it's up to the person who is HIV negative to protect themselves and shouldn't be the sole responsibility of the HIV-positive partner. This is also an oversimplification of what it means to be a sexually active person. It takes two to have sex and both partners can have a responsibility to protect themselves and each other.

When it comes to safe sex, what we are really talking about are levels of safety. Obviously, things like kissing, cuddling and mutual masturbation between an HIV-positive and -negative partner have essentially zero risk of transmission. On the other hand, when the positive partner engages in vaginal sex or anal sex without a condom, the risk of transmission rises dramatically, especially if the HIV-positive partner is not on successful antiretroviral (ARV) therapy. The big question is how to reduce risk wherever possible, while still having a rich and satisfying sexual relationship.

One of the things it's important to understand is that being HIV positive doesn't really change how you approach sex most of the time; it just means you are approaching it with more information. No HIV-negative person can ever be 100% certain about the HIV status of their sexual partner unless their partner is HIV positive and informs them of that fact. If their partner says they are HIV negative, how can they be certain? Has it been more than three to six months since the partner last had sex and were they definitively HIV negative before that took place?

HIV-negative people who assume their partners are also HIV negative and who engage in unprotected vaginal or anal sex may actually be at the highest risk for becoming infected, because their partner may be positive and not know it and their partner's HIV levels may be very high.

Although disclosing your HIV status can be complicated, most people who are infected with HIV take some steps to protect their partners from ongoing HIV transmission. Not all people change their behavior with HIV-negative partners, but most do. Here's a chart of HIV risk, let's go over it. (Some things, such as treatment as prevention and pre-exposure prophylaxis (PrEP), will be dealt with in more detail later.)



Lowest Risk

There are a range of activities that confer no risk between an HIV-positive and an HIV-negative partner. These include kissing, cuddling, massage, and mutual masturbation.

Very Low Risk

There is another range of activities that also confer extremely low risk of transmission. These include oral sex without ejaculation in the mouth, vaginal or anal sex when condoms are used and the HIV-positive partner has undetectable HIV levels due to ARV therapy, and vaginal or anal sex when condoms are used and the HIV-negative partner is taking PrEP. Anal and vaginal sex with condoms alone is also a very low risk activity.

Moderate Risk

So far there have been five very high quality studies investigating having the HIV-positive partner's viral load at undetectable levels due to ARV therapy, also called treatment as prevention, and PrEP, which is when the HIV-negative partner takes the ARV drugs tenofovir and emtricitabine. In all of the studies, people reported using condoms at least some of the time, so we don't know for sure how these tactics work if people didn't use condoms at all.

In studies where either the HIV-positive (treatment as prevention) or -negative partner actually took their drugs regularly, the reduction in the risk of transmission to the HIV-negative partner was cut anywhere from 90% to 96%.

Highest Risk

Vaginal sex and anal sex without condoms are among the highest risk activities. For the male who is the insertive partner, also sometimes known as the "top," the risk is a little bit lower, especially for vaginal sex and especially if he is circumcised, but the overall risk is still relatively high. The same is true for the insertive partner for anal sex.

For the receptive partner, vaginal sex and anal sex are both among the highest risk activities and receptive anal sex is the highest of all given how fragile the lining of the anus and rectum are, among other reasons.

Guarding Against HIV Transmission

While there are new tools to fight HIV, the oldest tool is still one of the best—condoms. They aren't perfect. They can blunt sensation for the male insertive partner. They can reduce spontaneity. They require that both partners agree to use them and to use them properly. Also, especially when both partners are HIV-positive, insisting on condoms can be seen as a sign of mistrust in your partner.

Using condoms can also, however, be a very loving act, both toward yourself and toward your partner. Using condoms is a way to say, "I care about my health and I care about keeping my partners healthy too."

When used properly, condoms can interrupt transmission of HIV by up to 90% for vaginal sex and by at least 70% for anal sex among men who have sex with men.

Condoms Are Not Just for HIV Prevention

Condoms are not only one of the best tools for HIV prevention, they also protect against a number of STIs. If you're living with HIV, other STIs may not seem like such a big deal, but there are a couple of very important reasons to take them seriously.

First, some STIs, syphilis in particular, can progress more rapidly and aggressively if you are also HIV positive. Also, if you develop an STI and you don't use condoms with an HIV-negative partner, you may significantly increase the risk that you will transmit the virus to your partner.

Condoms Are an Effective of Birth Control

We will be looking more deeply at reproductive health and pregnancy prevention in a subsequent module, but it should be noted that condoms are among several forms of preventing pregnancies. When used correctly, they can be about as effective as taking a birth control pill daily.

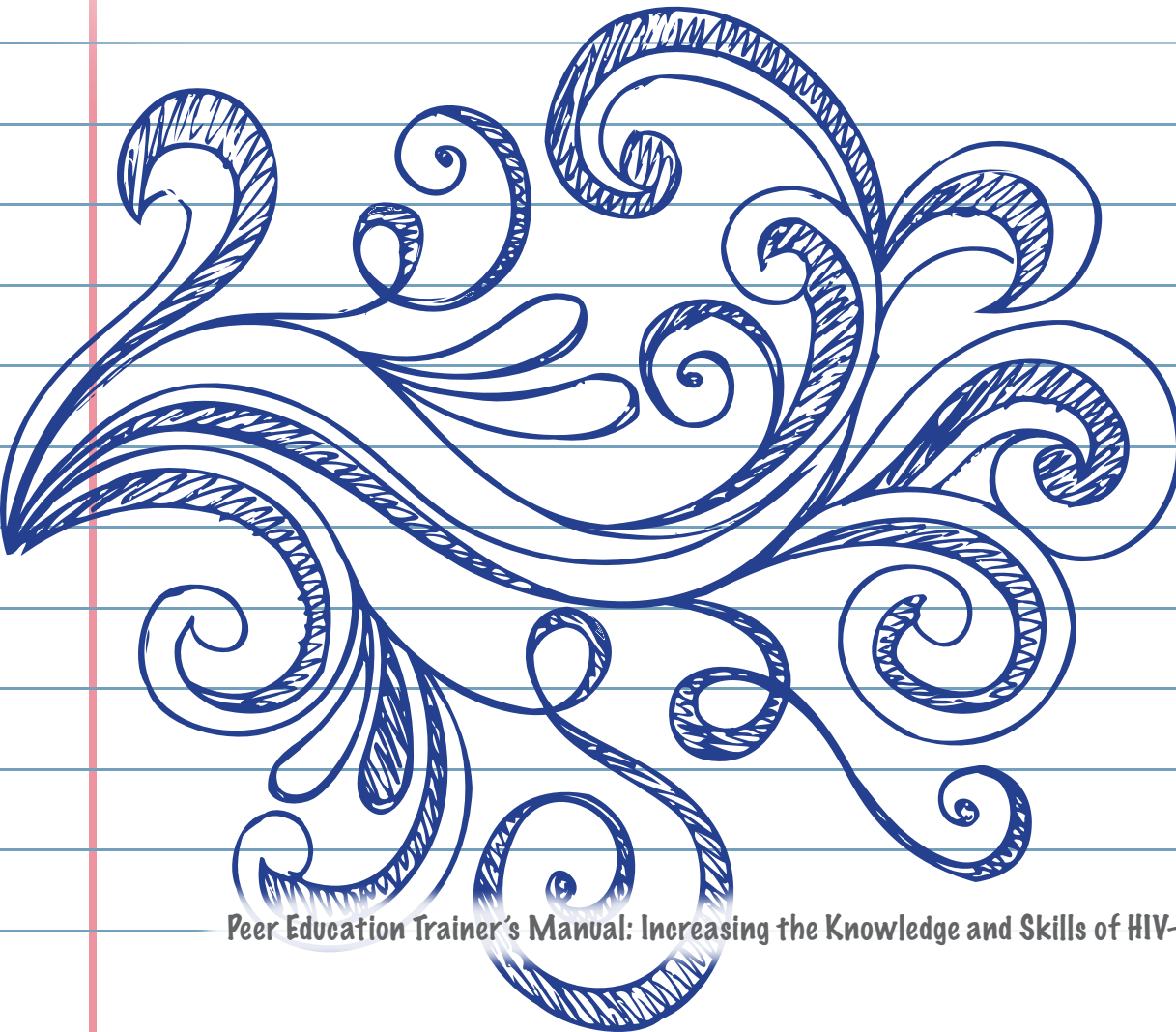
Condoms Can Guard against Super-Infection

A significant number of people with HIV have unprotected sex with other HIV-positive people. Their rationale is that there's nothing harmful that can happen. In addition to STIs, however, there is another potential problem.

It's possible to become infected with more than one strain of the virus. In fact, this is relatively common early in infection, usually before you even know you are infected. It is possible to become infected with another strain of HIV, however, even if you've been HIV positive for a while, and that strain of HIV may be resistant to HIV medications. If that were to happen, you wouldn't be able to use those medications.

While super-infection with a drug-resistant strain later on in the course of your disease is thought to be very rare, it has occurred, and may be something you'll want to think about if you have been having unprotected sex with others who are HIV positive.

Since proper use of condoms is so important, let's practice to make sure we know how to use them correctly.



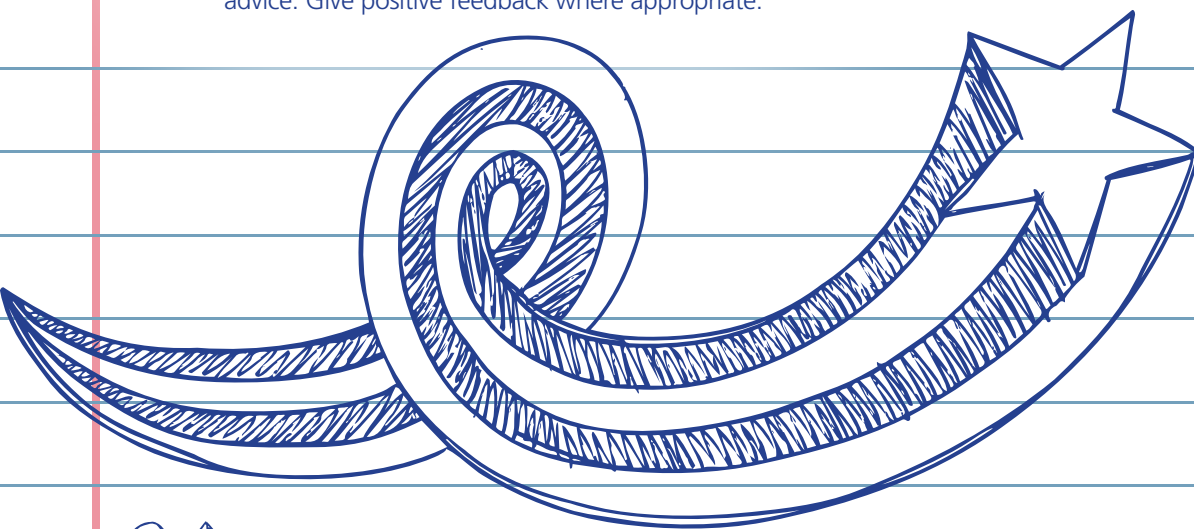
Interactive Exercise #1 - Condomania (10-15 minutes)

Explain that even though we now know that people on ARV therapy are less likely to transmit HIV than those who are not on ARV therapy, and even though we know that PrEP can help reduce the risk of transmission, male and female condoms are still the cheapest and most effective tools to prevent HIV and they are available to most people.

