

PREParing PEERS FOR SUCCESS: DAY 3

PEER CORE COMPETENCY TRAINING

A curriculum for engaging out-of-care
or newly diagnosed people living with
HIV in care and treatment



ASSESSING ADHERENCE

DRUG RESISTANCE

UNDERSTANDING LABS

STIGMA

VALUES



DAY 3: Assessing Adherence Drug Resistance Understanding Labs Stigma, & Values

An Overview of Today's Sessions and Topics

Topic	Duration	Slides	Page
Icebreaker*	25 min.		
Review of previous day*	5 min.		152
Session VIII: Assessing Adherence	2 hours (total)	55-69	107-128
Topic: Assessing Adherence	30 min	56	107-111
Topic: Adherence Barriers	25 min	57	112-113
Topic: Adherence Case Scenarios	30 min	58	114-117
Topic: Doctor-Patient Communications	35 min	59	118-128
Session IX: Drug Resistance	1 hour (total)	60-62	129-131
Session X: Understanding Labs	35 min (total)	63-79	132-134
Session XI: HIV Stigma	55 min (total)	80-84	135-142
Topic: Stigma	15 min	80	135-136
Topic: HIV-Related Stigma	15 min	81	137
Topic: The Effects of Stigma	10 min	82-83	138-139
Topic: What Not to Say	15 min	84	140-142
Energizer*	15 min.		
Session XII: Values	1 hr. 25 min (total)	85-89	143-151
Topic: Overview of Values	5 min	85	143
Topic: (Un)Push My Buttons—Examining Our Personal Values	10 min	86	144
Topic: Self-Assessment—What Pushes Your Buttons?	35 min	87	145-147
Topic: Patient-Centered Approach	25 min	88	148-149
Topic: Principles of Peer Work	10 min	89	150-151
Review, wrap-up, and evaluation*	20 min.		152-153

* See pages 7-8 for an explanation of these climate-setting activities

Throughout this curriculum, *italicized words* are intended to be spoken directly to the class.

This publication is part of the online curriculum *PREParIng Peers for Success: Peer Core Competency Training*. For the complete curriculum, accompanying PowerPoint slides, and other curricula in the series, visit <http://www.hdwg.org/prep/curricula>

This publication was supported by grant #U69HA23262, “Minority AIDS Initiative Retention and Re-Engagement Project,” through the U.S. Department of Health and Human Services, Health Resources and Services Administration’s HIV/AIDS Bureau, National Training and Technical Assistance. The contents of this publication are solely the responsibility of the Health & Disability Working Group and do not necessarily represent the views of the funding agencies or the U.S. government.

Suggested citation

Health & Disability Working Group, Boston University School of Public Health. (2014). PREParIng Peers for Success: Peer core competency training. Retrieved from <http://www.hdwg.org/prep/curricula>

SESSION VIII: ASSESSING ADHERENCE

Topic: Assessing Adherence

TOTAL TIME FOR SESSION VIII: 2 hours

SLIDES: #56-69

▶ ABOUT THIS ACTIVITY

 **Time:** 30 minutes

 **Slides:** #56

 **Objectives:**

By the end of this session, participants will be able to:

- Ask questions that assess prescription adherence

 **Training Methods:**

- Role-play
- Group discussion
- Brainstorm

 **In this activity you will:**

- Review the adherence handout
- Conduct a role-play
- Debrief the exercise

 **Materials:**

- Assessing Adherence Questions handout
- Assessing Adherence Role-Play Script
- Assessing Adherence Role-Play Trainer Answer Key
- Current medication chart

 **Preparation:**

- Prepare the handouts, including a copy of the provider and patient role-play scripts

Instructions

1. Ask participants to find the “Assessing Adherence Questions” handout and review together.
2. Ask for a volunteer to play the role of patient while one of the trainers plays the role of the peer [give the volunteer the “Assessing Adherence Role-Play” script]
3. The trainer playing the peer role should use the “Trainer Answer Key” to provide feedback to the patient after each question.

Summarize

- *Peers must learn how to assess adherence—it’s one of the most important parts of the job. Make sure you know well the answers to these questions before engaging the patient in the assessment.*
- *Over time, experience on the job will improve your knowledge and how to respond to adherence issues patients present with.*
- *Peers are responsible for providing accurate information to patients about meds and how they work.*
- *Medications are really hard to take for a long period of time. In the general population, even a 7- or 10-day regimen is difficult to finish.*

Segue

- *Next we will be exploring barriers that many HIV+ people face in taking HIV meds faithfully. We hope that you will bring up some of the adherence barriers that you face or have faced.*

SESSION VIII: ASSESSING ADHERENCE

Topic: Assessing Adherence

SESSION HANDOUT 1

ASSESSING ADHERENCE: 10 QUESTIONS YOU SHOULD ASK

1. Which meds are you currently taking?
2. How frequently do you have to take each of your meds?
3. What are the food restrictions for each of your meds (i.e., with or without food)?
4. Why do you think some meds need to be taken with food and some on an empty stomach?
5. Why do you think some meds are taken once a day and others twice a day?
6. What helps you remember to take your meds?
7. What do you do when you miss a dose?
8. What problems have you encountered from taking meds?
9. How soon before you run out of meds do you order refills?
10. Do you believe that the meds are helping you and, if so, how?

You may wish to share this handout with the patient during Peer-Patient Educational Session #5, HIV Medications and Session #6 Drug Resistance and Adherence (see guide on pages 18 and 19).

SESSION VIII: ASSESSING ADHERENCE

Topic: Assessing Adherence

SESSION HANDOUT 2

ASSESSING ADHERENCE ROLE-PLAY SCRIPT

One of the trainers plays the interviewer; a volunteer from the audience plays the patient.

Provider: Are you currently taking meds? If so, which ones?

Patient: Reyataz with Norvir, ziagen, 3TC, AZT.

Provider: Do you know why you are taking HIV meds?

Patient: I take them because I have HIV.

Provider: Do you know what the meds do when they get into your body?

Patient: Not really.

Provider: When do you take your meds?

Patient: I take Reyataz and Norvir once a day and Ziagen, 3TC and AZT twice a day.

Provider: How do you take your meds?

Patient: I have to take Reyataz and Norvir with food, and Ziagen, 3TC and AZT with food or empty stomach.

Provider: Why do some meds need to be taken with food and some on an empty stomach?

Patient: I don't know.

Provider: Why are some meds taken once a day and some twice a day?

Patient: I don't know.

Provider: What helps you remember to take your meds?

Patient: I rely on my memory.

Provider: What do you do when you miss a dose?

Patient: I double up next time.

Provider: What problems have you encountered while taking this medication, and how are you managing these problems?

Patient: Nausea and diarrhea, sometimes I take Pepto Bismal.

SESSION VIII: ASSESSING ADHERENCE

Topic: Assessing Adherence

SESSION HANDOUT 3

ASSESSING ADHERENCE: 10 QUESTIONS YOU SHOULD ASK

Question 1 (Which meds are you currently taking?): Congratulate the patient on remembering the names of her HIV meds.

Question 2 (Why are you taking HIV meds?): Validate this response – patient is right, she’s taking meds because she has HIV; however, a patient’s knowledge about why she is taking meds should be more expansive, and this is addressed in the next question.

Question 3 (What do the meds do when they get into your body?): This is an opportunity to discuss the HIV life cycle (keep it simple):

- When the medications get into your body they go into the T-cell to fight HIV and keep it from multiplying and infecting other T-cells. Without medications the virus can continue to multiply until there are too many viruses for your immune system to fight.
- Reyataz and Norvir are protease inhibitors and they prevent the formation of new HIV.
- Ziagen, 3TC and AZT are Nucleoside Reverse Transcriptase Inhibitors or “nukes” and they block HIV from changing, which it needs to get into the center of the T-cell. By preventing access to the center of the T-cell, the virus is unable to create more copies of itself.

Question 4 (When do you take your meds?): Validate this response—patient knows when each medication is supposed to be taken.

Question 5 (How do you take your meds?): Validate this response—patient knows how to take each medication.

Question 6 (Why do some meds have to be taken with/without food?): Some meds work better with food. Your body is better able to absorb them if taken with food. Some meds work better with an empty stomach. Your body is better able to absorb the medication if taken one hour before or two hours after you eat. Not following these rules can lead to poor absorption, which can decrease the medication in the blood to a level below what is needed to fight the virus. This can lead to resistance.

Question 7 (Why are some meds taken once/twice a day?): Every medication has a “life” in the blood before your body eliminates it; once-a-day meds have a 24-hour life. If you go more than 24 hours without taking the once-a-day med, the level of medication in the blood drops below the level needed to fight HIV. Twice-a-day meds have a 12 hour life before your body eliminates it. If you go more than 12 hours, the level of medication in the drug drops below the level needed to fight HIV. When medication levels drop, a window of opportunity opens up for HIV to replicate as fast as possible. If the level of medication in the blood drops frequently (more than twice a month), you can develop resistance.

SESSION VIII: ASSESSING ADHERENCE

Topic: Assessing Adherence

SESSION HANDOUT 3 (Cont.)

Question 8 (What helps you remember to take your meds?): Give patients different ideas for how to remember to take meds:

- Alarm clock or timer (including cell phone)
- Pill boxes
- Storing them visibly
- Have someone in your life to remind you
- Put in the shoes you're wearing the next day.
- Keep some meds at work and some at home (if the person is employed).
- Make an association between a daily activity and taking your meds, i.e., mealtime, before or after the gym, lunchtime, when you first get up in the morning, etc.

Question 9 (What do you do when you miss a dose?): Doubling up can be toxic and may exacerbate your side effects, or can lead to adverse reaction. If you forget to take a dose, try to take it within 3 or 4 hours of the time you were supposed to take it. Otherwise, wait until your next dose.

Question 10 (What problems have you encountered taking meds?): Nausea and diarrhea can be addressed with or without medicine. If your preference is with medicine, you can ask your doctor to give you a prescription to treat diarrhea and nausea. Or you may opt to use certain food to relieve these side effects, such as white toast, crackers, bread, bananas, white rice, apples/applesauce, tea, ginger ale or ginger snacks, etc.

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Barriers

▶ ABOUT THIS ACTIVITY

 **Time:** 25 minutes

 **Slides:** #57

 **Objectives:**

By the end of this session, participants will be able to:

- Identify and discuss barriers to adherence that HIV+ people face

 **Training Methods:**

- Brainstorm
- Group discussion
- Small-group exercise

 **In this activity you will:**

- Facilitate a brainstorm on barriers to adherence
- Conduct a small-group exercise on solutions to a barrier
- Debrief the small-group exercise

 **Materials:**

- Newsprint
- Markers
- Tape
- Video on adherence barriers

 **Preparation:**

- Prepare video for playing, if available.
- Contacting pharmaceutical reps may be useful in order to obtain a video related to this topic.
- Additionally, there are a variety of medication adherence barriers/side effect videos on youtube.com from which to choose. Here are some example videos to choose from:
 - <http://www.youtube.com/watch?v=myLpW7ThXkw>
 - <http://www.youtube.com/watch?v=xLvGK8aYk3A>
 - <http://www.youtube.com/watch?v=evRon-OKs9E>

Instructions

1. Turn to slide 57.



2. Facilitate a brainstorm on barriers to adherence and document on newsprint.
3. Encourage participants to name the barriers they themselves face or have faced. Some possible answers include: side effects, fear of toxicity, fear of lipodystrophy, constant reminder of HIV status, forgetfulness, breaking daily routine, living or working with people who don't know your status, not getting refills on time.
4. Once a list of barriers has been generated, break participants out into groups of 3.
5. Assign each group three of the barriers and ask them to come up with possible solutions for each barrier assigned. Each group should assign a recorder and a reporter.
6. Ask each group to report out their solutions.
7. Ask the larger group if they would add anything to the list of solutions.
8. Trainer should review all possible solutions.
9. Play a video on adherence barriers and side effects.
10. Facilitate discussion after the video.

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Barriers

Summarize

- *The most common reason that people stop taking their meds is side effects; sometimes people won't start meds because of the anticipation of side effects.*
- *Helping patients find solutions to barriers leads to better adherence and better health.*
- *Peers should learn as much as possible about adherence barriers and solutions so that they can be responsive to patients' adherence issues; try to offer more than one solution.*
- *If you don't know the solution, it's OK to tell the patient that you don't have the answer right now but will find it and get back to them. Don't be afraid to ask people you work with such as the care team. You can also conduct your own research by visiting HIV-related websites, e.g., Project Inform, the Body, Kaiser, Poz, etc.*

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Case Scenarios

▶ ABOUT THIS ACTIVITY

 **Time:** 30 minutes

 **Slides:** #58

 **Objectives:**

By the end of this session, participants will be able to:

- Discuss adherence with patients

 **Training Methods:**

- Small groups
- Large-group discussion

 **In this activity you will:**

- Facilitate a small-group activity around adherence
- Lead a discussion of results

 **Materials:**

- Adherence Case Scenarios
- Playing cards

 **Preparation:**

- Print out scenarios
- Spread playing cards face down on a table.

Instructions

1. Turn to slide 58.



2. Tell participants that we are going to do an activity. Ask them to go to the table with playing cards spread out facing down and to pick one card.
3. Ask participants whose cards are hearts to go to one corner, those with diamonds to another corner, clubs to the third corner and spades to the fourth corner. (This is another way to randomly group participants).
4. Give each group a case scenario for discussion and ask that each group answer the questions for their scenario (these questions appear at the bottom of each case scenario).
5. Ask for a recorder and a reporter from each group.
6. At the end of 20 minutes, ask participants to stop.
7. Ask each group to report out by reading their scenario out loud and presenting their answers to the 3 questions.
8. After each group reports out, ask the larger group to add any other ideas.
9. Give a round of applause after each presentation.

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Case Scenarios

Summarize

- *Adherence is achievable with education/mentoring, reminder strategies, side effects management and emotional support.*
- *Everyone on the care team plays a role in adherence, not just the patient or the peer.*
- *Always remember to talk to patients about challenges you've faced with your own adherence (storytelling) and how you came to address them—this is what role modeling means!*

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Case Scenarios

SESSION HANDOUT

ADHERENCE CASE SCENARIOS

Michelle

Michelle receives her HIV care at MGH and has been referred to you for adherence support. Michelle has been complaining about side effects that include intense nausea and diarrhea and overall sickness every day. She was prescribed 3 HIV meds, 1 has to be taken twice a day, and 2 only once a day. She takes the once-a-day meds with her dinner at 7:00 p.m. and has no trouble remembering to take them because she has made a connection between eating dinner and taking her meds. However, because she often forgets to take the second dose of the twice-a-day pill, she has decided to take ALL of her pills at the same time.

Questions for your group

1. What might be the reason for Michelle's intense side effects?
2. What would you say to Michelle about the way she's taking her meds?
3. What would you recommend to her?

Darlene

Darlene just saw her doctor who informed her that her viral load is higher than the last time it was checked. He asked her if she was taking her meds as prescribed and she said yes. The doctor asked her to come back in a month to have her viral load checked again and referred her to you in the meantime. Upon checking in with Darlene, you discover that she skips her meds on weekends because she likes to drink alcohol and doesn't want to mix the two.

Questions for your group

1. What may be the reason for Darlene's higher viral load?
2. What would you say to Darlene about the way she's taking her meds?
3. What is she at risk for?
4. What would you recommend?

SESSION VIII: ASSESSING ADHERENCE

Topic: Adherence Case Scenarios

SESSION HANDOUT (Cont.)

Lisa

Lisa has been referred to you because she is about to start meds for the first time. You go over the instructions and find that one of her meds must be taken with food and one must be taken without food. She doesn't understand what difference it makes to take them with or without food. She tells you that she's just going to take all of them with food because it would be easier on her stomach. She also said she's going to take them every other day to give her digestive system a break between meds because she's afraid of side effects.

Questions for your group

1. What would you say to Lisa about how she plans to take her meds?
2. What reasons would you give her about why some meds need to be taken on an empty stomach?
3. What would you say to her about giving her digestive system a break between meds?

Carmen

Carmen was told by her doctor that she has developed resistance to her meds. She was given a new prescription and was referred to you for support. Her doctor said to stop the old meds today and start the new ones tomorrow. Carmen tells you that she doesn't know why her current meds aren't working anymore; she's confused and doesn't know what it all means. She also shares that she's experiencing the same negative feelings she felt when she went on meds for the very first time and starts to cry.

Questions for your group

1. What do you do when Carmen starts crying?
2. How would you explain why her meds aren't working anymore?
3. How would you support her during this transition?

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

▶ ABOUT THIS ACTIVITY

 **Time:** 35 minutes

 **Slides:** #59

 **Objectives:**

By the end of this session, participants will be able to:

- Build skills in preparing for visits to the doctor

 **Training Methods:**

- Brainstorm
- Large-group discussion
- Role-play
- Skills practice

 **In this activity you will:**

- Brainstorm visit preparation activities
- Conduct two role-play activities to practice visit preparation skills
- Debrief both exercises

 **Materials:**

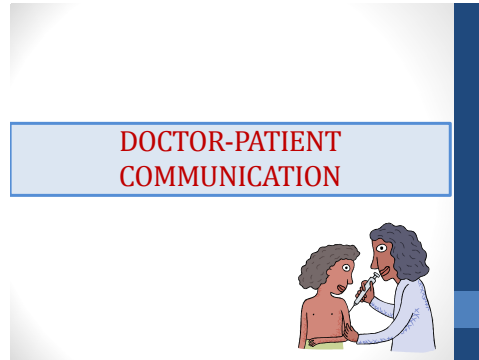
- Skit props (Hats, white coat, stethoscope, clipboard, bag, scarf)
- How To Prepare for a Visit to Your Doctor handout
- Symptoms Log sheet
- Questions for your Doctor about Medications
- Patient Rights handout
- Patient Responsibilities handout
- Role-play #1 and #2 scripts

 **Preparation:**

- Prepare role-play character instructions and scenarios (one for each role in the 2 skits)
- Identify participants to volunteer for the role-play and prepare them ahead of time.