Preparation

Pass out bananas, cucumbers or squash to all of the participants along with male condoms, female condoms, lubricant packets, and either alcohol hand sanitizer or small tubes of soap and water and paper towels.

- Demonstrate the proper use of a male condom on a banana or cucumber or squash. Place the fruit/vegetable on a desk or table. Demonstrate how important it is not to tear the condom when opening the package. Demonstrate that under ideal circumstances you will apply lubricant to the penis before putting on the condom. Explain that this will not only help reduce the risk that the condom will break, but that it will also enhance the sensation for the male partner.
- Show the need to pinch the tip of the condom closed before rolling it down the penis, and explain that doing so will provide space for the ejaculate. Then explain how lubrication on the outside of the condom can further protect against condom breakage, especially for anal sex. (It's a good idea to practice this demonstration before conducting it in front of the participants.)
- Next have each participant put a condom on his or her own fruit/vegetable. Go around offering tips and advice. Give positive feedback where appropriate.
- Next demonstrate how a female condom works. As it's not possible to use a prop, explain how the inner ring is inserted into the vagina and how important it is for the outer ring to be spread out so that the penis goes inside of the condom and not into the vagina. Explain that lubrication will improve the likelihood that the condom works properly, and also enhance the male's pleasure. Point out that condoms ideally shouldn't be used without lubricants.
- Explain that although the female condom has not been approved for anal sex, some people use them that way. The two most important points, being that the inner ring has to be inserted properly and that the outer ring must be outside of the anus so that the penis will be inserted inside of the condom. Explain that lubrication is perhaps even more important when the condom is being used for anal sex.



Interactive Exercise #2 - Motivation and Negotiation (20-30 minutes)

Explain that now that people know how to use condoms properly, we'll turn to motivations for using condoms (or not), and to negotiation strategies.

- If the group has more than six people, sort the participants into two groups. Give each group paper and pencils or pens, or ideally flip charts and markers. Ask the group to answer three questions:
 1. What qualities about condoms do you like the most and least?
 2. What kinds of situations make it easier to use condoms?
 3. What kinds of situations make it more difficult to use condoms?
- Give the group(s) between 5 to 10 minutes to answer the questions. If people are deeply engaged in discussions, give them more time.
- If you split the larger group into two or more small groups, ask the small groups to share their answers with the group-at-large.
- Next, explain to the group that they will brainstorm solutions for various types of situations where it can be difficult to use condoms. Start off by using the situations that participants identified as the most difficult to use condoms. Ask the group to come up with things they could say or do to ensure that condoms are used, even in situations where it is tempting to not use them. Encourage them to come up with multiple solutions.
- Here are some additional scenarios for the group to consider. If these kinds of situations have not already been identified, pose them to the group:
 - You've been out with someone a few times, but you haven't yet disclosed your HIV status. You begin to be sexual, and they make it clear that they would like to have vaginal or anal sex and to not use a condom. What do you say or do?
 - You are in a relationship with someone who is HIV negative. You begin to have sex. You reach for a condom and they stop you and say, "I love you. I'm not afraid."
 - You hook up with someone that you met at a party or online and you begin to have sex. When you bring up condoms, they say, "No it's cool. I'm positive, too."
 - You've been having unprotected sex with your partner for a while, maybe only once or twice or, maybe for longer. They know your HIV status and you know theirs. You've now decided that you should use condoms after all. How do you have that conversation?

Close this exercise and module by asking the participants to identify the positive reasons to use condoms, both for their own and others' physical health, but also for their self-esteem.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 6

Magnetic Love: Mixed-Status Partnerships

(45 minutes)

Learning Objectives

1. Participants will have improved communication skills to utilize with HIV-negative partners.
2. Participants will display an understanding of risk-reduction strategies for HIV and other STIs.

Treatment as Prevention Works

Researchers have suspected for many years that being on HIV medication and having fully suppressed HIV levels reduces the chance that an HIV-positive person will pass on HIV to his or her sex partners. That suspicion was confirmed by a large study called HPTN 052, which found that when a person started antiretroviral therapy early they were 96% less likely to transmit HIV to their HIV-negative partner than if they delayed therapy. The key details of the study are:

- 1,763 mixed-status heterosexual couples (one partner is HIV positive and the other HIV negative) participated in the study, 54% of them from Africa.
- Exactly half of the HIV-positive partners were men and the other half were women.
- 39 HIV transmissions took place. Using genetic analysis of the virus that people were infected with, researchers were able to link the transmission from the HIV-positive partner to the -negative partner in 28 cases. In the other 11, the infection came from outside of the relationship.
- Of the 28 transmissions, only one was in the early therapy group, and in this case the transmission happened early, before the person's virus levels were fully suppressed.

Studies Say its Effectiveness is Also Based on Condom Use

Several things are important to know about this study. Most important is that about 95% of the couples reported always using condoms. Because people sometimes tell researchers what they think the researchers want to hear, it is likely that fewer couples actually used condoms all the time. That said, these results were true for people who very often used condoms. If none of the couples had used condoms the results might not have been as positive.

Treatment as Prevention in the Real World

In fact, a completely different study that examined real-world data among more than 30,000 mixed-status couples in China found that the reduction in risk of transmitting HIV from the positive to the negative partner was only 26% when the positive partner was on treatment. This study was not as rigorous as the HPTN 052 study, and we don't have information about the HIV-positive partner's virus levels, so it is possible that this study underestimates the positive effect of treatment.

Possible Limitations of Treatment as Prevention

Also, we don't know how well antiretroviral therapy can reduce the risk of transmission from anal sex. Though anal sex is the primary risk of transmission for men who have sex with men, up to one quarter of straight couples also report having anal sex. In the HPTN 052 study, very few couples reported anal sex, however. For this reason, we can't say how much HIV treatment reduces the risk of transmission for men who have sex with men or for straight couples who frequently engage in anal sex. Biologically it's likely that treatment also reduces the risk of transmission from anal sex, but we don't yet know by how much.

Something else that matters a lot is the fact that levels of HIV in blood don't always match levels of HIV in semen, the vagina or in the rectum. This means that even when HIV can't be detected in the blood it might be present in these other parts of the body. Moreover, STIs can also increase the risk of HIV being present in these other body parts and this might increase the risk of HIV transmission.

What all of this means is that successful HIV treatment does substantially reduce the risk of HIV transmission between heterosexual mixed-status couples, especially in those who use condoms. Antiretroviral therapy can provide that extra level of protection for mixed status couples that can help increase intimacy and reduce fear.

That's huge. For many mixed-status couples one of the biggest obstacles to intimacy and one of the things that makes it so difficult to relax around sex is the fear on the part of the HIV-positive partner that they will pass on HIV to the person they love.

Pre-Exposure Prophylaxis (PrEP)

PrEP is another tool to fight HIV transmission that was recently proven to be effective. With PrEP, it's the HIV-negative partner who takes HIV medication. In this case, the medications are tenofovir plus emtricitabine; when they're combined into a single pill, they're called Truvada®.

How does PrEP work?

We use PrEP for a variety of conditions, whereby you give someone a medicine to prevent them from becoming infected with a disease. Malaria is a good example. Sometimes people take pills to prevent becoming infected with malaria. The same principle works with HIV and the use of tenofovir and emtricitabine for PrEP. By having HIV medications in the blood stream and genital tract when a person is exposed to HIV, the virus can't reproduce and cause a lasting infection.

How Effective is PrEP?

When HIV-negative people take their medication every day, or nearly every day, their risk of becoming infected drops by as much as 90%. This is true for men and women. It is also true for men who have sex with men and transgender women who have sex with men.



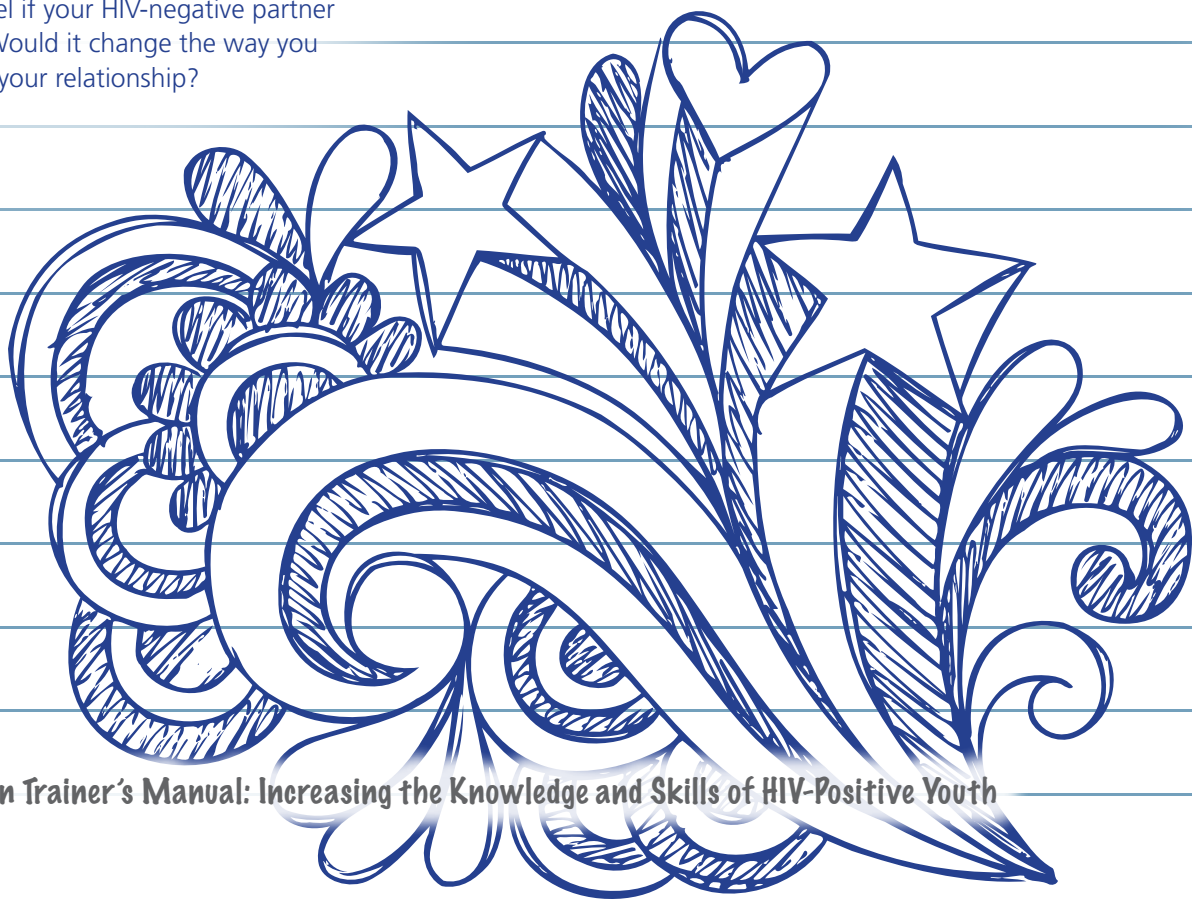
The Limitations of PrEP

HIV medications can be very expensive and not all countries and provinces can afford to treat every person living with HIV who needs the medications for their own health. For this reason, and because we don't yet know how PrEP will work in the real world outside of studies, PrEP availability may be quite limited. In some countries, however, PrEP is being given to the HIV-negative partner in mixed-status couples or to men who have sex with men and transgender women who are at high risk of becoming infected.