Instructions

1. Turn to slide 59.



2. Tell participants that we are going to do an activity: *This activity is a brainstorm about what you need to do to prepare for a visit with your doctor.*
3. Ask: *What are some things you do to prepare and be ready for a visit with your doctor?* Document responses on newsprint. Possible answers: Keeping a journal or calendar of symptoms, being prepared to describe side effects including symptoms, bringing medications in a bag or have them on a list, bringing a friend, bringing a list of questions for the doctor, etc.
4. Draw participants' attention to the handout "How to Prepare for a Visit with Your Doctor and Symptoms Log" and review together.
5. *These suggestions are ways to help us better communicate with our doctor. As patients, we all have the right to ask questions and get answers. Be honest with your doctor and have a dialogue. Your relationship with your doctor plays an important role in your health. One important part of communicating with your doctor is knowing and asking about your medications. If your doctor gives you a prescription, what questions should you ask?* Document responses on newsprint. Possible answers:
 - a. *Why have I been prescribed this medication?*
 - b. *How should I take it?*

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

- c. *Are there any special storage requirements?*
- d. *Should I take it with or without food? Will it make me feel worse? What are the side effects? How many and how often should I take them?*
- e. *What do I do if I forget a dose?*
- f. *How long will I have to take it? Will it interact with other medication?*

6. Draw participants' attention to the handout "Questions about Medications" and review together.

7. Introduce and set up role-play #1. (Participants will recognize this conversation from the Day 2 Reflective Listening exercise. This time the focus is on the doctor-patient communication.)

- a. A trainer and a volunteer act out the first role-play. The trainer is the doctor and the volunteer is the patient. Don't forget to use props and script. Co-trainer helps volunteer get into patient role and serves as the narrator.

b. Debrief first role-play:

Ask participants: *What do you think about this meeting?*

Responses may include:

- *The patient didn't appear to understand the word "T-cells" or "viral load"*
- *The patient didn't really seem to be ready to start therapy but didn't reveal this to the doctor.*

Next, ask the group what the patient could have done to improve the meeting. [Answer: the patient could

help to improve the meeting by asking the questions discussed above— Items 5a-5f].

8. Introduce and set up role-play # 2.

- a. Have two participants volunteer to be the patient and the doctor and conduct second role-play.

b. Debrief second role-play:

What do you think about this patient-doctor meeting? Answers:

- *The patient received information about the numbers (T-cells and viral load).*
- *Although the patient still wasn't sure about starting therapy, he or she discussed this with the doctor and made a plan to get more information through the peer, and then decide by the next medical appointment.*
- *The patient was honest.*
- *The patient understood he or she had the right to refuse until receiving more information.*

Summarize

- *It's important to take charge of your own health care and help patients take charge of theirs (mentoring, role modeling), to know what information to share with your doctor and what questions to ask, and to know your rights and responsibilities as a patient and how to be a partner with your doctor.*
- Draw participants' attention to the handouts "Patient Rights and Responsibilities" and "Preparing for a Visit with Your Doctor."

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 1

HOW TO PREPARE FOR A VISIT WITH YOUR DOCTOR

1. Keep a journal or calendar of symptoms.
2. Be prepared to describe side effects including symptoms.
3. Bring medications in a bag or have on a list.
4. Bring a friend.
5. Bring a list of questions.
6. Bring food and something to stay busy.
7. Be prepared to let provider know how many doses of HIV medications were missed in a week or month.

You may wish to share this handout with the patient during Peer-Patient Educational Session #3, Effective Communication and Self-Advocacy. (See guide on page 16.)

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 2

SYMPTOMS LOG

NAME _____ DATE _____

1. Is it hard for you to take your HIV medicines the way your healthcare provider told you to?

Yes No

2. How hard are your HIV medicines to take? Mark an X on the line below.

3. If you miss a dose, is it in the morning, evening, or middle of the day?

Morning Evening Middle of the day I don't forget or skip doses

4. Do you ever skip a dose because the medicines make you feel bad? Yes No

5. Do you ever go a day without taking your HIV medicines?

Yes; why? _____

No

6. Do you ever have any of these possible side effects?

Side Effect	How many times a month?	How long have you had this side effect?	How much does it affect your daily activities? 0=none; 1=somewhat; 2=always
Feeling sick to my stomach			
Vomiting			
Diarrhea			
Headache			
Feeling tired			
Rash			
Shortness of breath			
Trouble sleeping			
Change in skin color			
Bad dreams			
Nervousness			

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 2 (Cont.)

7. Has your energy changed since you started taking your current HIV medicines? Mark an X on the line below.

8. Are you concerned that the HIV medicines you are taking now might cause either of these side effects?

- a. Weight loss in the arms, legs, buttocks, or face Yes No
 b. Weight gain in the upper back and neck, breast, or trunk Yes No

9. Would you be interested in talking to your healthcare provider about whether a change to your HIV regimen is right for you? Yes No

10. If you could change one thing about your HIV treatment, what would it be?

Use your answers to talk to your healthcare provider.

You may wish to share this handout with the patient during Peer-Patient Educational Session #3, Effective Communication and Self-Advocacy, and Session #6 Medications and Adherence (See guide on pages 16 and 18.)

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 3

QUESTIONS FOR YOUR DOCTOR ABOUT MEDICATIONS

1. Why have I been prescribed this medication?
2. How should I take it?
3. Are there any special storage requirements?
4. Should I take it with or without food? Will it make me feel worse? What are the side effects? How many and how often should I take them?
5. What do I do if I forget a dose?
6. How long will I have to take it? Will it interact with other medication?

You may wish to share this handout with the patient during Peer-Patient Educational Session #3, Effective Communication and Self-Advocacy. (See guide on page 16.)

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

You may wish to share this handout with the patient during Peer-Patient Educational Session #3, Effective Communication and Self-Advocacy. (See guide on page 16.)

SESSION HANDOUT 4

HIV PATIENT BILL OF RIGHTS

- The person with HIV has the right to considerate and respectful care regardless of race, ethnicity, national origin, religion, age, sexual orientation, gender, or payment source.
- The person with HIV has the right to, and is encouraged to obtain current and understandable information concerning diagnosis, treatment and prognosis.
- The person with HIV has the right to know the identity of the physician, nurses and others involved in her care, including those who are students, residents or other trainees.
- The person with HIV has the right to work with the physician or nurse in establishing their plan of care, including the refusal of a recommended treatment, without the fear of reprisal or discrimination.
- The person living with HIV has the right to privacy.
- The person living with HIV has the right to expect that all records and communication are treated as confidential except in the case of abuse.
- The person living with HIV has the right to review his/her own medical records and request copies of them.
- The person living with HIV has the right to expect that an advance directive (such as a living will, health care power of attorney) will be honored by the medical staff.
- The person living with HIV has the right to receive timely notice and explanation of changes in fees or billing practices.
- The person living with HIV has the right to expect an appropriate amount of time during their medical visit to discuss their concerns and questions.
- The person living with HIV has the right to expect that his/her medical caregivers will follow universal precautions.
- The person living with HIV has the right to voice his/her concerns, complaints and questions about care and expect a timely response.
- The person living with HIV has the right to expect that the medical caregivers will give the necessary health services to the best of their ability. If a transfer of care is recommended, she should be informed of the benefits and alternatives.
- The person living with HIV has the right to know the relationships his/her medical caregivers have with outside parties (such as health care providers or insurers) that may influence treatment and care.
- The person living with HIV has the right to be told of realistic care alternatives when the current treatment is no longer working.
- The person living with HIV has the right to expect reasonable assistance to overcome language (including limited English proficiency), cultural, physical or communication barriers.
- The person living with HIV has the right to avoid lengthy delays in seeing medical providers; when delays occur, he/she should expect an explanation of why they occurred and, if appropriate, an apology.

Source: Wilder, Terri. "A Guide to Getting Good HIV/AIDS Medical Care." *Survival News*. 01 July 2000: 1-3.