Interactive Exercise #1 - What's Love Got to Do With It? (20 minutes)

Guide a 20-minute discussion with your group about what the HPTN 052 results mean to them. Following are the guided discussion questions:

- How does it make you feel that HIV treatment might reduce your risk of transmitting HIV to your partners? Does it change the way you feel about yourself or your relationship?
- Do you think that being on HIV treatment might reduce your fear of transmitting HIV to your HIV-negative partners?
- Does your knowledge about the prevention benefits of ARV therapy change how you think about using condoms?
- How would you feel if your HIV-negative partner was taking PrEP? Would it change the way you think about sex or your relationship?
- How would you imagine talking about the impact of HIV treatment as prevention with your HIV-negative partners?
- What kind of tools, for instance written materials, might help your HIV-negative partners understand the prevention benefits of treatment?
- What kind of support would you need to have these discussions with them?



Availability (This section will vary from country to country)

If you want to start ARV therapy to reduce your HIV transmission risk you will first need to understand the current treatment guidelines in your country.

The most current World Health Organization (WHO) guidelines on ARV therapy (as of July 2013) recommend offering treatment to people with CD4 counts under 500 cells/mm³, but also giving it to any HIV-positive heterosexual people in relationships with HIV-negative partners, regardless of a person's CD4 count.

There are a couple of potential problems with this. First, not all countries immediately change their own treatment guidelines to match the WHO guidelines right away. That means that guidelines in your own country might not currently recommend treatment for you based on your current CD4 count and sexual behavior.

Facilitator's Note

Check on your country's national HIV treatment policies in regard to starting therapy, and expand on this section specific to your country's policies in regard to mixed-status couples. Explain that you'll get into more detail on treatments in the next module. If your country doesn't follow the WHO guidelines this can be a good place to mention that getting involved in advocacy efforts to change your country's policies can be an empowering thing to do.

Second, and possibly even more complicated, getting HIV treatment, especially if your CD4 count is high, may mean discussing your sex life with your healthcare provider. Not all people feel comfortable discussing sex and romance with their healthcare provider. Similarly, not all providers feel comfortable talking about sex with their patients.

Third, the WHO guidelines talk about mixed-status heterosexual couples. This is because the data available so far is specific to couples with one male and one female partner and where the primary risk is through vaginal sex. Anal sex is a different matter. Because of how fragile the tissue is in the anus and rectum, the risk for transmission is much greater for the passive partner during anal sex. We don't yet have good studies in people where anal sex is the primary risk factor for HIV transmission. Because we don't yet have completed studies designed to answer this question, it might be more challenging to convince your provider to offer you therapy if anal sex is your primary risk for HIV.

What is the Best Way to Discuss Your Sexual Behavior and Treatment as Prevention with Your Provider?

A lot of this depends on your relationship with your provider and on how they feel about these issues.

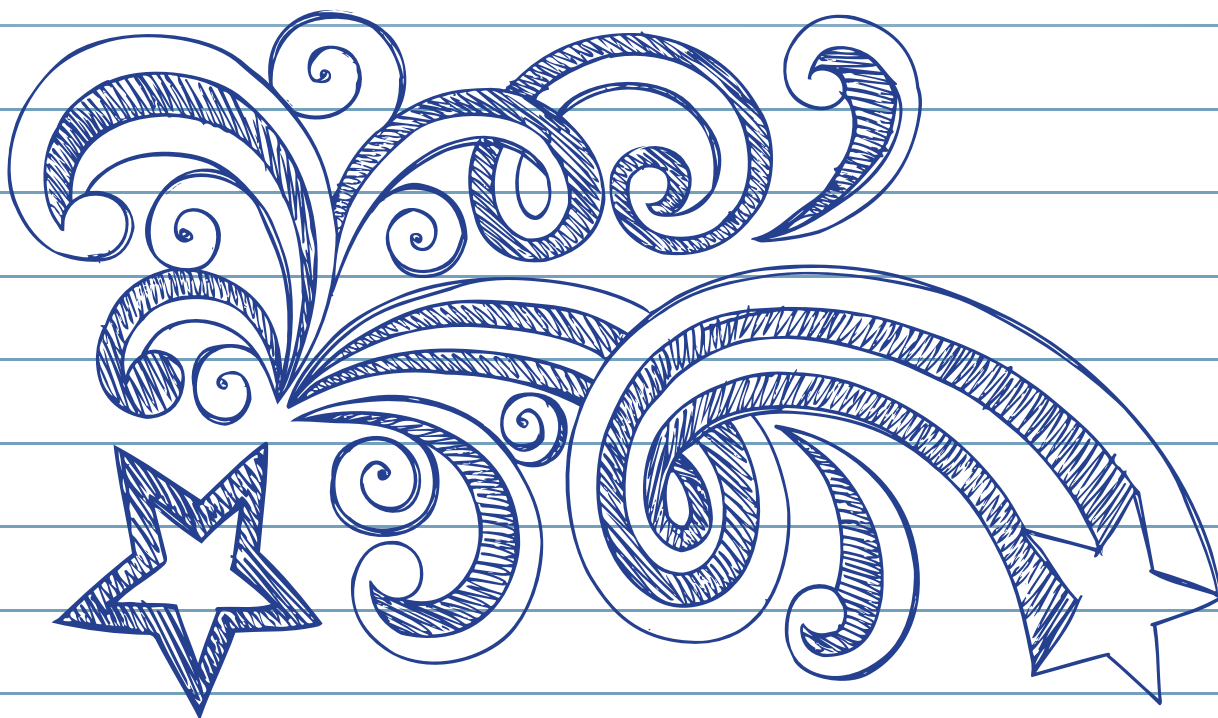
If you have a comfortable relationship with your healthcare provider, or they have asked you about your sexual behavior in the past, this puts you in a fortunate position. If you don't have as much comfort in your relationship, or you've never really talked about sex with your provider, things might be more challenging. In either case, asking them their opinions on the use of antiretroviral therapy for prevention is a good starting place.

Here is a list of important questions you can pose to your healthcare providers regardless of your relationship with them:

- Have you heard of the HPTN 052 study, which found that early antiretroviral therapy reduces the risk of transmission to an HIV-negative partner by at least 96%?
- What is your opinion about that study and how do you feel about using HIV treatment for prevention?
- I am in a relationship with an HIV-negative man or woman and I want to do everything I can to protect him or her. How would you feel about prescribing HIV treatment for me for this purpose?

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.



MODULE 7

Care and Treatment

(60-75 minutes)

Learning Objectives

1. Participants will be able to enumerate the specific steps in seeking and obtaining medical and other healthcare for HIV.
2. Participants will be able to enumerate the steps in the healthcare continuum.
3. Participants will be able to discuss the disadvantages of untreated HIV and AIDS-related and non-AIDS-related conditions.
4. Participants will be able to discuss basic HIV treatment strategies for HIV.
5. Participants will be able to discuss first and second line medications.

What Defines Good HIV Care?

The best HIV healthcare providers follow a very important principle. When it comes to treating the disease they never forget that they are treating a “person” who happens to have a virus and not simply treating a virus that happens to be inside of a person. That may seem like a frivolous difference, but it’s not.

Treating a person rather than a virus means taking into account every aspect of a person’s life and all of the things that make him or her healthy or sick. HIV is just one piece of that puzzle. It may be a very important piece, but it is only a piece. Treating the whole person usually means that a person with HIV is assessed for their mental and emotional well-being and their sexual health along with whatever else might be going on with the virus or their immune systems.

Finding a provider who responds to all of your needs is a critical step in staying well and living well with HIV. Just as important, however, is taking responsibility for your own wellness and staying engaged with your healthcare. As we’ve learned with HIV and many other diseases and conditions, the more you learn about and manage your own disease, the better off you’ll be.

Here’s a chart laying out the HIV treatment continuum. Let’s discuss it.

(NOTE: Display or pass out the HIV Care Continuum Handout on the next page.)

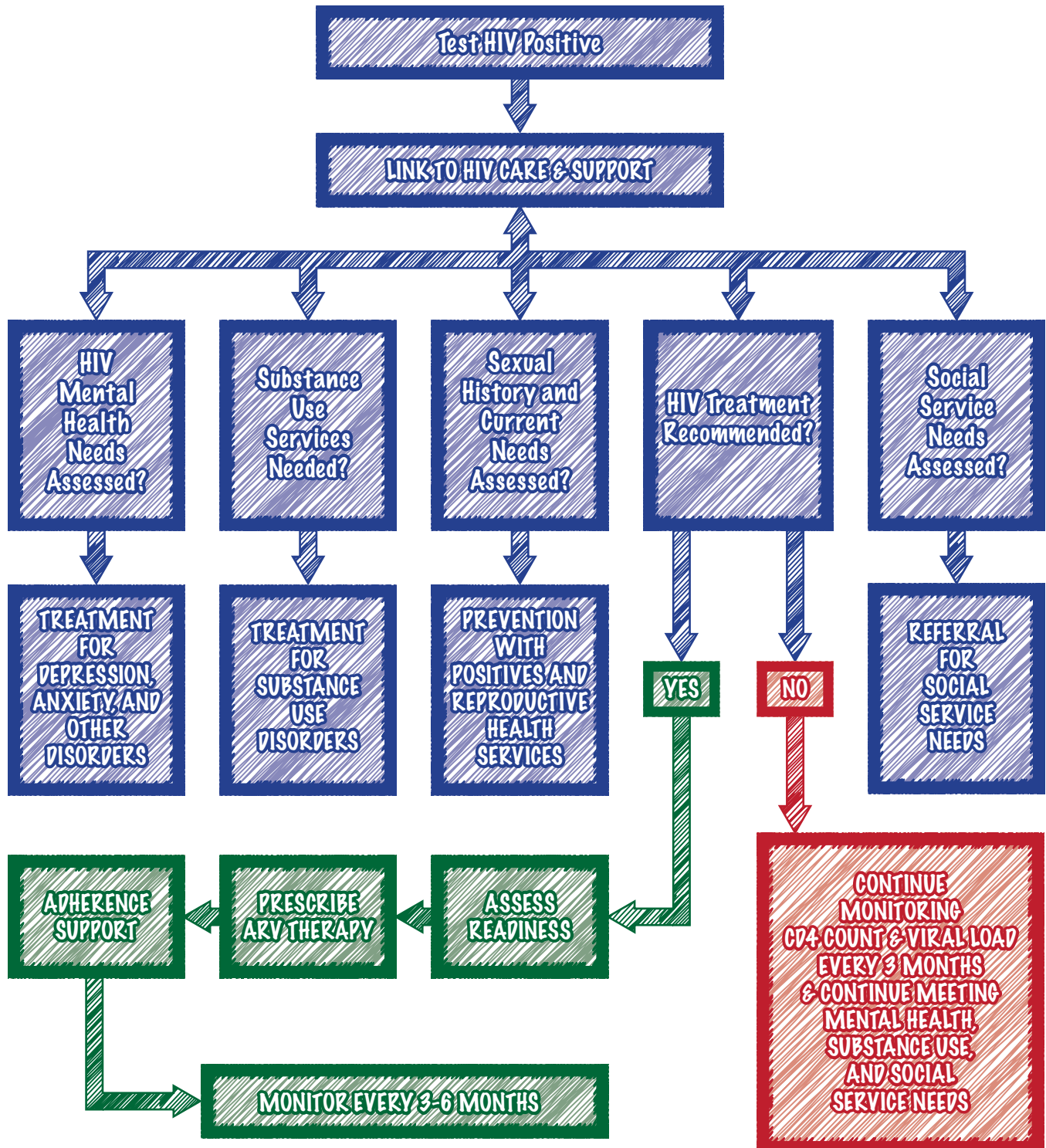
HIV Care Continuum

For adolescents who were infected at birth, the HIV care continuum will look similar to what we are about to see. Even though you have probably been on HIV treatment since you were a baby, there are many other needs that adolescents living with HIV might have, especially as they get older, and it might not matter how or when they were infected. We will discuss each.

This continuum represents an ideal range of services, which may not always be easily available or accessible to you, or may be more geared toward older adults in your area. If you have a parent or friend who can help you advocate for services this may be helpful. Local AIDS advocacy groups, where they exist, might also be able to help you get the services you need.

MODULE 7 HANDOUT

HIV Care Continuum



HIV Care Linkage

Whether you were recently infected, have known for a while, or were infected when you were a baby, there is a holistic range of services for which you should be assessed. These include mental health service needs and substance use service needs, as well as sexual health support services and assessment for HIV medications.

Mental Health Support Services

Your doctor should ideally ask you a short set of questions about your mood and your thoughts in the last few months. These trainings will go more deeply into signs and symptoms of depression and anxiety in a different module. If your healthcare provider does not ask you these questions, and if you have been feeling particularly depressed or anxious, ask them for a referral to mental health services. If your doctor cannot provide you with this kind of reference, or if those kinds of services are difficult to obtain, you may want to contact a local or countrywide AIDS service organization. (Facilitators should provide contact information for these local services where possible.)

Substance Use Health Services

While most healthcare providers would recommend that their patients refrain as much as possible from using alcohol and other drugs, this isn't always a reality for everyone.

Let's be real. When we are high or drunk, we often feel better. We may lose our inhibitions and anxieties. We may be able to forget about things that worry or depress us. We may feel more social and be able to carry on conversations with strangers in a way we wouldn't be able to if we weren't drunk or high. In short, alcohol and drugs aren't 100% negative.

Also, being an adolescent or young adult means trying new things, and it can also come with a lot of pressure from our peers to do things that we're not sure we want to do.

There is a difference, however, between casual use of alcohol and drugs and excessive use of alcohol and drugs. We will explore signs and symptoms of harmful alcohol and drug use in a future module. We'll also talk about potentially harmful interactions between street drugs and prescription drugs—especially some HIV medications—but your provider should hopefully ask you about your use of these substances so that they can provide you with the most beneficial healthcare.

As hard as it might be to be honest with your provider, unless you feel they will treat you badly, it is usually best to tell them about your actual alcohol and substance use. If they don't know, it can cause them to give you poorer care.

Sexual History and Current Sexual Health Needs

Ideally, your healthcare provider will also ask you about your sexual behavior and your risks for STIs, your risk and preferences around pregnancy, and the potential to pass on HIV to your partners. Though not all countries, provinces, and cities offer comprehensive sexual and reproductive health services that are sensitive to the needs of adolescents and young adults living with HIV, your provider should offer you at least minimum services in this regard.

Minimum services would include screening and treatment for STI and birth control options. Additional services would include counseling around risk behaviors and access to male and female condoms and lubricant.

As described in other modules, HIV treatment can prevent the potential for transmission to HIV-negative partners. There are also birth control methods other than condoms that can and should be explored.

Social Service Needs Assessed

Not all countries, provinces or cities offer the same level of additional supportive services. Some areas offer housing or financial assistance to people living with HIV and some offer specific services to HIV-positive adolescents and young adults. (Facilitators – provide local contact information and referrals to any social services in your area).

HIV Treatment Assessment

The need for HIV treatment is determined from several criteria. Perhaps most important is the immune health of the person living with the virus and any other infections they may currently have. Also of high importance is whether or not they have a regular sex partner who is HIV-negative as is discussed in another module.

Not all countries have the same guidelines for when to start ARV therapy or which drugs to use when a person first starts. Many countries base their own decisions about when and what to start on WHO guidelines, which were updated most recently in July 2013. Some countries recommend treatment more aggressive than the WHO guidelines and with more medications recommended, and others wait for a person's immune system to become more compromised before recommending treatment and recommend fewer or different medications. Often these choices are made as much because of cost and healthcare resources as they are on what is medically advisable based on scientific studies.

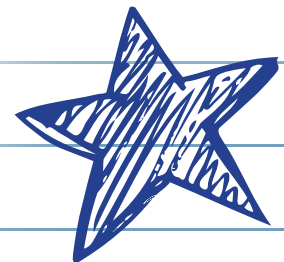
A Few Important Factors about Starting Treatment

Your Immune Health

HIV causes disease by damaging the immune system. One of the best ways to determine the health of your immune system is by measuring the number of a type of immune cell, called a CD4 cell, in a few teaspoons full of blood. In a person with good immune health the CD4 count is typically in the 600 to 1,200 cells/mm³ range and is almost always above 500 cells/mm³.

People with less than 200 cells/mm³ are typically at much higher risk of other types of infections and conditions that can cause severe illness. People with between 200 and 500 cells/mm³ may also be higher risk of certain diseases and conditions, but these occur more rarely and this is why current WHO guidelines and other guidelines recommend HIV treatment for people in this range.

The WHO guidelines recommend that children and adults older than 5 years with 500 or less cells/mm³ should begin HIV treatment. The guidelines also recommend that a priority be given to those with 350 or less cells/mm³. Children younger than 5 years are recommended to start treatment regardless of CD4 count.



Other Infections

Other infections can also influence when to start treatment. The WHO guidelines recommend that anyone with active tuberculosis (TB) disease start HIV treatment regardless of their CD4 count. The same is true for people infected with hepatitis B virus (HBV) who have serious liver disease. Also, those individuals with more serious infections or conditions that are common in people with damaged immune systems should be treated regardless of CD4 count.

Pregnancy

The WHO guidelines recommend that all pregnant women receive HIV treatment regardless of their CD4 count, both for their own health, but also very importantly to ensure that their babies are not infected during childbirth and breastfeeding. It is now recommended that women who've given birth stay on HIV treatment after pregnancy, especially through the period of breastfeeding.

Facilitator's Note

Group facilitators should outline both the most current WHO guidelines (see example above) and the country-specific guidelines for where the training is taking place. Guidelines to be covered should include not only questions of when to start, but also what to use for first-, second-, and third-line therapies. Produce hand-outs with this information and go over it in detail with the participants. Explain that providers will likely base their treatment recommendations on country-specific guidelines and that in areas where country guidelines are less aggressive than WHO guidelines this can be an important opportunity for adolescents to volunteer with AIDS advocacy organizations to advocate for changes.

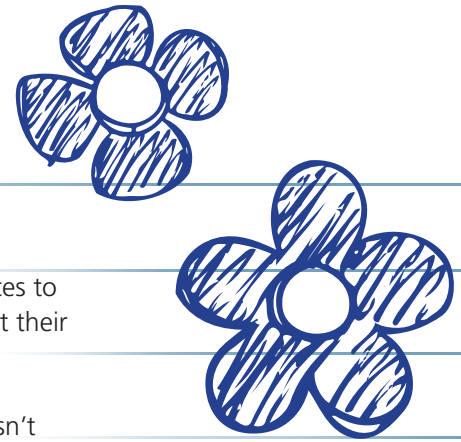
Treatment Adherence Support

Study after study has documented that adolescents and young adults have greater challenges with taking medication on time every day than older adults. Taking your meds on time every day is called "adherence."

Essentially, the older you get, the easier time you will generally have with adherence. Some of this is because older adults often have schedules that are far more routine. They do the same thing every morning at the same time and the same thing every night at the same time.

For adolescents and young adults, this is not often the case. Most of us brush our teeth every morning, and this is one of the most helpful reminders for taking medications at that time. However, you may not wake up at the same time every day or your medications may be recommended at bed time and you may go to sleep at different hours or in different places on some nights.

Between school, work and social demands, you might fall asleep in total exhaustion at 8:00 p.m. on one night and not until 3:00 a.m. or 4:00 a.m. on the next night. You might also have a boyfriend or girlfriend and sometimes stay there and other times at home, or the people you stay with once in a while might not know you are HIV positive and taking medications. All of these situations can make adherence a challenge.



The Reasons that Adherence Support Can be Necessary

When people take drugs for high blood pressure or diabetes they may have consequences to forgetting to take their medication, but one consequence they don't have is the risk that their medications will stop working.

Because HIV is a virus, and because the virus can change so much and so quickly, it doesn't take many missed doses for the virus to change enough that the drugs used to treat it don't work anymore. This is called drug resistance and it is the reason that adherence to HIV medications is so incredibly important.

Adherence Tips

There are some common adherence tips and tools that can be helpful. Some doctors and websites offer SMS text messaging support, sending text messages every day at the same time. Another tip that can be helpful especially for people who take their medications at night is putting their daily dose in a small, but secure, plastic bag or pill case when they leave the house for the day and combining that with an alarm on their cell phone. That way they you don't need to come home from wherever they are to take their medication and they are ready for unexpected events to happen.

Another barrier to adherence for some people is the use of alcohol and other substances. While this will be dealt with in greater depth in a different module of these trainings, it is important to note that if you are drunk or high this can cause you to forget to take your medications. If you happen to get drunk or high several days in a row and forget to take your medications on each of those days, your virus can begin to develop resistance to your medications.