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 5

HIV PATIENT BILL OF RESPONSIBILITIES

- Provide your medical caregivers with accurate and complete information, and convey your understanding about what is expected of you in regard to your treatment. If you believe you cannot follow through with your treatment, let them know.
- Meet your financial obligations as promptly as possible.
- Be considerate of the rights of other patients and medical personnel in the control of noise and respect of property at your appointments or in the hospital.
- Recognize the reality of risks and limits of the science of medical care and the human fallibility of the health care professional.
- Be aware of the health care provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- Become knowledgeable about your health care plan.
- Report wrong doing and fraud to the appropriate personnel or legal authorities.
- Keep appointments and notify the clinic if unable to do so.
- Inform the clinic of the existence of, and any changes to, advance directives.
- Notify the clinic of changes in your condition or care situation.

You may wish to share this handout with the patient during Peer-Patient Educational Session #3, Effective Communication and Self-Advocacy. (See guide on page 16.)

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 6

ROLE-PLAY #1

Narrator: The following is a discussion between a patient and his/her provider. It will be quite obvious by the response and body language of the patient that s/he is really unaware of what the provider is talking about; yet, the patient will not admit this to the provider. Trainers will use props to distinguish the patient from the provider.

Provider: Well, as I said earlier, I think it's time to start you on medications. Your T-cell counts are at 300 and your viral load is up at 50,000. How do you feel about starting meds at this time?

Patient: Okay...

Provider: Are you sure you're okay with this, you sound a little anxious.

Patient: No, it's okay, I guess, if you think I need to.

Provider: Well, let's start with this combination of medicines and see how it goes. If you should start having any side effects, such as high fever or rash, let me know as soon as possible.

Patient: High fever or rash. Okay, I will ... I'll let you know.

Provider: I'll see you back in about a month to see how it's going and to check on your liver. Any questions?

Patient: No, I don't think so. The patient leaves, saying to herself/himself: T-cells and viral load... wonder what he meant by that? And if this stuff is going to cause me to have a fever and a rash, I don't know if I want to take it. Plus he said something about my liver. I feel fine right now, I don't know about taking this stuff.

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 7

ROLE-PLAY #2

Narrator: Now let's take another look at a conversation between a provider and patient. This patient is more empowered and has a better understanding of the provider/patient relationship. This patient understands that s/he has rights and responsibilities. These rights ensure that he or she is working together with the provider to maintain the best of health.

Provider: Well, as I said earlier, I think it's time to start you on medications. Your T-cell counts are down at 300 and your viral load is up at 50,000. How do you feel about starting meds at this time?

Patient: To tell the truth, I'm not really sure. Can I ask you a couple of questions first? I wrote them down so I would remember.

Provider: Sure, what is it that I can help you with?

Patient: Well, I know you told me this before, but I'm still not sure if my T-cells are supposed to be down and viral load up or is it the other way around. I still get confused.

Provider: I understand. It confuses a lot of people. We like to see your T-cells up because it is a measure of how well your immune system is doing, and the viral load we want to be down because viral load is the amount of virus in the body.

Provider: I think there's someone in our office that can help you understand all these terms better. If you'd be interested in meeting with him or her, I can refer you to our peer for more information. But do you understand a little better now?

Patient: Yes, I think I would like to meet with the person you're talking about. But I have another question. Why do you think I should start meds now? I'm feeling just fine, and I heard those meds can sometimes make you feel bad.

Provider: Well, the reason I think we should start now is because we want to keep your immune system strong. Remember, we want to keep those T-cells up and we want to get that viral load down. The medicine will help make that happen if you take it correctly. Yes, you may feel bad at first and experience some side effects, but those should go away once your body has adjusted to the meds.

Patient: I heard about side effects. They can make you feel really bad. I'm still not sure I'm ready to do the medicine thing. Can I talk to this counselor or educator you were talking about for more information before I begin?

SESSION VIII: ASSESSING ADHERENCE

Topic: Doctor-Patient Communication

SESSION HANDOUT 7 (Cont.)

Provider: I understand, it is a very important decision to make and we want you to be sure you're ready to start these meds. We will need you to do your best to take these medicines exactly as prescribed in order for them to work. I'll make contact with the peer and he or she will give you a call to set up a time to meet with you and discuss your concerns. Then, you and I will talk again in a couple of weeks. Is that okay with you? Let's be sure to set your return appointment before you leave today.

Patient: Yes, doctor, I would feel much better doing it that way first. This way I'll get all the information I need before starting these medicines. I really don't think I'm ready to do this medicine thing right now. I appreciate your understanding.

SESSION IX: DRUG RESISTANCE

TOTAL TIME FOR SESSION IX: 1 hour
SLIDES: #60-62

▶ ABOUT THIS ACTIVITY

 **Time:** 60 minutes

 **Slides:** #60-62

 **Objectives:**

By the end of this session, participants will be able to:

- Define and understand drug resistance

 **Training Methods:**

- Large-group discussion
- Lecture

 **In this activity you will:**

- Review and explain materials on the slides
- Facilitate group discussions

 **Materials:**

- Video: HIV Resistance — What It Is.....And What You Can Do About It
- Laptop
- Projector

 **Preparation:**

- Prepare video for playing by downloading it onto the computer. Instructions for download and a link to the video may be found at <http://hdwg.org/prep/HIV-resistance-video>

Instructions

1. Play the video.
2. Facilitate a discussion of the video.

Ask participants about the patient vignettes in the video:

A. Jose

- New on medications.
- Works in construction.
- Wants to take all his medications at once.
- “Organize it so it works for me.”
- “Every dose, every day, every time.”
- “Nothing to it but to do it.”

B. Christy

- Mutant strain or wild-type strain.
- Resistance to therapy.
- Re-assess with genotype testing.
- She is not agreeing to a new therapy maybe because she will do some research on medications and resistance before starting another medication therapy.

C. Warren

- Has a new job.
- Stigma of his sexual orientation and being HIV positive.
- Options to help with adherence-Christopher (his partner) and his new watch.
- Realistic fears of feeling sick from side effects to medications.

SESSION IX: DRUG RESISTANCE

3. Facilitate a discussion of the picture in slide 60 and meaning of resistance.



4. Review slide 61 – What is drug resistance?

WHAT IS DRUG RESISTANCE?

- You have resistance when HIV can adapt and multiply in the presence of meds.
- A drug or class of drugs are no longer fighting the virus.

What Causes Drug Resistance?

- Not taking meds as prescribed

How Common is Drug Resistance?

- Most people with HIV have some form of drug resistance.
- Some newly infected individuals are already resistant to at least one drug or class of drugs (even without ever being on meds).

- The dictionary definition of **resistance** is “the act or power of opposing or withstanding; the opposition offered by one force to another; opposition, defiance, intransigence.”*
- The best way to prevent resistance is by achieving 95% adherence; that means not missing more than 1½ doses per month (for people on protease inhibitors).*
- Having to switch to another medication regimen is difficult both physically and psychologically - you don't know what new side effects to expect and you may feel as anxious as you felt the first time you were faced with the decision to start taking meds. It's best to stay on the same*

medication regimen for a long time. If the regimen you currently take is working, why would you want to switch?

- Link vignettes to common reasons drug resistance occurs.*

- Ask participants if they know how a newly diagnosed person, never on meds before, can have resistance to a medication or a whole class of medication? Allow responses. Answer: the person who infected the newly diagnosed person was resistant to the same medication or class of medication. There is significant evidence that it is possible to transmit HIV that is already resistant to medications.*

Summarize

- *Only 25% of people living with HIV in the U.S. and territories have an undetectable viral load. You are likely to have patients with resistance, so you have an important job to do as peers to help improve this number.*
- *The adherence support that you provide can significantly help reduce the threat of resistance for your patients.*
- *Becoming resistant to medication or classes of medication reduces your treatment options.*
- *Until everyone living with HIV has an undetectable viral load, we won't be able to stop the spread of HIV (unless a vaccine is developed first).*

SESSION IX: DRUG RESISTANCE

6. Review slide 62 – More on Resistance.



- Since no HIV medication has a life span of more than 12 or 24 hours, skipping a day or a week-end can lead to resistance.*
- Ongoing development of resistance can deplete treatment options for people who have gone through multiple drug regimens.*

c. Like a marriage, you have to participate every day, you must be faithful, if you cheat you lose, sometimes you need counseling, sometimes you need encouragement, sometimes it's rocky but doesn't have to mean the end. It's also true that poor adherence is like a bad marriage.

d. Some foods and drugs interact with HIV meds and can increase the severity of side effects (More on drug interactions later during the HIV and Substance Use module).

7. *Foods that interact with HIV meds.*

- Antacids (with protease inhibitor Rayataz).*
- Grapefruit (particularly with Norvir).*
- High fat meal with Sustiva (this interaction is actually good because high fat reduces the side effects of Sustiva).*
- As research continues and new medications are developed, other foods that interact with HIV meds are discovered, so these will continue to change in the future.*

SESSION X: UNDERSTANDING LABS

TOTAL TIME FOR SESSION X: 35 minutes
SLIDES: #63-79

▶ ABOUT THIS ACTIVITY

 **Time:** 35 minutes

 **Slides:** #63-79

 **Objectives:**

By the end of this session, participants will be able to:

- Understand the purpose of different lab tests and the meaning of values

 **Training Methods:**

- Lecture
- PowerPoint presentation

 **In this activity you will:**

- Conduct a lecture on the purpose of different laboratory tests and the meaning of values

 **Materials:**

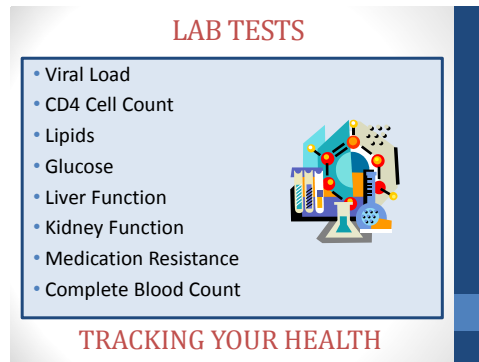
- Monitoring Tests for People with HIV handout printed out from <http://www.thebody.com/content/art2599.html>

 **Preparation:**

- None

Instructions

1. Explain that we are going to review the purpose of eight different laboratory tests and discuss the meaning of different laboratory values (slide 64).

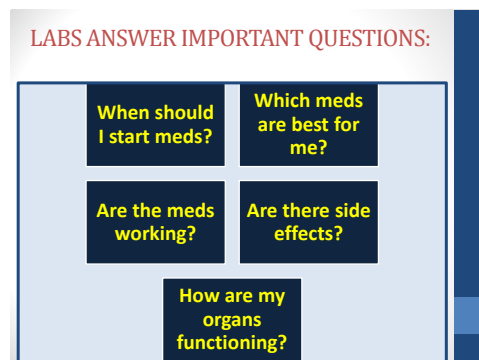


LAB TESTS

- Viral Load
- CD4 Cell Count
- Lipids
- Glucose
- Liver Function
- Kidney Function
- Medication Resistance
- Complete Blood Count

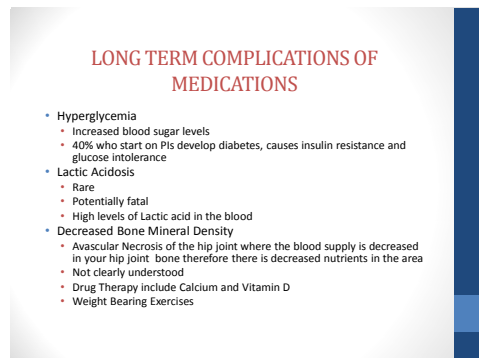
TRACKING YOUR HEALTH

2. Go through slides 65-79.



LABS ANSWER IMPORTANT QUESTIONS:

- When should I start meds?**
- Which meds are best for me?**
- Are the meds working?**
- Are there side effects?**
- How are my organs functioning?**







LONG TERM COMPLICATIONS OF MEDICATIONS

- Hyperglycemia
 - Increased blood sugar levels
 - 40% who start on PIs develop diabetes, causes insulin resistance and glucose intolerance
- Lactic Acidosis
 - Rare
 - Potentially fatal
 - High levels of Lactic acid in the blood
- Decreased Bone Mineral Density
 - Avascular Necrosis of the hip joint where the blood supply is decreased in your hip joint. bone therefore there is decreased nutrients in the area
 - Not clearly understood
 - Drug Therapy include Calcium and Vitamin D
 - Weight Bearing Exercises

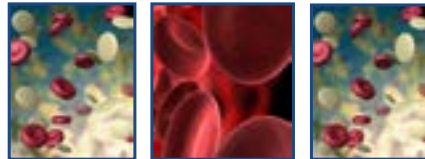
SESSION X: UNDERSTANDING LABS

Topic: Understanding Labs

WHEN SHOULD LABS BE DONE?

-  **When starting meds**
-  **When switching meds**
-  **Every 3 to 4 months**
-  **Whenever your doctor decides**

COMPLETE BLOOD COUNT (CBC)



White Blood Cells Red Blood Cells Platelets

UNDERSTANDING CD4 RESULTS

Results can be reported as two values:

- CD4 cell count

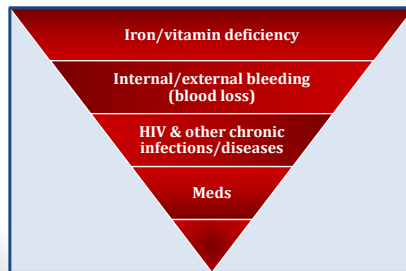


- CD4 percentage



RED BLOOD CELLS (RBC)

Low RBC=Anemia



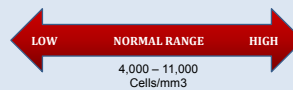
UNDERSTANDING VIRAL LOAD RESULTS

Less than 50 copies/mL = undetectable



WHITE BLOOD CELL COUNT (WBC)

Reported as the number of cells in a cubic millimeter of blood (cells/mm³)



Low WBC
May be caused by:

- Certain medications
- Chemotherapy drugs
- Long-term HIV infections

High WBC
May be caused by:

- Bacterial or other infections
- Leukemia/bone marrow diseases

CD4 CELL COUNT

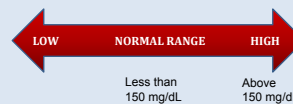
Measures how many CD4 in the blood.



High CD4 shows a strong immune system.

LIPIDS (fats): TRIGLYCERIDES

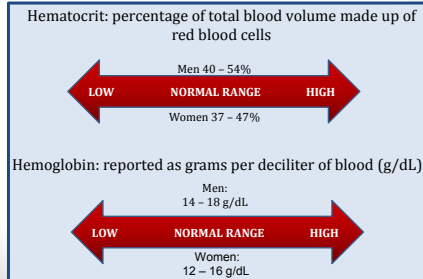
- A type of fat the body uses to store energy
- High levels are associated with an increased risk of heart disease



SESSION X: UNDERSTANDING LABS

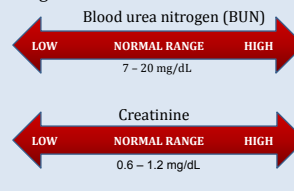
Topic: Understanding Labs

RED BLOOD CELL COUNT

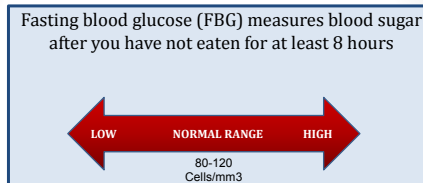


KIDNEY FUNCTION TESTS

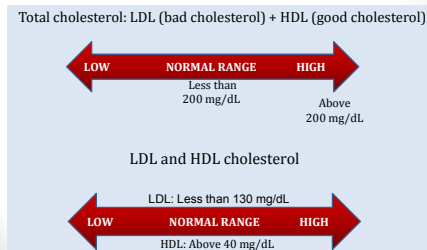
- Some HIV meds may affect the kidneys
- These tests show how well your kidneys are working



GLUCOSE (blood sugar)



LIPIDS (fats): TOTAL CHOLESTEROL



LIVER FUNCTION TESTS

- Blood tests show how well your liver's working
- Important for anyone taking HIV and other meds
- The liver helps process medications and can become "overloaded"

Test can identify possible:

- Liver disease
- Medication stress on liver function
- Infections of the liver such as hepatitis



- In "Understanding Viral Load Results," be sure to make the following points:
 - A person with HIV can have a viral load from less than 50 copies to over 1 million copies per milliliter of blood.*
 - Undetectable does not mean the person is cured.*
- Under "Complete Blood Count (CBC)," make the point that CBC tests measure the amount of:
 - White blood cells (fight infections).
 - Red blood cells (hematocrit, hemoglobin) carry oxygen throughout the body.
 - Platelets, that help blood to clot.
- Under "Red Blood Cells," note that high RBCs are very rare.