Interactive Exercise #1 - Adherence Brainstorm (5-10 minutes)

Facilitate a discussion, ideally with a flip chart and markers, asking participants to first call out those situations and conditions that may cause them to forget to take their medication. After identifying common adherence challenges, brainstorm to identify potential solutions.

What Does Quality Healthcare Look Like?

Ideally, you should be treated with kindness and respect in your dealings with your healthcare provider and other providers. They should listen and respond to your concerns and the realities of your life. If you have doubts about starting treatment or the medications your provider would like to prescribe for you, he or she should be respectful of those doubts and concerns, and also clearly share why their professional and personal judgment has caused them to make a particular recommendation.

Ideally, your provider should not be judgmental of your behavior or your specific situation. If you are having difficulties with your mood or using substances or adhering to your medication, or even showing up for appointments, your provider should ultimately work with you in a supportive manner to solve your challenges.

Unfortunately, not all providers are able to offer this kind of kindness and non-judgmental care. Also, providers are human. They sometimes have bad days, get frustrated (often out of concern), or get in a rush on particularly busy days.

One thing that is important to keep in mind is how your provider treats you on a consistent basis and not just on one particular visit to see them.

What Should I Do If My Needs Aren't Met?

Some people have the option of multiple different healthcare providers. If one doesn't treat them well or serve their needs, they can choose to try a different one. That isn't always the case, however. Some of us only have the choice of one or two providers, or else our provider can change without our control depending on when we come in for appointments.

Whether or not you have the option of multiple providers, the first step to getting good healthcare is to know what it is you most need and to find a non-threatening way to ask for that.

Some providers are very good at dealing with people and are very open to hearing that your needs have not been met. Others may feel more threatened or they may dismiss your concerns. Following is a guide to having a conversation with a provider who has not met your needs.

- First, you've got to identify and clearly state your needs.
- Second, you will probably want to investigate your options. Find a way, whether by talking to others with HIV or by doing research on the Internet for the best solutions for meeting your needs.
- Be clear about the needs you have and ask for them in a straightforward manner, but preferably without anger.
- If your provider has said something that upset you in the past, talk with a trusted friend, family member or counselor to find a way to bring it to your provider's attention in the future.
- Bring an ally with you to your appointments so that they can help you advocate for your needs.

Interactive Exercise #2 - Treatment Communication (10-15 minutes)

Facilitate a dialogue about people's experiences with healthcare and other service providers. Ask people to share both their negative and positive experiences. Ask people to share the entire experience whether their experience was negative or positive and not just abbreviated anecdotes.

- If their experience was negative, how did the experience start and how did it end?
 - What were the potential causes?
 - Did their provider ask an uncomfortable question or make unfair assumptions?
 - Did the provider discount their concerns?
 - When someone shares a negative experience, turn it back to the group and ask for ideas for how the person might be able to solve their challenge.
- When someone shares a positive experience, draw him or her out to explain what he or she valued most about the experience and ask him or her to explain what made his or her experience so positive?
 - What were the qualities about their provider that made the interaction go well?
 - Were there other parts of the experience that went particularly well?
 - How might receiving good care enhance their ability to advocate for quality care in the future with other providers?



Risks of Late Treatment

In many ways, HIV is a whole body disease that requires a whole body approach to treat it. As a virus, it primarily infects and reproduces in immune cells, mostly a type of cell called a CD4 cell, which functions as a leader in the army of the immune system.

The immune system, though, is so interconnected with every part of our body and every organ system, that when HIV damages our CD4 cells and other immune cells, it is also damaging our whole body. Because this damage can take place slowly over a very long period of time, the majority of people with HIV go for years without feeling sick, when in fact the foundations of later health problems are being put in place early on. Antiretroviral drugs can help minimize that damage. Unfortunately, when people wait to deal with their virus until they feel sick, they are often waiting to treat until after it is too late to protect the body against this damage.

The Dangers of Inflammation

Because HIV keeps the immune system in a hyper-agitated state it can cause something called inflammation. It can cause the blood vessels, liver cells, kidney cells, and brain cells to be inflamed. The consequences of this are that well before the immune system becomes damaged and people's immune systems lose control of the virus, there can be organ damage that puts people with HIV at greater risk of heart attacks, kidney disease and both subtle and more major forms of brain dysfunction later in life. This is true even in very young people. In fact, one of the consequences of late treatment that we see is that some very young people, as early as their 20s or 30s, have heart disease that doesn't usually affect people until their 50s or 60s. Antiretroviral drugs can significantly lower inflammation, and treatment can help you avoid organ damage.

All of this is why guidelines on treating HIV disease are recommending that antiretroviral therapy should be started earlier than in the past. It is not only to control the virus, but also to guard against both AIDS-related and non-AIDS-related illnesses. AIDS-related illnesses include things like pneumocystis pneumonia or an infection of the mouth and vagina called candidiasis. Non-AIDS-related illnesses include certain cancers, heart disease, and liver disease.

What is AIDS?

AIDS stands for "Acquired Immunodeficiency Syndrome." It refers to the later stage of HIV disease after the immune system becomes so damaged that the body is no longer easily able to fight off infections and other illnesses. AIDS-related illnesses refer to diseases and conditions that usually only crop up when people's immune systems become depleted. Immune depletion is measured by looking at the number of CD4 cells in a few teaspoons full of blood and the "magic number" is about 200 cells/mm³. When you have less than 200 cells/mm³ you are considered to have AIDS. When your CD4 counts are above 200 cells/mm³, AIDS is usually only diagnosed if you have other health problems.

Side Effects and HIV Treatment

So your doctor or someone else has said or written that with ARV therapy, you should be able to live a long and healthy life. That's great, but you may also be aware that HIV medications can have side effects.

There is no medicine in existence that doesn't cause side effects in at least some people. Even aspirin and ibuprofen can have serious side effects. Some side effects can be as mild as a light headache or slight stomachache. Other side effects can be far more serious or even life threatening.

HIV medications are no different, but fortunately, more modern drugs generally have fewer and less serious side effects than the oldest HIV medications.

Side effects can be broken down into three major categories:

- Short-term side effects
- Chronic side effects
- Serious side effects

Short-Term Side Effects

Most medications will cause at least some people to have short-term side effects, usually headaches, nausea and upset stomachs. Some HIV medications can cause additional side effects, especially vivid dreams, difficulty sleeping and feeling out of it in the morning or during the day. In most cases, these side effects get better after just a few weeks.

Chronic Side Effects

Sometimes people have side effects that don't get completely better and that keep going for long periods of time. These are called chronic side effects. Some of these side effects are things you can feel, such as an upset stomach or vivid dreams. Some of these, however, are things you don't feel, but that can be measured with a blood test. These can include changes in the fats in your blood, called cholesterol, or minor changes in how your kidneys or bones function.

People whose virus has become resistant to the best available ARV medications often have fewer choices and must continue to take medications that are more likely to cause chronic side effects.

As frustrating as it might be to have these side effects, it's important to remember that the alternative is far worse and that if we become sick with AIDS-related illnesses, we will feel far, far worse than the side effects generally make us feel.

Serious Side Effects

Occasionally, medications can cause more serious side effects. With HIV drugs, this can include dangerous rashes and more serious liver or kidney problems. Fortunately, serious side effects are far less common with most currently available HIV medications. However, your doctor should warn you about potential symptoms and be monitoring your health regularly to look out for serious side effects before they occur.

Interactive Exercise #3 – Overcoming Side Effects (10-15 minutes)

Facilitate a dialogue about people's fears about and experiences with side effects. The main goal is to help people understand that although they might have to deal with side effects, they don't have to let side effects ruin their lives. Following are the questions to discuss:

- What side effects have you heard about that you fear most?
- If you are on treatment for any condition, including HIV, what side effects have you found easiest and hardest to deal with?
- Some side effects you can keep a secret, and others might be more noticeable (such as if you had to go and vomit at school). What might be the best explanations you can come up with ahead of time if you have side effects that are noticeable to other people?
- What strategies can you use to deal with or overcome side effects. The facilitator may need to give examples.
- What would give you the biggest motivation to keep taking your medication even if you had side effects?

The Benefits of Treatment and Beyond

Though we have only had modern HIV medications for about 15 years, researchers have been able to do calculations about the life expectancy of people living with HIV who are on successful ARV therapy. Recent studies indicate that a person starting treatment in their adolescence or 20s, and who starts treatment early, will likely live almost as long as a person who is not infected with HIV. Even if you were born with HIV or infected as a baby, you can live a long and healthy life provided that you are able to preserve treatment options.

Also, researchers are furiously at work studying how we might one day be able to treat HIV without asking people to take pills every day. They are also working on a cure for HIV. Many avenues are being studied including therapeutic vaccines and gene therapy.

One thing for certain is that HIV treatment is likely to look different 15 years from now, just as it looked different 15 years ago. Science is proceeding rapidly, and there is good reason for hope for the future.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 8

Mind over Matter

(35-45 minutes)

Learning Objectives

1. Participants will be able to enumerate the psychosocial challenges of living with HIV as a youth.
2. Participants will be able to describe methods for positively handling the psychosocial challenges of living with HIV.

Facilitator's Note

In this module we will be discussing both everyday stress and more serious mental illnesses, such as major depression and anxiety. Before conducting this session, facilitators should be prepared with resources for both emergency and out-patient mental health services and be prepared to stay after if someone relates that they feel in crisis.

Stressed Out

As adolescents and young adults, HIV may sometimes seem like the least of our concerns. There are huge pressures to fit in socially. There are changes in our bodies, some of which can seem to happen almost overnight. There are enormous pressures to do well in school and to please our families. There are frequently pressures to work and to do chores at home. This is just the beginning of the list.

HIV can place additional pressures on us, however. These may include changes in how we feel physically due to illness or side effects from medications. They may also include the stress involved in managing how we disclose our HIV diagnosis—who we tell, when, and how.

For most human beings, stress is simply a part of life. Some of us have more stress than others, but all of us have stress. Learning how to deal with stress is a skill we usually start learning when we are children. We don't always get our way and we have to deal with a world that is often confusing and disappointing. Just because we have pressures on us, however, it doesn't mean that we have to be ruled or made miserable by those pressures.

Following are a few techniques for dealing with stress:

Talk It Out

Problems kept in a dark box tend to grow bigger, and keeping stress bottled up inside can really makes things worse. Not only does it leave you feeling alone with what you are experiencing, but also your emotions can build up and become more difficult to deal with. When you get stressed out you can end up lashing out in anger at others, fall down on your obligations, or be tempted to hurt yourself. All of this can make stress even worse.

Finding someone you trust and who listens well can be one of the most powerful things you can do to deal with the stress you feel. This is especially vital for HIV-positive young men. Culturally, boys and men are often taught to stuff their feelings and “tough it out,” but young men need to vent and share their feelings as much as young women.

Do think carefully, however, about with whom you discuss your problems. It’s important to choose someone you know you can trust to keep your confidences.

If you don’t have friends or family members you can talk to about your stress, there are usually peer-support groups or counselors who can often help.