SESSION XI: HIV STIGMA

Topic: Stigma

TOTAL TIME FOR SESSION XI: 55 minutes

SLIDES: #80-84

▶ ABOUT THIS ACTIVITY

 **Time:** 15 minutes

 **Slides:** #80

 **Objectives:**

By the end of this session, participants will be able to:

- Explore manifestations and consequences of internal and external stigma

 **Training Methods:**

- Large-group discussion

 **In this activity you will:**

- Lead a large-group discussion of stigma and provide examples and explanations to the participants

 **Materials:**

- None

 **Preparation:**

- None

Instructions

1. Ask participants: *What is stigma?* Allow responses and facilitate discussion. Direct participants' attention to the images on the slide and ask them what they see. Associate this kind of behavior with stigma.
 - a. *Stigma can be described as an attribute or quality which significantly "discredits" an individual in the eyes of others. This means that people will look at someone and have a negative attitude towards that person because of a certain quality or characteristics.*
 - b. *Stigma is synonymous with a mark of disgrace or infamy; a stain or reproach, as on one's reputation.*
 - c. *Back in the early days of the epidemic, stigma was really high because there was so much ignorance about how HIV is transmitted; people didn't want to be around you if you had AIDS, let alone touch you. In some cases people lost their homes and their jobs, their families. Stigma came in all forms: your own community, family, significant other, and of course, the larger society.*
2. Describe some causes of stigma
 - a. *Heterosexism/homophobia and trans-phobia can lead others to stigmatize individuals because of sexual orientation and gender identity and expression. Sex work is also highly stigmatized, as is injection drug use.*
 - b. *Shifting focus away from the patient by overly focusing on risks to the patient's partner instead of the health and well-being of the patient.*
 - c. *Giving directives; telling people how they should live their lives.*

SESSION XI: HIV STIGMA

Topic: Stigma

- d. *Profiling: assuming transmission modes and behavior based solely on a person's race, gender, or sexual orientation.*

3. Explain external stigma

- a. *External stigma refers to experiences of being treated unfairly and differently from everyone else. This discrimination may include oppression, rejection, punishment, harassment, blame, and exclusion. It can also sometimes lead to violence against people living with HIV/AIDS.*
- b. *Because HIV infection is connected to the taboos of sexuality and addiction, people face stigma upon stigma upon stigma.*
- c. *If I'm a man and I tell you that I'm living with HIV, what's the first thing people might think about me? Allow responses.*
Expected response: gay.
- d. *If I'm a woman and tell you I have HIV, what's the first thing people might think about me? Allow responses. Expected answer: loose, promiscuous.*
- e. *What if I'm a child with HIV, what's the thing people would think about me? Allow responses.*
Expected answer: innocent victim.
- f. *Generally, when people ask how you got HIV, it is often to determine if you're innocent or guilty.*
- g. *Children born with HIV and women who got HIV from their cheating husbands are considered "innocent victims" while everyone else simply got what they "deserved." This attitude or label can induce stigma.*

4. Explain Internal Stigma

- a. *Internal stigma is the way a person feels about themselves. For example, shame, fear of rejection and discrimination are all examples of internal stigma.*
- b. *Internal stigma is the worst kind of stigma because it comes from deep inside the person. It means that you have come to believe the negative messages people have about you and this leads you to feel shame, self-loathing, and a feeling that you got what you deserved.*
- c. *Stigma can be damaging to a person's dignity, and without dignity, people cannot be fully human. This alone can cause people to remain in denial or disconnect from medical care and services.*

SESSION XI: HIV STIGMA

Topic: HIV-Related Stigma

▶ ABOUT THIS ACTIVITY

 **Time:** 15 minutes

 **Slides:** #81

 **Objectives:**

By the end of this session, participants will be able to:

- Gain an understanding of how stigma affects individual access to care

 **Training Methods:**

- Lecture
- Group discussion

 **In this activity you will:**

- Facilitate a group discussion

 **Materials:**

- None

 **Preparation:**

- None

Instructions

1. Turn to slide 81.



2. Engage participants in a conversation about stigma.

- *What role has stigma played in your life?*
- *How did it feel to be stigmatized?*
- *How did stigma influence your decision to get tested, get into care or disclose to others?*
- *What did you do to get rid of the stigma inside of you?*

3. Allow responses and facilitate discussion.

4. This is an opportunity for participants to tell some of their stories—ask them to follow the frame and brevity learned earlier.

Segue

Unfortunately, 30 years since the beginning of the epidemic, stigma is still alive and well. Stigma still plays a role in whether or not people get tested, enter care, remain in care, disclose HIV status or practice safer sex. The next slide clearly illustrates this.

SESSION XI: HIV STIGMA

Topic: The Effects of Stigma

▶ ABOUT THIS ACTIVITY

 **Time:** 10 minutes

 **Slides:** #82-83

 **Objectives:**

By the end of this session, participants will be able to:

- Describe the effects of stigma on an individual

 **Training Methods:**

- Lecture
- Group discussion

 **In this activity you will:**

- Review the materials on the slides

 **Materials:**

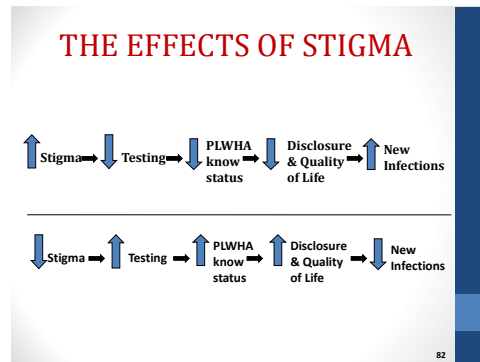
- None

 **Preparation:**

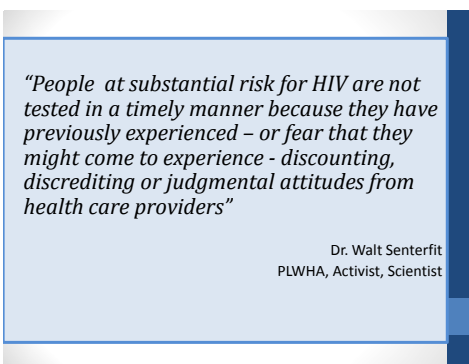
- None

Instructions

1. Review slide 82 with participants. *These findings came from a study done by Dr. Herek, a researcher from California.*



2. *When stigma is high, testing is low, fewer people know their status, fewer people disclose and new infections rise.*
3. *When stigma is low, testing increases, more people learn their status, more people disclose and new infections drop.*
4. *The sad thing is that people are sometimes stigmatized even in places they go for medical care and other services.*
5. Ask for a volunteer from the audience to read the quote on slide 83 out loud.



SESSION XI: HIV STIGMA

Topic: The Effects of Stigma

6. *The care system ought to be a place where people can find respite from oppression, a stigma-free zone; unfortunately, this is not always the case. Sometimes people drop out of care because they were stigmatized by their own doctor.*
7. Ask: *Why do you think stigma has gone down since the early epidemic?*

Expected responses: *There's less ignorance about how you get HIV and how you don't; more PLWHA have disclosed to partners, family, friends, coworkers and this has led to greater acceptance because it puts a face on the disease.*

I first became aware of the disease in the early 80's when my best friend, Michael was infected with 'the gay cancer.' I watched him wither away to nothing. He died at home in his mother's arms one cold February morning. I would continue to endure the passing away of many friends.

I have been positive since 1994. So much has changed since those dark days. We are now able to sustain and live our lives through the use of antiretrovirals. We still have a long road ahead. Stigma, misinformation, lack of compassion and ignorance are but a few of the day-to-day battles that anyone diagnosed with HIV faces.

A peer at CARE Resource in Miami

SESSION XI: HIV STIGMA

Topic: What Not to Say

▶ ABOUT THIS ACTIVITY

 **Time:** 15 minutes

 **Slides:** #85

 **Objectives:**

By the end of this session, participants will be able to:

- Recognize and address stigma

 **Training Methods:**

- Lecture
- Group discussion
- Large-group exercise

 **In this activity you will:**

- Model stigmatizing statements that are not intended to stigmatize
- Lead a discussion on how to address stigma

 **Materials:**

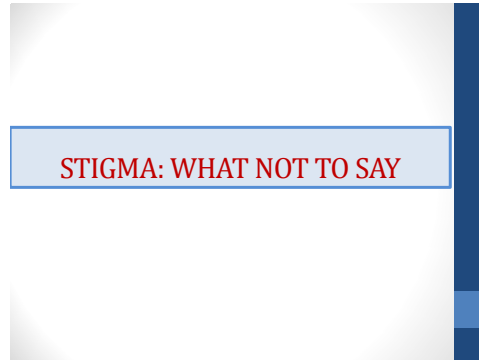
- Stigma Exercise: What Not to Say trainer sheet

 **Preparation:**

- None

Instructions

1. Turn to slide 84.



2. Tell participants that sometimes we can stigmatize people inadvertently even as we are trying to support them.
3. Go around the room and make eye contact with individual participants while reading a statement of things peers might say to patients that can stigmatize them (see statements on “Stigma Exercise: What Not to Say” trainer sheet); ask participants how they felt when each statement is made.
4. Move to the peer role in supporting patients who are experiencing stigma. Ask: *What is the role of peers with regard to stigma? What can you do to reduce stigma in people’s lives?*
5. Allow participants to respond and facilitate discussion. Expected answers (document on newsprint):
 - *Actively remove stigma from your interactions with patients.*
 - *Call out stigma when you see it in the workplace (but do so with respect and in a way that people can hear it; remember, sometimes people stigmatize without being aware of it).*
 - *Help the care team understand how people experience stigma and how their words and actions can sometimes stigmatize people (remember, your role can include educating your colleagues who may not have anyone in their lives living with HIV and thus may not understand how words and actions can stigmatize).*

SESSION XI: HIV STIGMA

Topic: What Not to Say

- Help patients work through internal stigma, the worst type of stigma, but one they can do something about.
6. Some important messages:
- You are not alone.
 - Being HIV+ is not shameful.
 - HIV is a health issue not a moral or social issue.
 - HIV doesn't see race, gender, or sexual orientation, it only sees humans.
 - No human being is more or less valuable than another simply because of a disease.

Summarize

- *Modeling how you manage stigma in your own life can inspire patients to do the same—share your experiences (story telling) with patients and how you've been able to manage stigma in your own life.*
- *Be careful not to minimize people's feelings around stigma; these feelings are real and need to be handled with care.*

SESSION XI: HIV STIGMA

Topic: What Not to Say

SESSION HANDOUT

STIGMA EXERCISE: WHAT NOT TO SAY

- “HIV is not a big deal anymore.”
- “HIV is a manageable chronic illness, like diabetes.”
- “Now that you have HIV you need to disclose to your sexual partner immediately.”
- “I’m really worried about you infecting your HIV-negative partner.”
- “How many people do you think you’ve infected so far?”
- “Having sex without a condom is like putting a gun to someone’s head.”
- “You have full-blown AIDS.”
- “Turn to Jesus.”
- “You got HIV because of your sins.”
- “Now that you are HIV instead of “now that you have HIV or are living with HIV.”
- “I’m a mandated reporter, so if you infect other people, I have to report you.”
- “Your behavior is what got you in trouble in the first place.”

SESSION XII: VALUES

Topic: Overview of Values

TOTAL TIME FOR SESSION XII: 1 hour, 25 minutes

SLIDES: #85-89

▶ ABOUT THIS ACTIVITY

 **Time:** 5 minutes

 **Slides:** #85

 **Objectives:**

By the end of this session, participants will be able to:

- Explain the meaning of values

 **Training Method:**

- Discussion

 **In this activity you will:**

- Conduct a group discussion

 **Materials:**

- None

 **Preparation:**

- None

Instructions

1. Ask participants: *What are values?*
2. Answer: *The term “values” implies qualities of mind and character, or moral excellence; implies intrinsic excellence or desirability; a person’s principles or standards of behavior; one’s judgment of what is important in life.*
3. *Keep this in mind for the next discussion and exercise.*

SESSION XII: VALUES

Topic: (Un)Push My Buttons: Examining Our Personal Values

▶ ABOUT THIS ACTIVITY

 **Time:** 10 minutes

 **Slides:** #86

 **Objectives:**

By the end of this session, participants will be able to:

- Identify their personal values and how they affect their actions

 **Training Methods:**

- Lecture
- Discussion

 **In this activity you will:**

- Facilitate a group discussion

 **Materials:**

- None

 **Preparation:**

- None

Instructions

1. Turn to slide 86.



2. Lead a discussion about how we all have buttons based on our values that when pushed can make us upset, angry, or even panicky.

- *In the context of peer work, this can influence how we view patients who “push our buttons” and can render us ineffective or judgmental and, in some cases, punitive.*
- *We all have these buttons and they are based on past experience, upbringing, culture, religious beliefs, etc.*

3. Ask participants: *What are some things that push your buttons about people in general?* Take a few responses and facilitate discussion; share some of your own button pushers.

4. Document these on newsprint and post on the wall.

Segue

- *In the next exercise, we will be exploring buttons based on our personal values that we may not even know we have and yet we react to them.*

SESSION XII: VALUES

Topic: Self-Assessment: What Pushes Your Buttons?

▶ ABOUT THIS ACTIVITY

 **Time:** 35 minutes

 **Slides:** #87

 **Objectives:**

By the end of this session, participants will be able to:

- Express how their personal values might interfere within their work as peers

 **Training Methods:**

- Individual exercise
- Debriefing
- Group discussion

 **In this activity you will:**

- Review common areas of discomfort for service providers
- Facilitate an individual activity where people self-identify their own levels of comfort
- Convene a report-back session
- Facilitate a group discussion

 **Materials:**

- Unpush My Buttons worksheet
- Newsprint
- Markers

 **Preparation:**

- None

Instructions

1. Review slide 87 with participants; explain that research shows these as 4 areas of discomfort for many HIV service providers.



2. Ask participants to find the “UnPush My Buttons” worksheet in their training packets and ask them to self-identify their own level of comfort in these key situations on the comfort inventory scale (very comfortable to very uncomfortable). Ask them to *circle the number that best reflects how comfortable you are in each of these situations.*
3. Encourage participants to be completely honest about their responses (otherwise the activity won't work); reassure them that no one will judge them for being honest about their values and feelings.
4. *If comfortable with all of these issues, think about a time when you weren't as comfortable as you are today. The worksheets will not be collected, so feel free to write how you really feel.*
5. *Once you rate yourself, identify the most uncomfortable area and the SOURCE of your discomfort (could be religion, culture, upbringing, personal history, etc.) and write it down.*
6. When participants are done proceed to debriefing.
7. Ask participants to report out their assessment and to state the area of most discomfort and source of discomfort.

SESSION XII: VALUES

Topic: Self Assessment: What Pushes Your Buttons?

8. Try to get every participant to report out – one way to do this without calling anyone out is to give an item like a pencil or ball to the first participant – as the item is being passed around that next participant reports out and so forth.
9. As participants report out, record on newsprint their source of discomfort; this should generate a long list of sources of discomfort. When documenting responses on newsprint, start every source of discomfort with an “I” or “My” statement; for example, “**I** feel HIV+ people should always disclose to sexual partner” or “**MY** religious beliefs prevent me from using drugs.”
10. Once everyone has had a chance to report out, ask participants to take a few moments to contemplate the list generated, then ask “*What do you see, what stands out for you?*” Expected response: these sources of discomfort represent our own personal values and beliefs (all are “I” and “My” statements).
11. If an expected response is not forthcoming, prompt participants by asking:
 - “*To whom do these issues/values belong?*”
Expected answer: to us, to every person in this room; then ask:
 - “*What do our values have to do with the patient sitting in front of us?*”
Expected response: nothing
12. Ask: *How does this apply to our work as peers? What is the lesson in this exercise?*

Expected answer: Don’t judge your patients; don’t project your own stuff onto your patient.

Summarize

- *No one can tell you how to feel or ask you to change your personal beliefs and values; however, as peers, you are required to suspend your judgment during your interactions with patients.*
- *If we show our patients, through words and action, that we don’t approve of what they are doing or that we judge them for who they are and what they do, they may feel stigmatized and may never engage with us again. Because of our own biases, we will have missed opportunities to empower patients to make more informed choices about their health and well-being.*
- *Values are very personal, so don’t impose yours or expect patients to share yours.*
- *This is a good exercise to do in your head when faced with uncomfortable feelings elicited by the patient: Ask yourself, “Why am I suddenly feeling uncomfortable?” You will find that you’re likely to be experiencing countertransference* and having this awareness in the moment will enable you to identify the feeling as your own “stuff” trying to get in the way.*
- *What other situations do you think will push your buttons or make it difficult for you to remain objective when you are with patients? Allow responses and facilitate discussion.*

Segue

Instead of passing judgment on our patients and projecting our feelings onto them, we ought to focus on being patient-centered.

* *countertransference is the peer’s response (often negative) to the transference behavior of the patient in which the patient unconsciously transfers feelings and attitudes from a person or situation in the past onto the peer.*

SESSION XII: VALUES**Topic: Self-Assessment: What Pushes Your Buttons?****SESSION HANDOUT****(UN)PUSH MY BUTTONS EXERCISE**

This is an individual exercise. You will not be asked to hand in this worksheet or show it to anyone else, so feel free to assess your discomfort level or “button pushers” as honestly as possible.

Please circle the number that best describes how you would feel in the three situations listed below: (1 being very comfortable and 5 being very uncomfortable)

	1	2	3	4	5
	Very Comfortable	Comfortable	Somewhat Comfortable	Uncomfortable	Very Uncomfortable
1. Working with sexually active HIV+ people who don't disclose	1	2	3	4	5
2. Working with HIV+ people who actively use drugs				1	2
				3	4
3. Working with HIV+ people planning a pregnancy				1	2
				3	4
				5	

Source of Discomfort

Take a moment and consider what might be at the root of your discomfort.