Count to 10

One of the things we tend to do when we are stressed is to act more impulsively. We may yell at someone or say something we didn’t mean to say. We may take an action we later regret. We may decide at the last minute not to do something important to us. When we are feeling emotions very powerfully, it can be helpful to literally count from one to 10 (or even 100) in our heads, breathing deeply along the way.

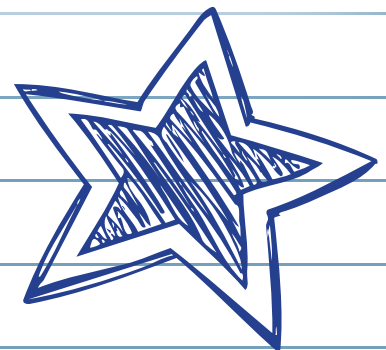
What this does is put space between our initial reaction and how we choose to act or what we choose to say. This is especially helpful when we feel anger and frustration or fear. When we’re angry we may say hurtful things and when we’re afraid we may be tempted to be dishonest in a way that may later come back and harm us and that may cause pain to others.

Take Baby Steps

Sometimes problems seem so huge we don’t think we will ever be able to deal with them. Often, however, it is possible to break those large problems into much smaller problems, which by themselves are not so overwhelming. Let’s say that you have a huge paper that is due in school. If you stay focused only on the final product and the due date, it is easy to become overwhelmed.

Instead, start small. Is there something you have to read first before doing the paper? Can you start by reading only a single chapter or a page? Can you write an outline first and focus only on that? Can you put together a to-do list for everything you will need to do in order to complete the paper and tackle only the first step or two?

The same skill can be employed with personal problems. Have you been arguing a lot with your parents? As a first step, who can you talk to in order to share your frustrations and feelings? Can you chart out the things you tend to argue about most? Can you think through the reasons your parents might be upset with you or coming down on you? Can you think of ways to express how your parent’s behavior has made you feel in a way you think they might listen to and practice what you want to say with a trusted friend? Focusing on these smaller steps can help a lot in the long run and keep you from being overwhelmed.



Interactive Exercise #1 – The Stressinator (15 minutes)

- Pass out strips of paper (five per participant) and pens or pencils. Have participants write down three to five things that have stressed them out recently. Let the participants know that they will be discussing these things with the group, so they shouldn't write down anything they don't feel comfortable talking about. Give the participants about 3 minutes to write down their stressors and then collect them in a bowl or a hat.
- Ask for a volunteer to randomly pick the stressors out of the bowl and read them aloud. When a person recognizes their stressor they should be invited to share more information about how and why they get stressed out. They should then be offered the chance to suggest ways that they might be able to deal with the stress, but shouldn't be made to feel bad if they can't think of one themselves.
- After the person introduces their stressor and what they might do about it, turn to the rest of the participants and ask them if they've dealt with similar stresses in the past. Ask them to share their experience and if they were able to do things that reduced or eliminated that stress. Ask people to focus not so much on giving advice as on sharing their personal experience. Provide a model for this behavior. Continue for another 10 to 12 minutes.

Mental Health Realities – More Serious Problems

Most people struggle at one point in their lives with feeling down, and many also experience more serious mental illness. Roughly one in four people will experience a serious episode of depression, anxiety or other mental illness during the course of a single year.

For people living with HIV, mental illness is even more common. In some surveys, roughly half of all people living with HIV report symptoms of serious clinical depression or anxiety. This is likely true for two reasons. First, people with depression, anxiety, bipolar disorder and other mental illnesses tend to engage in activities that place them at higher risk of HIV in the first place, including unprotected sex and injection drug use.

Second, and this is very important, simply living with HIV and all of the stigma and stress it can cause is also very hard on your heart and mind and by itself can cause depression and anxiety.

The most important thing to remember is that just as with HIV, there is no shame in having a mental illness. Mental illnesses are diseases like any other.

Mental Health and Age

Though children also experience mental health issues, many common mental disorders don't show up until people enter their adolescence or early adulthood, and these changes in how we feel can be stressful and surprising. This is even truer when you must deal with a major life stressor such as HIV.

How to Recognize the Signs

Treatment for most mental illnesses is the same whether you are HIV-positive or -negative, though people living with HIV—and especially adolescents—should ideally seek individual or group counseling with someone who understands their unique challenges; especially stressors around disclosure and dealing with family, friends, and sex and romantic partners.

The first step to treating mental and emotional problems is recognizing them when they occur and seeking help. Here are the symptoms for major depression and anxiety:

[Facilitator's note – Make a page in the training manual that can be photocopied so that participants can read along with the signs and symptoms, pass these around before starting the exercise]

Interactive Exercise #2 – Please Stand Up (15 minutes)

Explain to the participants that you are going to be reading off a list of symptoms of both depression and anxiety. Ask them, to the degree that they feel comfortable, to stand up or raise their hands when they hear a symptom read aloud that they have experienced at one time or another. The point of the exercise is not to expose people or to diagnose someone as having major depression or an anxiety disorder, but rather to demonstrate how common it is for people to experience these symptoms. You should also raise your hand or signal when you come to an experience that you've had. Read the following aloud, giving people time to stand up or raise their hands:

Symptoms of major depression

- Thoughts or attempts of suicide
- Feeling sad most of the time
- Feeling guilty or worthless
- Feeling emotionally numb
- Feeling like life is overwhelming and beyond control
- Feeling helpless to change one's circumstances
- Feeling fatigue and low energy
- Feeling irritable and restless
- Feeling achy or having an upset stomach or a headache that won't go away even with medication
- Feeling more or less hunger
- Having trouble sleeping (especially waking early and being unable to get back to sleep)
- Sleeping all the time
- Losing interest in the things that one used to find important or pleasurable
- Losing the desire for sex

Symptoms of anxiety disorders

- Excessive, ongoing worry and tension
- An unrealistic view of problems
- Restlessness or feeling "edgy"
- Irritability
- Muscle tension
- Headaches
- Sweating
- Difficulty concentrating
- Nausea
- The need to go to the bathroom frequently
- Tiredness
- Trouble falling or staying asleep
- Trembling
- Being easily startled

Next, ask people to discuss the following questions:

1. How do you think society feels about people who experience more serious depression and anxiety? Are there stereotypes about "crazy people?"
2. Do you think there are similarities between the stigma of HIV and the stigma of living with a mental illness?
3. How did it feel to see how common it is for people to experience the symptoms of depression and anxiety?
4. How do you think you might talk about it with a provider, friend, partner, or family member when you feel these kinds of symptoms?

Getting Help

Just because someone has experienced a symptom or two or three, that doesn't necessarily mean that they are having a major depressive episode or a formal anxiety disorder. To be diagnosed with major depression or anxiety, you usually need to have multiple symptoms that have persisted over a period of time. It's also best not to try and diagnose yourself. Instead reach out to a trained and licensed mental healthcare provider.

The most important things to know about mental illness are:

- You won't always feel this way. You can feel better.
- Treatment, both talk therapy and medication, are effective treatments for both depression and anxiety.
- Medication is effective even for more serious illnesses, such as bipolar disorder and schizophrenia.
- Untreated mental illness can cause you to have problems with friends and family, to do poorly in school and at work, and to do less well taking HIV medications.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.



MODULE 9

Alcohol and Other Substances

(45 minutes)

Learning Objectives

1. Participants will be able to talk about how alcohol and other drugs can interact with HIV medications.
2. Participants will be able to discuss strategies for negotiating and avoiding misuse of substances and will know where to turn for help

Facilitator's Note

Before the training, gather resources for people who may have substance use challenges. These can include brochures about alcohol and drugs from programs and groups as well as contact information for substance use treatment programs.

Drugs and Alcohol - An Introduction

It is extremely common for adolescents and young adults to experiment with alcohol and other drugs and that is just as true for adolescents living with HIV as it is for adolescents who aren't HIV positive. It's important to know, however, that if you are HIV positive, you might be more likely to have negative effects from using alcohol and other drugs and this is especially true if you are also taking antiretroviral medication. Our intention here is not to make judgments about whether it's right to drink or use drugs, but instead to provide you with information and skills to keep you healthy and safe no matter what you choose to do.

The "Upsides" of Drugs and Alcohol

To be honest, drugs and alcohol can have effects that we can mistakenly consider good for us. When we are drunk or high we may have more confidence and care less what others think about us. We may feel less emotional and physical pain. We may be able to forget about things that usually stress us out. We may feel more attractive and more sexual. Alcohol and drugs can make it easier to talk to or flirt with someone we are attracted to or to have sex with someone.

Interactive Suggestion

Stop here and ask people if they can list other ways that alcohol and drugs may offer positive experiences. This can help increase trust that people who drink and use drugs won't feel as put down or preached at because they drink or use drugs.

The Downsides of Drugs and Alcohol

HOWEVER, there are a number of downsides to drugs and alcohol that should also be kept in mind. As much as we might like to feel high or drunk, eventually we have to come down, and coming down can be painful, especially when we have a hangover from alcohol or come down from ecstasy or crystal methamphetamine.

Drugs and alcohol can also be addictive. The common vision of the alcoholic or drug addict is the person who stays drunk or high all day every day, but the much more common reality is that people who get addicted to drugs and alcohol simply have a hard time dealing with the realities of daily life without drinking or using. The consequences of that can be relationship difficulties with parents, friends and family, problems in school or at work, and an increased risk for depression and anxiety.

Breaking Down Substances

Alcohol and most drugs are broken down in the body in the liver and kidneys. The liver and kidneys actually treat these substances as toxic poisons and do their best to get rid of them as quickly as possible. Alcohol, in particular, is really hard on the liver.

Unfortunately, HIV can have negative impacts on the liver and kidneys as well. When the virus is reproducing, especially at high rates, this can cause cells in the liver and kidneys to become “inflamed” and to work too hard, and eventually they can burn out, leading to liver scarring or kidney cell death and reducing the ability of both organs to do their jobs properly.

When you add antiretroviral drugs or other medications into the mix, this gets particularly complicated and potentially more harmful, as those drugs often must also be broken down by the liver.

When one drug, say ecstasy, competes with another drug, say the ARV drug ritonavir, one of them wins and the blood level of the other can rocket sky high, which not only increases the effect of that drug, but also its side effects. Blood levels of the other drug can also plunge, meaning that the drug can't work well. This is especially important with HIV drugs, as taking something that lowers the dose of HIV medications too often not only allows your virus to reproduce, it could lead to drug resistance.



Complex Interactions

Our liver is an amazing organ. Not only does it produce the building blocks of all of our cells, it also helps to break down the food we eat and the medicines or drugs that we consume.

The way the liver breaks down drugs and alcohol is to produce proteins and enzymes that latch onto those substances and break them into different chemicals that can then be eliminated from the body.

As we've already said, competition for those liver enzymes among various drugs and foods can be quite fierce. This is especially true for antiretroviral drugs, many of which are quite vulnerable to changes in liver enzymes.

Here are some of the complex types of interactions that can happen with a hypothetical ARV drug and a street drug:

- Blood levels of both the ARV drug and the street drug could go up.
- Blood levels of both the ARV drug and the street drug could go down.
- Blood levels of the ARV drug could go up and the street drug could go up, down or stay the same.
- Blood levels of the ARV drug could go down and the street drug could go up, down or stay the same.
- Blood levels of the ARV drug could stay the same, but levels of the street drug could go up or down.

As you can see, understanding what happens when we combine different drugs is very complex.

One type of ARV drug that can have particularly strong interactions with alcohol or other drugs is the protease inhibitors. This includes lopinavir and ritonavir, which can be prescribed with other protease inhibitors. Another type of ARV drug that can cause problems is the non-nucleoside reverse transcriptase inhibitor (NNRTI) efavirenz, which is sometimes prescribed alone and sometimes in a single combination pill that contains two other ARV drugs.

It's also important to remember when we say "other drugs" that may interact with ARV drugs; this includes drugs we or others were prescribed, such as mental health medication and painkillers and sedatives.

Because depression and anxiety are so common in people living with HIV, a lot of people also take psychiatric medication. It's important to know that these drugs can also interact with alcohol and other drugs and that they may not work as effectively or have worse side effects.

When Is Too Much a Problem?

As we said, there's nothing inherently or morally wrong with drinking alcohol or using drugs, and we understand that many adolescents and young adults, including those living with HIV, do drink and use.

Aside from potential problems with drug interactions, however, there is the risk that these substances can be addictive in at least some people. But how much is too much?

Following is a list of hints that you might be drinking too much or using drugs too much and that you might need help to moderate or stop using.

Interactive Exercise #1 - Hope and Help (10-15 minutes)

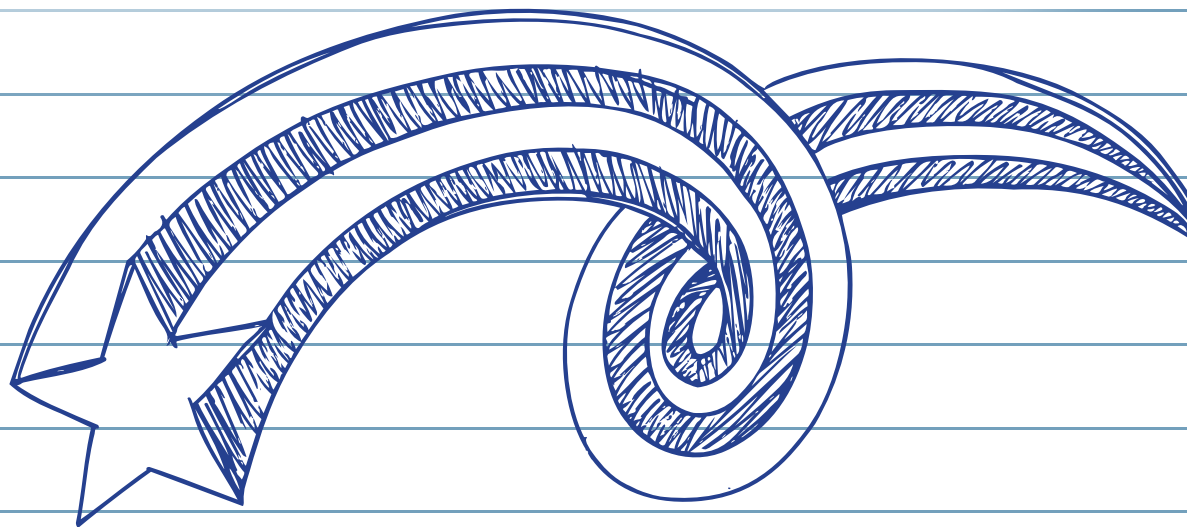
Pass out a photocopy of the list and read through it. Explain that no single symptom guarantees that someone is addicted to drugs and alcohol, but that several symptoms together can indicate a problem that should be explored. If you care to elaborate on any of the signs and symptoms, feel free to do so.

Signs and Symptoms of Alcoholism and Drug Addiction

- Feeling that you have to use the substance regularly — this can be daily or even several times a day
- Failing in your attempts to stop using the substance
- Making certain that you maintain a supply of the substance
- Spending money on the substance, even though you can't afford it
- Doing things to obtain the substance that you normally wouldn't do, such as stealing or engaging in sex with people you don't want to
- Feeling that you need the substance to deal with your problems
- Driving or doing other risky activities when you're under the influence of the substance
- Cutting classes and failing to do your homework, because you were drunk or high
- Regularly passing out and not remembering what you've done
- Frequently arguing with friends or family members about your drug or alcohol use
- Focusing more and more time and energy on getting and using the substance

Next, lead a discussion using the following questions:

1. What are common stereotypes that people have about alcoholics and drug addicts?
2. How are those stereotypes true, and how are they not true?
3. Do you know someone who is an alcoholic or drug addict? How did it affect their lives and how did they affect you? If no one has a story to share, be prepared with a story of your own.
4. What have you heard about methods to help people moderate or minimize their drinking and using?
5. If you are using or drinking too much, what are some things you could do to slow down, stop, or seek help?



Interactive Exercise #2 – Hot Potato (15-20 minutes)

Equipment Needed

Large potatoes and a stereo or MP3 player with speakers

Instructions

- Have the group gather around in a circle standing up. Pass out one potato per group.
- If the group has more than 12 participants, break the larger group into two or more smaller groups of six to eight.
- Explain that we will be playing “Hot Potato” and that the goal is to be the last person in the group who is NOT holding a potato.
- The facilitator will start the music and people will toss the potato to one another. If someone drops the potato, they simply have to chase the potato and then toss it to someone else. When the music stops, whoever was holding, catching or chasing the potato will be out. Continue playing until there are only two people left. As before, the one left “holding” the potato will be out and the other person will win the game. Facilitators should play the music for about 20 seconds between rounds.
- To get people energized and engaged play a second and third round.
- Facilitators may offer small gifts (e.g., candy, small gift cards, etc.) to the winners.

Facilitator: After you conclude playing the game explain that the purpose is to demonstrate how frustrating and anxiety provoking it can be to be the person left holding the potato and how this can be similar to the moment that someone offers you a drink or drug or encourages you to drink or use when they aren’t certain that they want to or when they know it might cause problems.

When this happens people often don’t know what to say. While we’d like to just toss the potato and have someone else make the decision, it is up to us to make that choice. Use a guided discussion to allow people to generate ideas for how to decide in a quick moment what to do and what to say.

Discussion Questions

1. If you don’t want to drink or use, but you’ve been offered something, what do you say and how do you say it? Can someone think of an example?
2. What would you do or say if you were being pressured really hard to drink or use by a friend or by a group of people?
3. Does anyone have an example of a time you faced a lot of pressure to drink or use when you weren’t sure you wanted to or should?
4. Does anyone have an example of a time they did drink or use when they didn’t want to? How did it feel and what happened?
5. If you want to use or drink, but know it might cause problems, how would you handle that? Potential problems could be that you have homework due, or you have to go to work, or that you have to be home for dinner in a short while.
6. If you decide to blow off your commitments, how do you best handle that later?

Closing

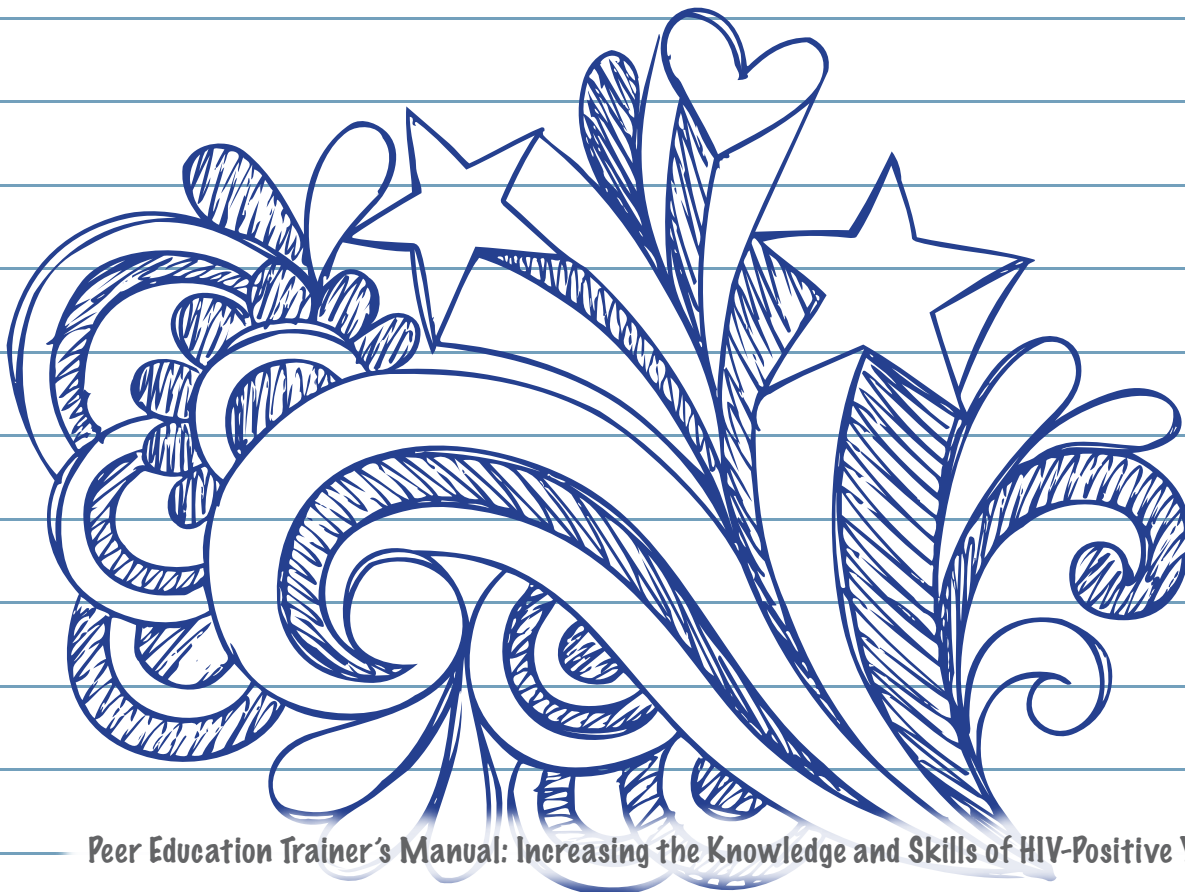
As we said before, drugs and alcohol are not all good and they're not all bad. Some people manage not to have problems, but some people do have problems and the consequences of their drinking too much or using drugs too much can sometimes be severe.

One of the most important things you can do if you are HIV positive and decide to drink or use drugs is to tell your HIV healthcare provider. They may react judgmentally, at least at first, but it is important for them to know, especially if you are taking any kind of medication.

Lastly, if you are using more than you want to, don't hesitate to reach out to a trusted friend or family member, social service provider or healthcare provider.

Facilitator's Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.