What is it that makes this situation a button pusher for you? *(Could be personal history, religious/cultural beliefs, inexperience/unfamiliarity with behaviors or situations)*

SESSION XII: VALUES

Topic: Patient-Centered Approach

▶ ABOUT THIS ACTIVITY

 **Time:** 25 minutes

 **Slides:** #88

 **Objectives:**

By the end of this session, participants will be able to:

- Explain the patient-centered approach

 **Training Methods:**

- Group discussion
- Round robin

 **In this activity you will:**

- Lead a group discussion around the patient-centered model
- Facilitate an activity designed to elicit participant examples of patient-centered approaches

 **Materials:**

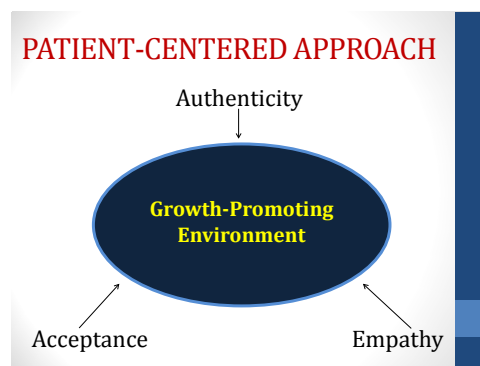
- Newsprint
- One marker for each participant

 **Preparation:**

- Prepare 3 newsprints on the walls, in separate corners of the room, with the headings: Authenticity, Acceptance, Empathy

Instructions

1. Present slide 88 to the group and explain that this model was created by Carl Rogers, American Psychologist from the 1940s. *Carl Rogers believed that when these three conditions are present during interactions with patients, you are actually creating a growth-promoting environment, one in which patients can find solutions. This model can be applied to any relationship in which the growth of the individual is the goal, e.g., parent and child, teacher and student, etc. The patient is in the driver's seat, which often leads to taking control of his or her health and life.*



2. **Authenticity:** Ask participants: *What is authenticity?*
 - Expected answer: being genuine, being yourself, being real, being true, candor, trustworthiness, credibility, dependability.
3. **Acceptance:** Ask participants: *What is acceptance?*
 - Expected answers: favorable reception, positive regard, understanding, unconditional engagement. *You accept patients even when you know they are doing things that can harm them or that “push your buttons.”*

SESSION XII: VALUES

Topic: Patient-Centered Approach

4. **Empathy:** Ask participants: *What is empathy?*

- Expected answer: identification with the feelings, thoughts, or attitudes of another; understanding and imaginatively entering into another person's feelings; the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having the feelings, thoughts, and experience fully communicated in an objectively explicit manner. Synonymous with communion, appreciation, compassion, sympathy. Imagining yourself in another person's shoes.

5. Listening empathetically is one of the most powerful forces for movement and change.

6. Round robin exercise: Pass out some markers and ask participants to go to each newsprint and write words/phrases that describe how a peer leader can demonstrate being Authentic, Accepting, and Empathetic.

7. Tell participants they are allowed to go around again and again if they have more than one word/phrase for each heading.

8. At the end of the exercise, summarize what participants wrote and add any not mentioned.

Summarize

- *Your role as peers is not to change patients but to create a space/conditions that allows them to do that for themselves.*

Segue

- *Following certain principles will help us assure that we are creating the appropriate environment for patients.*

SESSION XII: VALUES

Topic: Principles of Peer Work

▶ ABOUT THIS ACTIVITY

 **Time:** 25 minutes

 **Slides:** #89

 **Objectives:**

By the end of this session, participants will be able to:

- Describe the principles that honor the dignity of their patients

 **Training Methods:**

- Lecture
- Discussion

 **In this activity you will:**

- Facilitate a discussion around a patient-centered approach to care

 **Materials:**

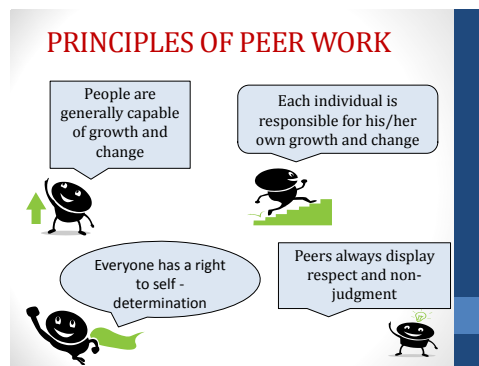
- None

 **Preparation:**

- None

Instructions

1. Show slide 89 on the screen and ask for volunteers to read what's in each callout box, then elaborate and facilitate discussion.



2. 1st callout box: *Being in the driver's seat; believing in patient's capability of their own growth will help keep us from forcing our will upon them.*
3. 2nd callout box: *Growth and change is dependent on the patient; your responsibility as a peer is to provide the tools for growth and change, such as mentoring, motivating and supporting.*
4. 3rd callout box: *What is self-determination? Take a few responses – expected response: the right of each individual to make their own decisions about their lives. Everyone has a right to decide their own lives; PLWHA did not give up these rights when they tested positive for HIV. The right to self-determination includes the right to have sex, get married, have a baby, the right to say no, the right to refuse treatment or even peer support services, and the right to be treated with respect and dignity even if we disagree with patients' choices.*
5. 4th callout box: *Respecting our patients values their dignity as human beings: If we respect a person's individual rights we won't point the finger at them, tell them what they should or must do, or try to rescue them. Resist the temptation to rescue people from their behaviors—no one is quite that powerful (even licensed professionals).*

SESSION XII: VALUES

Topic: Principles of Peer Work

Summarize

Real, meaningful, sustainable change comes from within the individual, not from the outside.

DAY 3: REVIEW

Review and remind participants how they will use their knowledge in working with patients. Refer to the Peer-Patient Educational Session Conversation Guide handout (pages 14-22) as you review.

Let's take a moment to relate what you've learned so far to the Peer-Patient Educational Session Conversation Guide handout. Today we learned a lot of things that will be helpful in Educational Session 6 when you talk about drug resistance and adherence and understanding and managing side effects.

Session VIII Review

You will probably want to use the 10 questions handout to help you remember to ask patients some important questions about adhering to their meds.

- *What are some questions to ask? (refer to handout on pg. 108 for answers)*
- *What are some things that prevent people from adhering to their meds? (side effects, fear of toxicity, forgetting, living with people who don't know their status, a break in daily routine, not getting refills, etc.)*
- *What are some things that help to overcome these barriers?*
- *In Educational Session 3, you will be talking with patients about how to communicate with providers. What are some things we can suggest to patients so they are ready for a visit with their doctor? (keeping a journal of symptoms or side effects, bringing medications, bringing a list of questions, etc.)*

Session IX Review

*We also talked about **drug resistance**. This is something you will be discussing with patients in Educational Session 6.*

- *What's the result of becoming resistant to medications? (medications no longer work to keep you healthy, reduces your treatment options, sometimes you have to switch treatments)*
- *What's the best way to prevent resistance? (adhering to treatment and engaging in safe sex by using condoms)*

Session X Review

*In Educational Session 4, you will be talking about **lab values** with patients. The article about the different lab tests that we went over would be helpful when you talk with patients about their lab values.*

- *What are some of the lab tests you might go over with patients? (CD4 count, lipids, glucose, liver function, kidney function, medication resistance, complete blood count)*
- *Why should you get your labs done regularly? (keep you healthy, an indication of whether things are going well or not so well for you)*

Session XI and XII Review

*We also talked about external and internal kinds of **stigma**.*

- *Can you give an example of each?*
- *This is something that might come up any time when you talk with patients but especially when you talk with them about disclosure in Educational Session 7.*
- *What are some affirming messages we can use to counteract stigma? (Being HIV+ is not shameful, HIV doesn't see race, gender or sexual orientation, only humans; HIV is a health issue, not a moral or social issue, etc.)*
- *We also talked about how our own values can get in the way of working with patients. Can you give an example of what a patient might do that "pushes your button?"*

DAY 3: REVIEW

- *Another thing we learned about is the patient-centered approach. What are the three conditions that help create a growth-promoting environment for our patients? (acceptance, authenticity, and empathy, give an example of each.)*
- *We wrapped up the day talking about some principles of peer work. Can you tell me what they are? (people are capable of change, each person is responsible for his or her own growth and change, everyone has a right to decide their own lives, peers show respect and do not judge.)*

This publication was supported by grant #U69HA23262, “Minority AIDS Initiative Retention and Re-Engagement Project,” through the U.S. Department of Health and Human Services, Health Resources and Services Administration’s HIV/AIDS Bureau, National Training and Technical Assistance. The contents of this publication are solely the responsibility of the Health & Disability Working Group and do not necessarily represent the views of the funding agencies or the U.S. government.

Suggested citation

Health & Disability Working Group, Boston University School of Public Health. (2014). PREParIng Peers for Success: Peer core competency training. Retrieved from <http://www.hdwg.org/prep/curricula>