MODULE 10

Pregnancy and Family Planning

(20-30 minutes)

Learning Objectives

1. Participants will be able to enumerate methods for avoiding conception and how those are similar to safer-sex practices.
2. Participants will be able to discuss the use of ARV drugs in early pregnancy.
3. Participants will be able to discuss how some antiretroviral drugs may interact with hormonal contraceptives.
4. Participants will be able to discuss how HIV-positive women and mixed status couples may be able to safely conceive children.

Facilitator's Note

This module will be more relevant to some participants than others. If the majority of the participants are heterosexual females or males, this module can be combined with the module on Latex and Safer Sex.

HIV and Family Planning

Family planning means exactly what it says: we can plan when and whether to have children. Though no method is foolproof, condoms and other contraceptives can be remarkably effective when used properly.

Family planning for men and women has changed dramatically since the beginning of the epidemic. Before the introduction of ARV therapy administered during pregnancy, nearly a quarter of all HIV-positive women passed on the virus to their infants. Breast feeding resulted in even more transmissions taking place in infants who weren't infected prior to birth or in the birthing process.

Today, where good prenatal care and antiretroviral therapy is available, the risk of transmission from mother to child has fallen dramatically. In some parts of the world, there have been no HIV-positive babies born for several years in a row.

This dramatic change in the risk of mother-to-child transmission has resulted in similarly dramatic changes in how motherhood and contraception are viewed for HIV-positive women. Whereas HIV-positive women once were told they must do everything possible to avoid pregnancy, experienced obstetricians now regularly help HIV-positive women to have a safe pregnancy and to avoid passing on the virus to their children.

The whole point of this module is to help HIV-positive young men and women learn to avoid pregnancy if they choose not to have children right now and to explain how to safely have children if they choose to.

First, however, let's talk about tools to avoid pregnancy.

Condoms and Birth Control

One of the simplest, cheapest and safest methods of HIV prevention—the use of either a male or female condom—also happens to be one of the cheapest and safest methods to avoid having a baby. This is important not only for mixed status couples, where one person is HIV positive and the other is not. It's also important when both partners have HIV, as it is possible to be infected with more than one strain of HIV. This is called “super-infection.” Thus, condoms should be a central part of any strategy to avoid pregnancy.

Other methods can provide additional protection against pregnancy, even though they do not prevent HIV transmission or sexually transmitted diseases.

Diaphragm

A diaphragm is a shallow silicone cup that is inserted in the vagina. Diaphragms are relatively inexpensive and easy to use. They last about one to two years.

Intra-Uterine Device (IUD)

An IUD is a very small “T”-shaped object that is inserted by a healthcare provider into the uterus of a woman. While IUDs are a bit more expensive, they can last for up to 12 years.

Birth Control Sponge

This is a foamy sponge that has a substance in it that kills sperm. They can only be used once. Also, the sperm-killing substance, called nonoxynol-9, may increase the risk of HIV infection for the woman.

Hormone-Based Birth Control

There are a variety of ways to deliver hormones to the blood stream or the uterus to avoid pregnancy. The hormones used to block pregnancy are estrogen and progesterin. Most hormone-based contraceptives use both hormones. Methods for delivering the hormones include:

- Pills that are taken daily;
- An “emergency” pill that can be taken up to five days after unprotected sex;
- Skin patches or vaginal rings that last about a month and are used while the woman is not having her period;
- A hormone shot that lasts for about three months; and
- An implant, usually inserted into the arm, which can last up to three years.

It is important to know that the effectiveness of hormones delivered “systemically” through the blood stream can be reduced by some drugs used to treat HIV. If you are an HIV-positive woman, the doctor who prescribes your hormonal birth control should know about any other medication you are currently taking, especially HIV medications.

The drug interactions between hormonal contraceptives can go both ways. On the one hand, the contraceptives may cause the blood levels of HIV drugs to change. On the other hand, some antiretroviral drugs can cause the hormone levels to go up or down and this could increase the risk of side effects and pregnancy.

Being on HIV Medications When in Early Pregnancy

Drugs and chemicals may affect a developing fetus or young child in ways that are different to how those drugs and chemicals affect older children or adults. This is as true for HIV medications as it is for other medications. In fact, certain drugs, such as alcohol and tobacco, are particularly harmful for the developing fetus.

If you are HIV positive and trying to get pregnant, or if you become pregnant and decide to keep the baby, you should consult with a specialist in HIV and childbirth to decide which medications are the best for you and your baby.

Recommendations for HIV-Positive Women who are Pregnant

If you are an HIV-positive woman and become pregnant, there are a number of things you can do to make sure to have a healthy baby if you decide to keep it.

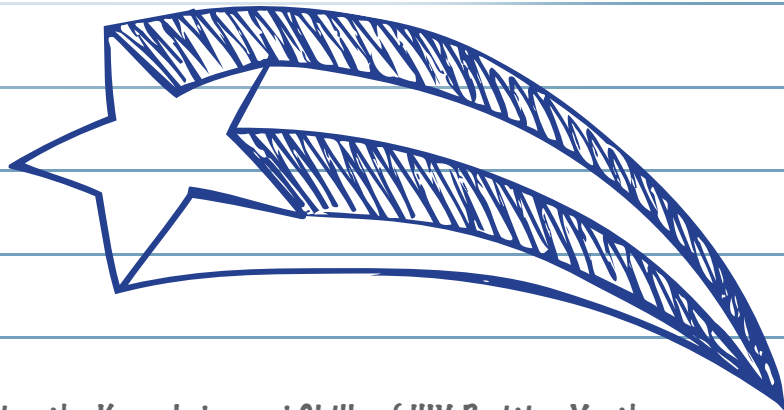
The first step is to see an obstetrician and begin good prenatal care. Prenatal care usually means taking special vitamins, avoiding alcohol, tobacco and other drugs as well as having regular monitoring of your own health and your baby's health.

Another important step is to continue or start ARV therapy. Women who keep their virus levels at or near undetectable levels are far less likely to transmit HIV to their babies. This is especially true for women during the last months of their pregnancy.

In the past, women who were taking the drug efavirenz were advised to switch medications out of fear that the drug could harm the developing baby. This was especially true during the first three months (trimester) of pregnancy. This risk of side effects for the baby has so far proven to be much lower than was previously suspected, and women who are taking efavirenz when they become pregnant are no longer recommended to switch to a different medication as long as their HIV viral load levels are undetectable.

Certain drug regimens are still preferred for pregnant women. These are included in WHO guidelines, although country-specific guidelines may be different.

NOTE: Facilitators should have research and country-specific guidelines available and discuss them.



Trying to Have a Baby

If both you and your partner are HIV positive, there is much less concern about the two of you having unprotected sex in order to conceive a child. With mixed-status couples there is much more of a concern about HIV transmission without the use of condoms.

There exist special reproductive services that have helped mixed status couples to bear children. These services, especially services where the HIV-negative partner is the woman, are fairly rare and very expensive.

More recently, the British advocacy and education organization HIV iBase produced a fact sheet on mixed-status couples who are trying to become pregnant. This was based on a guidance document produced by the British HIV Association (BHIVA) and the Expert Advisory Group on AIDS (EAGA). That statement outlined the prevention benefits within mixed-status couples when the HIV-positive partner is on ARV therapy. This was dealt with in more detail in *Module 6: Magnetic Love – Mixed-Status Partnerships*.

Based on the knowledge that antiretroviral therapy can reduce the risk of transmission to such a great degree the BHIVA and EAGA stated that, “the risk of a person living with HIV, who is taking effective [ARV therapy], passing HIV on to sexual partners through vaginal intercourse is extremely low...”

Because of this, the HIV iBase information sheet surmised that mixed-status couples can take steps to reduce the risk of transmission if they are trying to have a baby. These steps include:

- The HIV-positive partner is on ARV therapy, has no STIs, has had an undetectable viral load for six months and continues to be monitored every three to four months.
- The couple only stops using condoms during the time of the month when the woman is most fertile. This is called “timed intercourse.”
- The HIV-negative partner may consider using PrEP, whereby the HIV-negative partner takes HIV drugs to prevent themselves from becoming infected.

It is very important to note that these methods have not been studied formally as a way for mixed-status couples to safely conceive children.

Facilitator’s Note

With each module you should summarize the main points of the discussion, highlight good moments that came out of the interactive exercise, and give a brief description of the next module. If the modules are not being presented over the course of a single weekend, remind participants of the next meeting time.

MODULE 11

Into the Future

(60-70 minutes)

Learning Objectives

1. Participants will be able to express aspirations for their future.
2. Participants will be able to express how their concerns and plans around HIV disclosure have evolved through the course of the training.
3. Participants will be able to express their personal commitments to leading a safe and satisfying sexual and romantic life.

Into the Future

Adolescence and young adulthood is a unique time in a person's life. This is a time when we are often thinking as much about the future as we are about the present. We may have goals about school, partnership, families and careers. Hopefully, we will also be able to set goals for achieving or maintaining physical and mental health.

This module can be used as an opportunity to check in with participants to see how their own goals, thoughts, and feelings may have changed since the beginning of the modules. It can also be used as way to evaluate the success of the modules. More than anything, this module is as much more about drawing out the participants than it is about education, and allowing people a place to share their thoughts and feelings in a safe atmosphere. Some of the suggested discussion topics are optional, depending on how much time you would like to spend and how comfortable people are in sharing their experiences.

Before the discussion begins, set up a circle of chairs or ask participants to gather in a circle on the floor. Pass out the goal sheets to the participants that they completed during the first module. Ask people to take a minute to read through their goal sheets and to reflect on what they wrote.

After a couple of minutes, begin a guided discussion, drawing people out with additional questions as needed. Without putting people on the spot, try to get everyone to share at least something for each question.

1. When you look at the personal goals you put down on your sheet, have your goals or priorities changed since the beginning of the training? Share your goals with us and talk about why they are important to you and what you can do to help achieve them?
2. What does it mean to have wellness? How can each of you achieve that?
3. How would you define "healthy sexuality" now and what steps can you take to achieve it or maintain it?
4. Talk about how you feel about disclosing your HIV status to others and what you can do to make this process easier for yourself going forward.
5. What were your favorite parts of the modules?
6. What were your least favorite parts of the modules?
7. If we do another training, what would you do differently?
8. Is there anything you'd like to say or share with your fellows before we depart?

Conclusion

Congratulate the workshop participants on completing the modules and celebrate their commitment to their own personal wellbeing. Provide them with their small gifts (even something as simple as a polished stone or large bead to serve as a memento can be meaningful), and if you have chosen to do so, their Certificates of Completion. If you have set up a Facebook group, explain that it can continue to be a source of support and information.

By completing these modules, the adolescents and young adults have been provided with the knowledge and tools they need to minimize stigma around HIV and sexuality, make healthy and happy sexual and romantic decisions, and to achieve their personal goals. Explain that this type of learning is an ongoing process.

Advise the participants that if they wish to access the training materials or would like to run their own training, all relevant materials are available at www.iapac.org.



